Who Cares About Us?

The Hidden Population of Current and Former Aotearoa/New Zealand Young Carers Reflect on Their Experiences

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Abstract

New Zealand [NZ] young carers are an invisible and disadvantaged population of children, youth, and young adults aged 25 years and under providing significant, ongoing care for a family member with a disability, illness, mental illness, substance misuse, or who is elderly. There are an estimated 40,000 NZ young carers aged 15-24 (Ministry of Social Development, 2019), however, this statistic does not include the many more possible young carers younger than these age parameters. In the United Kingdom and Australia, findings suggest that young carers are a hidden population facing adverse educational, vocational, and health outcomes (Becker & Sempik, 2019). The seven published studies in NZ recommend further research, policies, and services for young carers. This thesis addresses these gaps by examining the experiences and needs of NZ young carers, accessing their voices in order to contribute to our understandings of their roles and provide relevant information that could inform legislation. Due to the challenges of recruiting a hidden population, an innovative sampling method was used, in which I shared via social media a 5-minute video outlining my own experience as a young carer, and the aim of the research. Consequently, the thesis features the largest-known cohort of self-identified NZ current and former young carers (11 aged 25 and under, 17 aged <26). The research is framed by Bronfenbrenner's (2005) Bioecological Systems Theory and employed a phenomenographic methodology to explore young carers' conceptions of their roles. Young caring was found to be a natural and valued part of growing up in Aotearoa/NZ, embedded within a collective family/whānau/aiga effort to support a loved one's holistic wellbeing. However, young carers' unaddressed nonfinite loss, alongside shortcomings in societal, institutional, and political support for people with disabilities and illnesses, their informal carers, and their family/whānau/aiga, results in the nature of care becoming overwhelming, with young carers experiencing negative educational, social, vocational, and health outcomes. As such, the thesis argues that policies and services must be targeted towards the factors underlying the overwhelming nature of young caring roles, rather than simply addressing the existence of young caring itself. This exploratory thesis opens up the conversation about young caring in Aotearoa/NZ, and both offers and begins to address possible pathways to address identified persistent gaps in the policy and services landscape, based on young carers' own expressed needs.

Dedication

This thesis is dedicated to my family – my enfranchisers of grief, love, and happiness.

My big brother Beefy, the reason for my thesis, and an integral part of who I am today. Thank you for letting me share with the world what makes us special. I will always be in awe of your energy, resilience, and ingenuity. Your Nerdy.

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Dad, forever my number one fan. Thank you for your selfless support of my pursuit in a topic that is so close to home. Thank you for saying yes to every request for help: with the kids, cooking dinner, bringing coffee(/wine!). I love you more than the whole wide world ... and then some. Your Scamp.

My mum, who continues to guide my life with the strong values and work ethic that she instilled in me. I wish you could see me now. Your Gorgy Girl.

To my little family, my endless sunshine, and the driving force behind my success. Our adventure days, Little Shoal Bay afternoons, and fish n' chip Fridays sustained me.

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CHAPTER ONE

Introduction

One in 10 New Zealanders identifies as an informal or family caregiver, providing support "for a friend, family, whānau or aiga[1] member with a disability[2], health condition, illness or injury who needs help with everyday living" (Ministry of Social Development [MSD], 2019, p. 5). In 2019, this population was identified as comprising 430,000 NZ[3] *adult*[4] carers, many of whom are Māori[5], Pacific[6], and women (MSD, 2019). According to the Minister of Social Development, the Honourable Carmel Sepuloni, informal carers are "an essential and valuable part of Aotearoa[7] NZ. They contribute to our country's economic sustainability, as well as playing a major role in improving individual wellbeing and community cohesion" (MSD, 2019, p. 1). Nevertheless, whilst the value of informal care is estimated at NZ$10 billion per year, NZ families with informal carers have on average 10 percent less income than families without (Grimmond, 2014). The body of NZ *adult* carer research has resulted in an understanding of their experiences and needs, with literature highlighting the ever-increasing requirement for informal caregivers (e.g., McDonald, McKinlay, Keeling, & Levack, 2017), alongside positive caregiver outcomes including closer familial bonds, and negative impacts such as poor physical and emotional health (e.g., Swain, 2018). Studies have also contributed to key policy and service initiatives aimed at improving the lives of *adult* caregivers and their care recipients[8], ranging from respite provisions and counselling to employment and financial support.

However, little is known about NZ young carers aged 25 years and under, whose voices and experiences are almost invisible in the broader caring literature. This thesis sheds some light on the lives of NZ young carers, by sharing their stories, as told by young carers themselves. It recognises these are real lives in all their emotional, intellectual, and interrelational complexities. I first share my story, to acknowledge the place of the young carer voice in my thesis, and to introduce the multiple dimensions of the experience of young caring.

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[1] Whānau is the Māori term and aiga is the Pacific term for the family unit. Whānau can denote the immediate family (whānau ake) or the much wider extended family including deceased members, and those non-blood related but who are seen as family nonetheless (Walker, 2017). The term whānau as used in the present study refers to its wider connotation of the extended family, unless otherwise specified. Aiga spans beyond any nuclear family or blood-relations to the extended family, incorporating "the whole union of families of a clan", and inclusive of those not related but who are "subject to the family control" (Tuvale, 2016, p. 1).

[2] The use of person-first language used throughout the thesis aligns with American Psychological Association [APA] (2014) stipulations for nonhandicapping language putting the person before the disability or illness, e.g., person with a disability.

[3] NZ is the abbreviation of New Zealand, and will be employed throughout the thesis.

[4] To avoid confusion, I will always italicise *adult* carers, to distinguish them from young carers.

[5] Māori are the tangata whenua (indigenous) people of NZ (Webber, McKinley, & Hattie, 2013).

[6] This research uses the term Pacific to refer to individuals who have ancestral or heritage links to the Pacific region comprising 22 countries and territories, and who are living in NZ.

[7] The Māori term for New Zealand (https://www.maori.com/aotearoa) which I will use throughout the thesis alongside or interchangeably with the Pākehā term (NZ).

[8] I acknowledge that the term 'care recipient' does not do justice to the reciprocal nature of caregiving relationships. However, as this was the most convenient term, I have used it throughout the thesis.

My Story

I was 25 when I found out that I had been a young carer. Reading a magazine, I stumbled across a story about an adolescent girl who cared for her sister, and I thought, “Oh my gosh, that was me!” Through Google, I discovered a whole world of young caring about which I had been totally oblivious. I learned that I was one of 40,000 NZ young carers (MSD, 2019), about whom little research had been undertaken, and for whom no services existed. The latter part was a real blow. I remained alone, despite my discovery.

Big-balls, Beefy, Cockroach, and Nerdy. When I was 14, my mum passed away. Because my dad was an international flight attendant, my two older brothers – Beefy (then 21) and Roddy (then 19) – and I spent periods of time at home without him. Beefy has autism and an intellectual disability, so when dad was away, I took over caring for him. I cooked us dinner, made sure he showered, washed his clothes, gave him medication, and kept his behaviour in check. In turn, Roddy took care of me: taking me to school, sports games, and birthday parties, and always being there for whatever it was that I needed. It felt like a natural family arrangement for us that I guess just fell into place.

I have such cherished memories of that time together. Being 14 and waiting with my friends to head home after school, Roddy would pull up in his little car, and I would swell with pride that my older brother was there to pick me up. I’d hop in and he’d say, “Check the glovebox”. Every time there’d be coins so that we could go to the dairy [shop] for lollies on the way home. Time with Roddy was the best; he’s got an adventurous spirit and endless energy, and anything we did together was fun.

My brother Beefy has a similar sense of adventure but is more of a loose cannon. He is hilarious, unpredictable, and embarrassing (mostly intentionally!). I remember one time he wanted McDonald’s. We pulled up at the drive-through speaker, and he reeled off the biggest order – I’m talking several combos. But when we drove up to the payment window, he realised that he didn’t have his wallet – your guess is as good as mine as to whether he actually had it! – and neither did I. So, before I knew it, Beefy had opened the passenger door and gapped it down the road as fast as he could. I was left sitting in the drive-through, holding up a long line of cars, and dealing with an impatient and rather perplexed sales attendant. I arrived home to find Beefy relaxing on the couch. He looked up casually and said, “Oh, hey Nerdy, where’ve you been?” That’s Beefy in a nutshell: oblivious to social norms, in his own little world, and incredibly forgiving and ready to move on.

Nerdy has been my nickname since intermediate school, and for good reason: I loved sticky notes, was a mad swat, and lugged a schoolbag the size of a house around on my back. Beefy loves to give nicknames. My mum was Neville, named after a collectible card that you got in a chip packet as a kid. Roddy’s name became Cockroach, because he’s quite a small guy. And my dad is Big-balls: no explanation needed there.

I loved it when dad came home from a trip. He’d walk in the door in his crisp uniform, smelling of the excitement of being on an aeroplane, and give me the biggest hug. Dad and I have a very special relationship. Like the rest of our family, he is loving, thoughtful, always there for you, and up for a laugh. One weekend he took me to a speech and drama competition. I was very studious as I rehearsed my lines for a monologue of Oliver Twist. Once on stage, it all went smoothly … until I got to “Please Sir, can I have some more”, at which point I caught my dad’s eye. He was sitting in the front row, mouthing the words dramatically. It took all my grit not to crack up laughing on stage – something that wouldn’t have gone down well with the very serious judges of the local high school competition.

Figure 1. Images of Nerdy and Beefy.

A part of us was gone: grieving mum. Looking back, it must have been really difficult for dad: the sole breadwinner with two teenagers and a young-adult son with a disability. Dad’s life consisted of long hours on even longer trips, then coming home and getting straight into mum-dad duty – there for whatever we needed or wanted. He worked extra jobs, and never missed a sports game or school event when he was home. All this after recently losing his wife of over 20 years, something that only now, married with children myself, I can begin to comprehend.

It was hard on Roddy too, not that he ever said it. But trying to do well at university, have a social life, work part-time, and look after your little sister, all while grieving the loss of your mum, was a lot. At a time when his mates would have been hedonistic, he had a big responsibility.

I also know that Beefy was struggling. For a young man whose life revolved around consistency and stability, losing mum was especially hard. It took him a long time to understand mum’s passing, and he still grapples with the concept of her being gone. He has experienced many waves of depression, become a chronic hoarder, and has issues with aggression, but has received very little support (not for our lack of trying). People don’t realise how deeply he feels, perhaps because he cannot express it in words, nor how hard it is for him to comprehend the concepts of death and loss.

Then there’s my experience. Losing mum and dealing with the many changes to my family is a painful topic. I was *so* angry back then, and I remain livid today. We had spent 14 years hand-in-hand, singing songs, taking walks, and me being her Gorgy [gorgeous] Girl. Every day after school she’d pick me up and take me to the café for a hot chocolate and a chat. Whenever I was with her, I felt like I was her whole world. I never had to doubt that she would be there. So, being told one day that she had six weeks to live was earth shattering.

The saving grace was that mum lived for six months, and she made that time truly special. But it was hard. Over that time, I hid my pain, because I was so afraid of what I was feeling, and I was scared that I’d make mum sad if I opened up. I remember many nights in bed, buried deep under my covers, crying to my cat, Tom. He was the only one that I dared tell how I was feeling. But one night, mum came in and lay next to me. And for the first time in that whole journey, I let her in. I told her how scared I was, and I begged her not to go. I *pleaded* with her. And she listened and comforted me. She said she’d choose a gravesite somewhere nice and quiet where she could watch me. She did, and it remains a place that I love to go. I can still feel her lying next to me in my single bed, the familiar smell of the nighties she always wore, her curly hair soft against my face. Soon after that night, I went on holiday to our family friends’ place. Returning, instead of taking me home, they brought me to a hospital. Walking into mum’s room, I was confronted by her smallness, her frailty. Suddenly she *looked* sick, and there was no way I could avoid it anymore. I had to face the reality that our time together was coming to an end.

When mum eventually passed, I felt relieved for her: it had been a hard battle. But I was so deeply hurt to have lost the person that I needed the most. Losing mum rocked my world in the deepest sense, but for many years I wouldn’t let the loss affect me. I went to school a week after she died and worked diligently to always be okay. I excelled at school because I tried to convince myself that if I was doing well, then everyone else would think that I was okay … and maybe I would be?

Just the two of us: Beefy and Nerdy. Life could be lonely, especially once Roddy moved out a few years after mum died, and it was just me and Beefy when dad went away. Beefy goes to bed at about 6pm, so I had many nights eating dinner alone, doing my homework, and watching TV. And Beefy and I argued a lot. I went through my teenage years with all the hormonal sass that brings, and Beefy’s behaviour was challenging: even little tasks like brushing teeth and taking a shower became a battle.

Adding to my loneliness was the sense that I was different. None of the other girls at school had been through a loss like mine, had a sibling with a disability, or did any care responsibilities. I never spoke about any of it, but I *yearned* to. I longed to meet other people like me, to talk about our sadness, frustrations, gripes, and guilts. But I thought no one else was going through what I was. I felt completely alone.

On top of that, my grief started to creep into my life in the strangest ways. I became increasingly anxious, to the point that I feared going out. My mental health got so bad that one day when I was 22, it all became too much. I was in my bedroom on the phone to a friend, dad cooking dinner downstairs, and I broke down. I couldn't handle what was happening to my body and my mind. I asked my friend to call dad for me, and he came upstairs. He talked me through the hardest point in my life, got me help, and for months supported me back to good mental health. He was selfless and caring: everything a mum-dad should be. I learned that I had anxiety and depression, because I had never grieved the loss of my mum and the changes in my life thereafter. I had repressed so much that my body was telling me that enough was enough. My coping tank was too full. I should have accepted offers for support all those years earlier, but I wasn't ready. The loss was of such a magnitude that it was simply too great to face.

I still grieve to this day, but now I relish the memories. I think of mum every day because, as my husband says, I am strong enough to keep her front-of-mind.

Where is the support? The services saga. I still care for Beefy too, alongside my dad. Beefy is finally in a full-time care facility, where he is safe and happy. But he is being moved on. This is just another frustration in our long saga with services. We have faced constant battles with disability funders and providers. Beefy is often put in the "not disabled enough" category by providers (for whom mental illness and behavioural problems don't seem to count), and the "too hard" basket by care staff (for whom *unknown* mental illness and behavioural issues very much count). The constant need to be a squeaky wheel is worth it to access the services, but they are a strain on our family, and everyone's mental health, including Beefy's. The predictability and security that Beefy lost when mum died has only been exacerbated by inconsistent services.

My dad is getting older, and I wonder what life will look like in the years to come. I used to think that Beefy would live with me but, as a mum now, I realise that would be too difficult. I live with a lot of guilt about that, and about the decisions I've made with Beefy as a teenager, I didn't always make the best calls or put him first. But I also learned a great deal from my experiences. My work ethic, maturity, and perspective all grew from my roles and experiences in my wonderful family. I have no doubt that caring for Beefy put me in good stead to succeed in many facets of life.

Looking back on my experience, the main thing I wish is that I'd *known* about young caring. I see 14-year-old me, feeling lonely and different, and I imagine what an impact that connection with other young carers would have had for me and Beefy. And I see 25-year-old me, excited to discover my young carer identity, but let down that the realisation came too late, and that no supports existed anyway. Something had to change.

My strong desire to contribute to redressing this invisibility of young carers has led to my doctoral research into the experience of being a young carer in Aotearoa/NZ, with the overall goal of using young carers' own voices to inform care and disability policies and services. I hope my study will open conversations that will lead to the kinds of changes that our NZ young carers and their families deserve. To honour the uniqueness of the NZ context of this study, I share a prominent Māori whakataukī[9] that echoes the embeddedness of this thesis, and any actions that follow, in the voices of NZ young carers.

Ko te ahurei o te tamaiti ka ārahiā o tātou mahi.
Let the uniqueness of the child guide our work.
(Anon, whakataukī).

Background

There are only seven published studies on young caring in NZ. However, the desire to meet the needs of young carers is evident in the second and third iterations of the NZ Carers' Strategy Action Plans (Ministry of Social Development [MSD], 2014, 2019). The NZ Carers' Strategies (MSD, 2008, 2014, 2019) are the central documents providing the framework from which the government offers carer supports, and are updated in five-yearly cycles to remain at the forefront of caregivers' needs. The inaugural strategy in 2008 marked the government's commitment to meeting the needs of family carers, with the subsequent two strategy iterations demonstrating the government's continued pursuit of that commitment. In the second (MSD, 2014) and third (MSD, 2019) iterations, the government identified several sub-sets of caregivers who faced additional challenges, and thus required targeted attention, including Māori, Pacific, younger, and older carers. The focus in these strategies on younger carers aged "between 15-24" is warranted because caring is understood to affect their "participation in school and study, and the usual things kids do", and can "impact on their opportunities in later life" (MSD, 2019, p. 9).

The government soon realised that little is known about NZ young carers. This realisation led to the first of five serendipitous opportunities that resulted from growing awareness of my research. It is important to acknowledge these opportunities because, as a former young carer, I have been active in policy and advocacy roles, and have thus been involved in some of the key NZ young caring initiatives. I took up each opportunity due to my theoretical commitment to Bronfenbrenner's (2001) Bioecological Systems Theory, which encourages research that enacts real-world change for participants [discussed in Chapter Three].

The first serendipitous opportunity came when the Ministry of Social Development (MSD) commissioned me to write a Young Carer Evidence Brief based solely on my literature review (Donnan, 2014), which they used to inform the 2014 Carers' Strategy (MSD, 2014). In response to the Brief, and other studies' recommendations, the 2014 Carers' Strategy sought to meet young carers' information needs, via assembling and disseminating several informative booklets for young carers and educators[10], and establishing a young carer Facebook page[11]. The second opportunity came when videographer Michelle Vergel de Dios asked if I would be part of her documentary on NZ young caring. The resulting video[12] became the most effective recruitment method (discussed in Chapter

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[9] A Māori proverb, which Pohatu (2003) described as "valued and wise cultural sayings" (p. 16).
[10] e.g., http://carers.net.nz/wp-content/uploads/2017/03/YOUNG_CARERS_BROCHURE_WEB.pdf
[11] https://www.facebook.com/youngcarersnz/
[12] https://www.dropbox.com/s/pkxwqm8wk0ihzmr/Young%20Carers%20-%20Inspiring%20Stories%20Film%20Competition%20Entry-HD.m4v?dl=0

Three). The third opportunity was my involvement in the MSD-funded and Carers New Zealand (Carers NZ)-led re-establishment of Young Carers NZ (YCNZ) in 2014. This came about as the inaugural 2005 organisation had been unsustainable long term. YCNZ, which shares similar aims to Carers NZ, is a national not-for-profit special interest group that aims to provide information, recognition, training, support, and an online community for young New Zealanders who provide care (Carers New Zealand [NZ], 2019). The fourth opportunity that I accepted was to act as Convenor for the reinstatement of a Young Carers Advisory Group in November 2014 – after the original group disbanded several years after the 2005 launch – so that young carers' own voices could lead the goal of translating their needs to change-making platforms. The reinstated Young Carers Advisory Group was an initiative of YCNZ, and was made up of five demographically, ethnically, and regionally diverse current and former NZ young carers, who supported various family members with wide-ranging care needs. A key challenge that emerged, however, was recruiting young carers to be part of the Advisory Group and YCNZ, due to the largely hidden nature of young caring in NZ. Despite a real effort to raise awareness and recruit new members, YCNZ membership uptake has been minimal and, like its predecessor, the Advisory Group ceased in 2016, as the young carers transitioned out of care, or into *adult* caregiving.

The MSD's ongoing interest in my research led to the fifth opportunity in 2018, to write a second commissioned Evidence Brief that incorporated key aspects of my findings[13] (Donnan, 2018). This second Brief, outlining young carers' needs extending beyond information, and as stated by young carers themselves, contributed to the greater breadth of support included in the latest Strategy. Specifically, the 2019-2023 Carers' Strategy Action Plan *Mahi Aroha* (MSD, 2019) aims to, in the context of NZ, identify the prevalence of young carers, ensure young carer representation in key issues by re-establishing the Young Carers Advisory Group, and invest in further research targeted at the experiences and needs of young carers. With NZ young carers being posited as "a vulnerable, invisible group who require recognition and respect" (Hanna & Chisnell, 2019, p. 7), then such actions are imperative in order to gain greater understanding and awareness that can guide the implementation of effective policies and services that will address their needs. The 2014 and 2019 Strategies represent the first instances of young carers being included in any NZ policy.

Internationally, however, over the past 30 years, young carers have been identified and researched in the United Kingdom (UK) (Aldridge & Becker, 1993; Dearden & Becker, 1995; Frank, 1995), Australia (Gays, 2000; Noble-Carr, 2002), and more recently in the USA (Kavanaugh, Cho, & Howard, 2019), Canada (Stamatopoulos, 2018), Europe (Leu, Frech, & Jung, 2018), Sub-Saharan Africa (Evans & Skovdal, 2016), and India (Sahoo & Suar, 2010). As a result, a greater depth of understanding has been achieved about young carers' characteristics, roles, and support needs. From the limited national research, NZ young carer needs appear to be largely similar, so that themes established in international literature also appear pertinent to NZ. The international and national studies identify that young carers are most often school-aged, the eldest female in the household, and caring for their mother or for someone with a disability or mental illness (Leu, et al., 2018; Sempik & Becker, 2013). Caring is more likely to take place in sole-parent households, where a dearth of

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[13] Both Evidence Briefs (Donnan, 2014, 2018) remain confidential until after my PhD is published.

support is available for the person requiring care, and among ethnic minority and immigrant populations (Aldridge, 2018; Sahoo & Suar, 2010). An estimated two to eight percent of all children, youth, and young adults[14] in first-world societies are thought to be young carers (Becker, 2007; Day, 2015). However, the hidden nature of young caring results in prevalence data being difficult to gather (Becker, 2007). The Mahi Aroha Carers' Strategy (MSD, 2019) used NZ Census[15] data to identify that approximately 40,000 (9%) of the estimated 430,000 NZ carers were young carers aged between 15-24. Considering that across several studies, the mean starting age of young caring varied between nine and 12 years (Dearden & Becker, 2004; Leu et al., 2019; Sempik & Becker, 2013), with some studies identifying that care can begin as young as three to six years old (Barry, 2011; Lackey & Gates, 2001; Noble-Carr, 2002), then it appears that NZ could have a significant young carer population.

Whilst young carer definitional discrepancies exist between studies, researchers are overwhelmingly in agreement that the substantial level of tasks carried out distinguishes young carers from their non-caring peers (e.g., Leu et al., 2018). The extent, nature, and duration of care seem to principally rely on the nature of the care recipient's disability or illness (e.g., Aldridge & Becker, 2003), resulting in young carers' tasks being dynamic rather than predictable (e.g., Aeyelts, Marshall, Charles, & Young, 2016). The most common tasks undertaken include domestic chores extending to managing household finances, emotional support including providing counsel in times of distress, intimate care comprising toileting and bathing, and nursing support in the form of administering medications and changing bandages (Becker, 2007; Leu, et al., 2018; McDonald, Cumming, & Dew, 2009).

Young carers experience a range of positive and negative health, social, educational, and vocational impacts as a consequence of their roles. Negative short- and long-term physical and emotional health outcomes are highlighted by many researchers (Heyman, 2018; Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Sempik & Becker, 2013), alongside limited social networks for young carers (Aldridge, Cheesbrough, Harding, Webster, & Taylor, 2016; Levine et al., 2005; Stamatopoulos, 2018). Educational implications are also frequently identified, with young caring being found to affect school experiences and attainment (Becker & Sempik, 2019; Ferguson, Griessel, Lao, Singh, & Ure, 2001; Moore, McArthur, & Morrow, 2009). Of particular concern are young carers' reduced educational completion rates compared to their non-caring counterparts, which can result in adolescents becoming Youth not in Education, Employment, or Training (Y-NEET) between the key transitional ages of 16-19 (Becker & Sempik, 2019; Hounsell, 2013; IARS International Institute (IARS), 2016). Studies commonly highlight the difficulty of accessing and completing university or college despite young carers' desires to attend (Cass et al., 2011; Robison, Egan, & Inglis, 2017; Stamatopoulos, 2018). This is reflected in young carers' employment opportunities, with the lack of

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[14] I employ the term 'children, youth, and young adults' when referring to young carers in order to acknowledge the extended age parameters of young caring (up to 26 years) used in some studies (Becker & Becker, 2008; Hamilton & Adamson, 2013; McDonald et al., 2010) (see Chapter Two for full discussion of age parameters).

[15] It is important to note that the NZ Census collected data on caring only in the four weeks prior to the Census, and only included persons aged 15 and over (Grimmond, 2014).

vocational success for young carers being commonly cited (Becker & Sempik, 2019; Noble-Carr, 2002; Warren & Edwards, 2017). Despite the many negative outcomes, however, positive impacts of young caring are also evident. Researchers describe the strengthening of familial bonds and young carers' enjoyment of their roles, alongside their development of resilience and empathy (Aldridge, 2009; McDonald, Cumming, & Dew, 2009; Shifren & Kachorek, 2003).

Internationally, a range of policy and service initiatives exist for young carers. In the UK, young carers have legal rights as carers that enable them to access dedicated information, respite, education, financial, and counselling-based programs and support (Tullo, 2014; Frank & Thompson, 2015). Similarly, in Australia, a range of supports exist for young carers, with a key initiative being the Young Carer Bursary Programme that financially backs young carers to stay in education. Despite such advances, however, studies emphasise the inconsistencies in policy and service implementation within and between countries (Aldridge, 2018; Becker & Sempik, 2019; Hanna & Chisnell, 2019). This is due to the complexity of providing age-appropriate services to a widespread group of largely unrecognised young carers (Kennan, Fives, & Canavan, 2012), and the impact of a predominantly grassroots and philanthropically funded model of support in light of widespread governmental fiscal austerity (Aldridge, 2018; Stamatopoulos, 2015a). As such, despite young carers being increasingly included in research, services, and policy, in many countries they remain "children in need" (Aldridge, 2018, p. 155). Young carers' key support needs include disability- and illness-related information (Kavanaugh et al., 2019), counselling services (Noble-Carr, 2002), and greater teacher awareness of their caring roles (Lakman, Chalmers, & Sexton, 2017; Leu et al., 2019). Becker and Sempik (2019) highlighted the importance of studies being undertaken with young carers in order to inform any policy or service implementations.

Overall, increasing international literature is emerging that adds a greater depth of understanding of young carers' experiences, which results in key policy and service initiatives being implemented to meet their unique needs. However, in NZ, both the body of scholarship and policies and services initiatives remain in their infancy.

Research Problem and Purpose

Despite the latest NZ Carers' Strategy Action Plan (MSD, 2019) providing some promise for public policy and practice initiatives moving forward, there remains a dearth of research into the experiences of NZ young carers. In particular, lacking in current NZ research are studies that include participants[16] that represent all NZ's major population groups – including Pākehā[17], Māori, Pacific and, increasingly, Asian – and that afford agency to young carers by accessing their own conceptions of their roles, including during and after their transition to adulthood, and contribute to relevant public policies and practices. In response to gaps and limitations in the literature, the purpose of my study was to examine young caring in Aotearoa/NZ, by recruiting diverse current and former young carers to share their perceptions and understandings of their carer identities and experiences. Their experiences were examined within the context of wider social and institutional influences, with the

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[16] Please note I use the terms 'participant' and 'young carer' interchangeably throughout the thesis.
[17] The Māori term for "New Zealanders of European/British ancestry" (Webber et al., 2013, p. 43).

intention of using their own perceptions of their needs to identify persistent gaps in the policy and services landscape, and to identify new strategies for reaching out to this group of carers. As such, my study meets the need for more research that can inform change. The key research question guiding my study was: What does it mean to be a young carer in Aotearoa/NZ? Six sub-questions focused the research, and addressed: the circumstances creating and maintaining young caring roles; young carers' perceptions and understandings of their carer identities; the nature and extent of care tasks carried out; the ongoing health, education, vocation, and social effects of being a young carer; the impact of public policies, services, and practices on young carers' use of formal supports; and key ways in which young carers' insights could inform care policies and services.

One challenge I faced was finding young carers to be participants. Reflecting the well-documented difficulties of recruiting young carers, more traditional methods for recruitment, including posters displayed at universities, youth organisations, and in the community [Appendix A], were unsuccessful. An unplanned but innovative sampling method that worked was the sharing, via social media, of a 5-minute video (Vergel de Dios, 2015) that I was invited to co-create with a videographer – Michelle Vergel de Dios – that focused on my own experience as a young carer and the aim of the research project. In addition, I shared my experience and call for participants in-person with groups of young people, and in response to interest from key grassroots organisation and University of Auckland newsletters and magazines [Appendix A]. Over a year, I interviewed four current and 24 former NZ young carers about their current or former realities of caring. Four additional interviews were undertaken with service and agency representatives (three NZ and one international), which sought to offer background information pertaining to the service and broader sociocultural environment.

Sources of Information: Theory, Methodology, and Methods

The study is framed by Urie Bronfenbrenner's (2005) Bioecological Systems Theory (BST). BST focuses on the young carer within overlapping concentric circles of influence, each comprising a level. These levels (discussed in detail in Chapter Three), include: face-to-face interactions in the young carer's home (microsystem); connections between settings such as the young carer's home and school (mesosystem); contexts where young carers themselves are not present but which impact them, for instance, decisions made at their parents' workplace (exosystem); underlying belief systems and social and institutional environments within which interactions take place (macrosystem); and "constancy and change" over time in young carers and their immediate and wider environments (chronosystem) (Bronfenbrenner, 1992, p.119, 2001).

Participants each took part in one interview which, in line with the study's phenomenographic framing, sought to examine the "qualitatively different ways" that young carers understood their roles (Marton & Pong, 2005, p. 335). In keeping with the exploratory nature of phenomenographic interviews, I asked several broad open-ended questions, but the actual route of the interviews and the sequence of themes discussed were chosen by the young carers themselves (Marton, 1986). The focus of my research was gathering participants' own meanings about young caring, so the purpose of my analysis was to discover those meanings. The phenomenographic whole of transcript approach was used, so that I dealt with the whole narrative of each interviewee, rather than selecting and removing particular utterances (Bowden & Green, 2005; Bowden & Walsh, 2000). This approach enabled the exploration of similarities and differences within and between young carers' context-bound and relational conceptions of young caring (Bronfenbrenner, 1979; Marton, 1986). "Categories of description" were created through iterative readings of transcripts, with each category of description containing similar conceptions of young caring held by participants (Marton, 1986, p. 43).

Throughout the research process I wrote retrospective autoethnographic vignettes about my young carer role and related adolescent and adult experiences, triggered by what I was reading and hearing in the interviews. Autoethnography enabled me to reflect upon how the research was impacting me, and how it may be affecting my participants, and to enact continual researcher reflexivity (Sikes & Hall, 2019). I chose not to include the vignettes in the thesis, however, in order to protect my family's stories, and respect their "desire for privacy, positive representation, and control over the stories of their lives" (Ellis, 2009, p. 3).

The study's BST and phenomenographic framing captured the experiences of young carers in their own voices, by positioning young carers at the centre of the research, recognising their wider contexts, identifying interdirectionality as young carers were both affected by and affected others, and acknowledging that young carers constructed their own realities (Bronfenbrenner, 1979, 2001; Marton, 1981; Marton & Pong, 2005). BST and phenomenography encouraged me to regularly reflect on my own conceptions of young caring, gained in my 11 years (aged 14-25) as a young carer. In addition, BST supported a social justice orientation, as Bronfenbrenner (2001) asserted that research is most effective when it affects "social policies and practices" that can bring about real-world change (p. 4).

Significance of the Research

The research is significant for several reasons. One significance lies in the accidental discovery of an effective innovative recruitment method – a video of my personal story posted on social media – that enabled young carers to identify with my experiences. Through this method, it appears that I was able to become the only NZ study to successfully recruit via encouraging self-identification rather than using social services or other agencies as gatekeepers. The significance of the study also lies in the rich insights gained into what it means to be a young carer in Aotearoa/NZ. Specifically, the research identified the holistic nature of young caring, with care tasks meeting not only unwell loved ones' physical needs, but also contributing to their emotional, social, and spiritual wellbeing. In addition, the study identified the profound effect of nonfinite loss – a loss experienced even when a death has not occurred, for instance, when a degenerative disease is diagnosed (Bruce & Schultz, 2002) – so that it was not simply enacting care tasks themselves, but the loss underlying such tasks, that defined the experience and impact of being a young carer in Aotearoa/NZ. The thesis also highlighted key discrepancies between the existing definition of young caring used in NZ research, policy, and practice – including in this study – and NZ young carers' lived experiences, that resulted in participants' ongoing resistance to self-identifying as young carers. Finally, the study recognised the value of taking a family/whānau/aiga-wide approach to understanding young caring in its broader context, incorporating all levels of Bronfenbrenner's BST.

Three potential limitations were inherent in my research. First, biases may have emerged due to my 11 years as a young carer, which could have influenced how I interpreted the findings. Certainly, researching as an 'insider' (Berger, 2015) could have resulted in blurred boundaries between myself and the participants (Dickson-Swift et al., 2006; Johnson, 2009), wherein it would have been easy for me to move "into the realm of friendship or therapy" (Butler, Copnell, & Hall, 2019, p. 229). In addition, I could have imposed my "own values, beliefs, and perceptions" (Berger, 2015, p. 224) on the participants, and thus missed some meanings embedded in their stories. Researcher reflexivity is posited as a key means of mitigating such negative effects of being an insider researcher (Berger, 2015; Dickson-Swift et al., 2006). In fact, Johnson (2009) asserted that reflecting on personal experiences related to the research enables researchers to "draw on our closeness and knowledge of the topic", which in turn can "play a significant and beneficial role" to the study by gaining "a greater insight into" participants' lives (p. 29). As such, I used autoethnographic writing throughout the thesis process as a way to continually reflect on my reactions, in an attempt to mitigate against possible bias. In addition, I had regular counselling in order to learn effective means of supporting the young carers, whilst maintaining the boundaries of the researcher-participant relationship (Dickson-Swift et al., 2006).

Second, the extent of impact on myself was unexpected. During the interviewing process, data analysis, and writing up of the thesis, I was confronted with the unexpected depth of emotion that the participants' stories elicited in me. I not only faced the emergence of buried or forgotten experiences, but also reconceptualised my adolescence and young adulthood, adding sometimes painful meanings to past experiences, now looking back as an adult and as a mother myself. This was in addition to the emotion I experienced hearing the young carers' stories, and sharing in their emotional responses. According to numerous studies, my unpreparedness for the extent of my emotional response is not uncommon, especially among researchers exploring sensitive topics, addressing vulnerable populations, or investigating close-to-home experiences (Johnson, 2009; Dickson-Swift et al., 2006; Sikes & Hall, 2019; Tillmann-Healy & Kiesinger, 2001). Certainly, Kiyimba and O'Reilly (2015) asserted that the "potential emotional impact [on the researcher] is often not something which is accounted for in the planning stages of research" (p. 469). Regular counselling and autoethnographic writing were thus integral methods "for dealing with the emotional burden of sensitive research" (Johnson, 2009, p. 42) throughout the thesis process, to provide me with space to be vulnerable, unpack my own experiences, and receive support when I felt overwhelmed (Dickson-Swift et al., 2006; Sikes & Hall, 2019).

Third, my identity as a Pākehā New Zealander could have limited my analysis of Māori, Pacific, and Asian young carers' responses. In turn, I continually reflected on my own assumptions regarding young caring and key issues raised in interviews via my autoethnography. In addition, I sought to learn about Māori, Pacific, and Asian beliefs and understandings of key issues raised, to deepen my ability to understand the culturally-relevant aspects of their experiences.

Thesis Roadmap

In Chapter Two, the literature review will embed the thesis within the wider disability, caregiving, and international and national young caregiving contexts. Specifically, the review will present a thematically structured, cross-cultural examination of similar themes in local and global young caring scholarship, policy, and services, in order to facilitate the reader's understandings of, and locate the research findings within, the young caregiving field. The review will highlight the absence of NZ research, policies, and services addressing young carers' needs, and highlight key gaps in research that this study aimed to fill. The purpose of the thesis to examine the experiences of young carers in Aotearoa/NZ will be explained.

Chapter Three will present an in-depth look at how this research purpose was achieved. The theory and methodology chapter begins with an explanation of the BST research framing, followed by a close look at the phenomenographic methodology, participant interview and researcher autoethnographic information sources, and ethical considerations. Such an examination provides the rationale for my choices, and details how the rich information pertaining to NZ young carers' experiences was achieved. The chapter will also address the difficulty of recruiting NZ young carers without using gatekeepers, and outline the measures taken to achieve this goal.

The findings will be presented in four findings and discussions chapters, founded on participants' own conceptions of what it means to be a young carer in Aotearoa/NZ. The key argument across these four chapters is the need to address the *overwhelming* nature of young caregiving roles in NZ, which contributed to many of the negative educational, social, vocational, and health outcomes for young carers.

Chapter Four speaks to the nature and extent of young carers' roles. A key finding is the *holistic* nature of young caregiving, which encompasses physical, emotional, social, and spiritual care. These four dimensions of care are examined within a specific Māori health framework, Te Whare Tapa Whā[18] (Durie, 1994), with which young carers' roles closely align. The chapter then discusses the difficulty of ascertaining the true nature and extent of young caring roles, which meant that aspects of caregiving can go unseen, even to participants' themselves. In this chapter, *nonfinite loss* (Bruce & Schultz, 2001) arose as a new construct that has not been explored in this field. The discovery of significant nonfinite loss underlying participants' care tasks meant that the aim of their caring was to 'close the gap' between their imaginings of their loved ones as they were or 'should' be, and the reality in light of their illness or disability. Ultimately, Chapter Four argues that young carers often carry out overwhelming care loads – a finding that runs throughout the subsequent three chapters.

Chapter Five addresses how young carers perceive and make sense of their young caring identities. The chapter begins by highlighting the lack of a shared NZ young carer identity, and then presents a key finding, being participants' conceptualisations of young caring as a *familial- and culturally-normal or natural role*. The chapter then identifies that the existing definition of young

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[18] Te Whare Tapa Whā is one of the most common Māori models of health and wellbeing (Durie, 1994). Other models include Pere's (1985) Te Wheke (The Octopus), and Durie's (1999) Te Pae Mahutonga (Southern Cross Star Constellation).

caregiving employed internationally and in NZ is in tension with young carers’ own understandings of their everyday natural family/whānau/aiga support roles. Specifically, the tendency for the existing definition to only acknowledge young carers’ overwhelming or crisis-related care will be discussed. Overall, Chapter Five will argue that until our definition of young caring is reflective of NZ young carers’ everyday care experiences and understandings, then their desires for self-identification and access to relevant services and supports will remain unmet.

Chapter Six expands on many of the ideas outlined in the previous chapter, by exploring the familial, cultural, societal, and service-related ‘push’ and ‘pull’ factors that create and maintain young carers’ roles. Key factors pulling participants into caregiving and underlying their everyday roles will be explained, including the cultural and familial normality of young caregiving, and positive outcomes of care including the development of cherished relationships. Thereafter, the many situations pushing young carers into often-overwhelming care will be explored, for instance, the expectation felt by families to care for their own, the need to support primary *adult* carers experiencing burnout, and, of greatest impact, the inadequacy of existing services. Ultimately, Chapter Six contends that whilst young caring is a natural role in Aotearoa/NZ, the many factors pushing children, youth, and young adults into overwhelming caregiving means that care no longer represents a natural familial or cultural model of support, but instead reflects a forced choice made by the family/whānau/aiga and young carer.

Chapter Seven continues to build on our understandings of what it means to be a young carer in Aotearoa/NZ, by exploring the educational, social, vocational, and health implications of young caring, especially during the transition to adulthood. Participants’ negative educational experiences and outcomes despite their positive school attitudes will be discussed. This section incorporates the socialisation impacts of young caregiving, as a lack of opportunities to form deep friendships had a significant impact on participants’ sense of school connectedness and enjoyment. The chapter also considers young carers’ overrepresentation among early school exit and Y-NEET (Youth not in Education, Employment or Training) statistics, alongside their constrained higher education and vocational opportunities. Finally, an overview of the health implications of young caring will be presented, with a key focus on the high instance of unaddressed poor mental health among participants, which often endured into adulthood. Wider exosystem, macrosystem, and chronosystem influences will be discussed throughout the chapter (Bronfenbrenner, 2001), as family/whānau/aiga and young carers’ forced choices are highlighted. The overall argument of Chapter Seven will be that young caring results in significant negative impacts for young carers, stemming not simply from their roles as caregivers, but from wider injustices that result in overwhelming care loads.

Chapter Eight presents the conclusions and recommendations. The chapter will weave together the many argument threads to tell a story of what it means to be a young carer in Aotearoa/NZ, from the perspective of the participants. The principal argument of Chapter Eight is that whilst young caring is a natural role, the overwhelming nature of care brought about by injustices existing at the mesosystem, exosystem, and macrosystem levels for individuals with disabilities, their primary *adult* carers, and wider family/whānau/aiga, results in considerable negative educational, social, vocational, and health impacts for young carers. As such, it is the key factors underlying young carers’ overwhelming roles, rather than simply the existence of young caring in itself, that requires considered attention. Key policy, service, and research recommendations will be presented to address the overwhelming nature of young caring, and thus mediate some of the negative impacts experienced, with some of the recommendations extending beyond young carers to recognise their embeddedness within their family/whānau/aiga units and wider communities. In doing so, Chapter Eight will outline key ways in which young carers’ insights can inform care policies and services, including the possibilities opened up by engaging with Government and organisations during, rather than solely at the end, of the research.

CHAPTER TWO

Literature Review

This literature review provides a thorough examination of the international and national young caregiving scholarship. I begin with the search statement, followed by an exploration of the NZ, disability, and caregiving contexts in which this study is embedded, to provide a deeper understanding of the experiences and needs of NZ young carers outlined later in the thesis. Thereafter, a thematically structured, cross-cultural examination of similar themes in the young caring literature will outline current knowledge and understandings. In line with my privileging of the voices of young carers throughout my thesis, I will embody young carers' voices where possible in the literature review.

I completed an extensive literature search across multiple disciplines and fields, spanning 1990-2019. My search used a range of national and international care and disability terms – including young carer, youth caregiver, next of kin – with truncations employed to increase search "hits" (e.g., young car* to capture carer(s), caregiver, caring) that were updated as supplementary terms surfaced. Literature sources included: (a) databases (e.g., Google Scholar, ProQuest), (b) journals (for which email alerts were created), (c) books, (d) theses and dissertations, (e) policy documents, and (f) government and relevant organisation reports. Literature was accessed from the University of Auckland library, and through external organisation library and learning services nationally (e.g., Donald Beasley Institute, IHC Foundation). I expanded my search parameters to incorporate related bodies of literature (e.g., palliative care, cancer care). Further networking proved fruitful for new sources of literature, particularly at conferences, in exchanges with postgraduate students and staff within and outside the University, and through contact with key interest groups (e.g., University of Auckland Young Adult Research Group and Equity Office). My literature review therefore represents a wide breadth and depth of existing research relevant to my thesis topic.

NZ Context

It is important to embed this study within its specific context. Aotearoa/NZ is a small, relatively remote island nation of just over 4.9 million people, located in the Pacific Ocean (Statistics New Zealand, 2019). Three official NZ languages are recognised: Te Reo Māori, English, and NZ Sign Language. Whilst NZ culture is largely Western-influenced, communities are becoming increasingly diverse (IOM, 2015), with Census data identifying NZ's major ethnic groups as European, Māori, Asian, Pacific, Middle Eastern, Latin American, and African (Statistics New Zealand, 2014). Today, NZ has a rich cultural diversity, with the largest city Auckland being the fourth most diverse city in the world (IOM, 2015) with 39 percent of its population born overseas (Statistics New Zealand, 2014a).

In order to truly understand the culture, it is essential to recognise the influence of tangata whenua (indigenous) Māori people. Māori arrived as the first settlers over 1000 years ago from Eastern Polynesia. The 1840 signing of the Treaty of Waitangi – NZ's founding document – marked the beginning of, and continues to define, the relationship between Māori and Pākehā and other immigrants (O'Malley, Stirling, & Penetito, 2011). The New Zealand Government (2019) highlighted the place of Māori culture as “a big part of NZ's identity, so respecting, preserving and promoting it is vital” (p. 1). More than one in seven NZ residents is of Māori descent (nearly 700,000 people) (Statistics New Zealand, 2013).

Whilst NZ has 11 main centres with populations of 60,000 plus, the relatively small population and 1,600km length of the country divided into two main islands means that individuals can live far from one another, and far from formal services. At the time my study was undertaken (2013-2019), the country was experiencing record-high housing and rental prices and living costs, which were particularly impactful on beneficiary households (Statistics New Zealand, 2019a).

It is also important to understand disability and illness in the NZ context. This is because attitudes towards, and the treatment of, individuals with disabilities and illnesses have implications for understanding the experiences and needs of NZ young carers. Whilst numerous disability models exist – for instance the Human Rights (Degener, 2016) and Affirmation (Swain & French, 2000) models – two key models, medical and social, represent the historical shift in policy, services, and societal thinking regarding illness and disability in NZ. These models are particularly important in understanding the epistemology of how service providers have historically and currently ‘treat’ the individuals for whom young carers provide care.

Historically, the dominant framework for understanding and responding to disability in NZ was the medical model (Hickey, 2006). According to the medical model, a person’s functional limitations (impairments) were the source of disadvantages experienced (Crow, 2010). From a medical perspective, individuals with disabilities were contrasted against healthy, normal, fully contributing members of the community (Hedlund, 2009). Under the guidance of the medical model, services and society reacted to individuals with disabilities by stigmatising, criminalising, marginalising, medicalising, and institutionalising them, in an effort to isolate people with disabilities from the rest of society (Crawford & Ostrove, 2003). As the main form of segregation, institutionalisation, in which patients “were, in a real sense, out of society” (Jenkins, 1991, p. 572), was often carried out.

Through the evolution of disability rights, however, it is evident that time and events have transformed NZ societal views of individuals with disabilities (Hickey, 2006). A key legal transformation was the closure of the Kimberley Centre, the last large-scale NZ institution for individuals with disabilities, in 2006 (Moriarity & Dew, 2011). The goal at the core of this deinstitutionalisation was to achieve inclusive communities, through the integration of individuals with disabilities into society (Clement & Bigby, 2009; Robertson et al., 2001). Such an integrative goal aligns with the social model of disability, born out of the experiences of individuals with disabilities who challenged the dominant individual models espoused by nondisabled people (French & Swain, 1997). The crux of the social model is the disassociation of impairment – the functional limitation(s) which affects a person’s body – from disability – the loss or limitation of opportunities as a result of direct or indirect discrimination (Crow, 2010). The overriding emphasis is on the removal of disabling barriers through social change, to end discrimination against people with disabilities (Crow, 2010).

Despite this removal of barriers, there remains a social distance between individuals with and without a disability, which Swain and French (2000) call a “disability divide” (p. 569). Research on community integration consistently confirms that it has led to greater *physical* community presence of individuals with disabilities rather than community *participation* in the form of new relationships with other members of society (Clement & Bigby, 2009). This is reflected in the 2013 NZ Disability Survey, which reports discrimination and loneliness being experienced "more often by disabled people", and participation in employment, popular leisure activities, and life satisfaction being less common among individuals with disabilities (Office for Disability, 2016, p. 5). Overall, despite a significant positive shift in societal attitudes, widespread misunderstandings of disability and illness still permeate NZ society, negatively impacting upon the lives of individuals experiencing disability (Hickey, 2006).

Caregiving

The latest NZ Carers' Strategy Action Plan (MSD, 2019) identifies carers as "anyone who cares for a friend, family, whānau or aiga member with a disability, health condition, illness or injury who needs help with everyday living" (p. 5). Whilst international literature commonly speaks about informal or family caregivers (e.g., Aldridge et al., 2016), in NZ, the terms whānau or aiga carers, supporters, or manaakitanga[19] are also used interchangeably "to describe the diversity of individuals, families and whānau who provide this support" (MSD, 2019, p. 5). The latest NZ caregiving statistics identify over 430,000 carers, meaning one in ten New Zealanders provides care (MSD, 2019). Data identifies that two-thirds of NZ carers are women, with Māori women being "more likely to be carers than women in other population groups", especially at a younger age (MSD, 2019, p. 8).

Existing research outlining the experiences of NZ *adult* family/whānau/aiga caregivers has resulted in a greater understanding of their experiences and needs (Collins & Willson, 2008; Lapsley et al., 2019; Moeke-Maxwell, Mason, Toohey, & Dudley, 2018). Six key aspects in NZ and international *adult* carer work provide some context to the experiences of NZ young carers. First, studies highlight an ever-increasing need for informal caregivers in NZ (MSD, 2019), due to: individuals' growing preference to be supported in their home (Lapsley et al., 2019; MSD, 2019); longer life-expectancies for people with illnesses and disabilities, extending to their need for support in middle and old age (Ministry of Health, 2011); and an ageing populace with individuals aged 65+ expected to make up 20–22 percent of the population by 2032, compared with just 15 percent in 2016 (Statistics New Zealand, 2013).

Second, caregiving has been identified as having economic benefits (MSD, 2019), with the value of informal caregiving estimated at NZ$10.8 billion (Grimmond, 2014). Caregiving has also been cited as improving the care recipient's physical and emotional wellbeing and sustained independence and community participation (Goodhead & McDonald, 2007; MSD, 2019). Furthermore, studies have highlighted positive impacts for caregivers, such as closer bonds with their loved ones (Pakenham, 2005), and a sense of satisfaction and achievement (Nikora, Karapu, Hickey, & Te Awekotuku, 2004; Roud, Keeling, & Sainsbury, 2006). Third, negative outcomes of caregiving are commonplace and can go unaddressed, including stress (Moeke-Maxwell et al., 2018), isolation (MSD, 2019), financial strain (Grimmond, 2014; Nikora et al., 2004), educational and vocational disadvantage (Grimmond,

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[19] A Māori word denoting "cultural and social responsibility" (Moeke-Maxwell, Nikora, & Te Awekotuku, 2013, p. 192).

2014; Worrall, 2005), and poor physical and emotional health (Goodhead & McDonald, 2007). Fourth, research identifies caregivers' desires for greater role recognition, respite opportunities, financial assistance, information, and service consistency (Goodhead & McDonald, 2007; MSD, 2019; Nikora et al., 2004). Fifth, *adult* caregiving literature has resulted in a number of key policy and service initiatives, targeted at improving the lives of family caregivers and the people in their care. These initiatives include: the establishment of Carers NZ in the 1990s to provide caregiver information, advocacy, and support (Carers NZ, 2019); the development of three national Carers' Strategies (MSD, 2008, 2014, 2019), "to provide government focus and direction on caregiver issues" (Goodhead & McDonald, 2007, p. 31); and the consideration of informal caregivers' financial and respite needs during Needs Assessments carried out to establish the service requirements of individuals with disabilities and illnesses (Goodhead & McDonald, 2007). Finally, *adult* caregiving research has also extended to addressing cultural differences in caregiving (Collins & Willson, 2008; Moeke-Maxwell et al., 2018). In particular, the experiences of Pacific and Māori informal caregivers are pertinent to providing context for the experiences of young carers in Aotearoa/NZ.

Figure 2. The Samoan Fonofale Model of Health (Health Hawkes Bay, n.d., p. 3).

Within Pacific cultures, and including Pacific people in NZ, "the extended family is touted as the model support network" with care ideally being "shared between extended family members" (Suaalii-Sauni et al., 2009, p. 24). Pacific family carers often support multiple aiga members, including those with a disability or illness and those without (Agnew et al., 2004). It is commonplace to marry traditional and Western models of care, for instance, by using traditional Samoan healers (fofo) alongside a range of Western health services including hospitals (Suaalii-Sauni et al., 2009). Pacific people are “very active interpreters of illness symptoms” (Norris, Fa'alau, Va'ai, Churchward, & Arroll, 2009, p. 1473), and use numerous models of care reflecting a Pacific perspective and philosophical values system (Agnew et al., 2004). Spirituality is a key aspect of all Pacific models of care, alongside an individual’s physical, mental, and social wellbeing (Agnew et al., 2004). For instance, using the metaphor of a Samoan meeting house, the Fonofale[20] model [Figure 2] highlights that “in order for the house to stand firm its core structure must exist and hold together – from the foundation to the posts and roof” (Suaalii-Sauni et al., 2009, p. 27), with one of the four posts connecting the foundation (family) and the roof (culture) representing spirituality. The Fonofale model reflects Pacific values “in its promotion of a holistic view of health care” (Agnew et al., 2004, p. 13).

Holisticity is also embodied in the concept of Hauora, “a Māori philosophy of health” that is strongly linked to wellbeing (Durie, 2004, p. 31). However, Kohere (2003) warns that simply translating Hauora as wellbeing does not acknowledge the Māori world view espoused in the concept, nor recognise the deeper meaning of the term as “the driving force for the unfolding of the potential of individuals to act in this world for and with others” (p. 23). The concept of Hauora is housed in Mason Durie’s (1994) Te Whare Tapa Whā health framework [Figure 3], which was developed “from an analysis of Māori views” (Durie, 2011, p. 29). Seen through the lens of Te Whare Tapa Whā, an individual’s health is viewed as a culmination of their Taha Tinana (physical wellbeing), Taha Hinengaro (mental and emotional wellbeing), Taha Whānau (social wellbeing), and Taha Wairua (spiritual wellbeing). Durie (2011) describes how all “four dimensions of health” (p. 29) that make up the four walls of the wharenui[21] represented in Te Whare Tapa Whā are integral to an individual’s overall health, with a “whole-person approach to healing” being advocated (p. 30). Te Whare Tapa Whā is not only integral for the “cultural knowledge contained in the model” (Durie, 2011, p. 30) but reflected a shift from Māori as passive to active service users with a voice regarding the care that

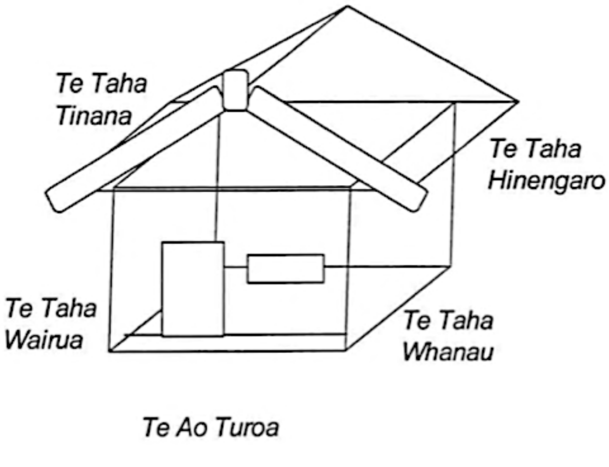

Figure 3. Te Whare Tapa Whā Māori Health Model (Durie, 1994, in Glover, 2000, p. 20).

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[20] Fonofale is a Samoan model of health widely attributed to Fuimaono Karl Pulotu-Endemann (Agnew et al., 2004; Ministry of Health, 1995, 1997; Pulotu-Endemann, 2001). This model has been used as an example because Samoa represents the largest Pacific diaspora in NZ, and because Fonofale is amongst the most common of the numerous Pacific health models employed in NZ (Agnew et al., 2004). Other models include the Te Vaka Afataga (Tokelauan) (Logologo, 1992), and Fonua (Tongan) (Tu’itahi, 2007) models.

[21] Māori meeting house (Metge, 1967).

they received (Durie, 1994). In turn, the four dimensions became “seen as platforms for an integrated approach to the delivery of health services to Māori” (Durie, 2011, p. 29), with the model continuing to be widely espoused as a kaupapa Māori[22] best practice model for care provision by NZ services and agencies (e.g., Egan & Timmins, 2019).

Collins and Willson (2008) stress that whānau is at the heart of caregiving relationships for Māori families, who often have a strong preference for whānau care over formal support systems. The concept of whānau is wider than the nuclear family. The concept includes “kin, as in whakapapa whānau [genealogically-related], or people with a family-like commitment to a common interest, as in kaupapa whānau” (Collins & Willson, 2008, p. 5). Whānau carers also extend to young whānau, with Māori participants in Nikora et al.’s (2004) report asserting that it was common for young children to provide care for a parent with a disability when the child demonstrated the aptitude or conditions became desperate. The authors highlighted the importance of examining and meeting the unique service needs of Māori whānau. This is especially pertinent as the latest Carers’ Strategy Action Plan (MSD, 2019) identified that “Māori communities have higher rates of multiple and long-term health conditions” (p. 8). Furthermore, Māori with a disability “tend to fare worse than non-Māori” leaving them “particularly vulnerable to poor economic and social outcomes” (Office for Disability, 2012, p. 8). However, Nikora et al. (2004) point out that Māori may be hesitant to identify any disability, which can be seen as the consequence of a breach of “tapu” (sacred rules), “atua affliction” (result of supernatural circumstances or passed down from ancestors), or “mākutu” (a sign of witchcraft or magic) (p. 8). As such, Māori families may feel tension with the disability-focused and individualist position on care dominant in NZ.

Largely missing from NZ caregiving research, policy, and practice, however, are the experiences of the estimated 40,000 younger carers aged 15-24 (MSD, 2019), and the many more possible NZ young carers sitting outside this age parameter (those aged up to 15, and those aged 25), for whom prevalence data is not available. Hamilton and Cass (2017) highlighted that “the age and life-course stage of carers” (p. 79) has a key influence on their uptake of care, alongside the experiences and effects of providing care: as such, young carers’ unique experiences and needs require attention.

Young Caregiving

The corpus of young caring literature comes mostly from the UK (e.g., Joseph et al., 2019), followed by Australia (e.g., Pakenham & Cox, 2018), the USA (e.g., Kavanaugh et al., 2019), Canada (e.g., Stamatopoulos, 2018), and Europe (e.g., Leu et al., 2018). There are also small bodies of literature from NZ (e.g., Gaffney, 2009), Sub-Saharan Africa (e.g., Becker, 2007), and India (e.g., Sahoo & Suar, 2010). While the term young carer is most commonly used, some countries employ alternative terms, such as “young caregiver” in the United States (Shifren & Kachorek, 2003, p. 338), and “children as next of kin” in Norway and Sweden (Järkestig Berggren & Hanson, 2016, p. 277). With the exception of some research from Sub-Saharan Africa, where young carers largely support a

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[22] The term kaupapa Māori refers to “Māori desires to affirm Māori cultural philosophies and practices” (Pihama, Cram, & Walker, 2002, p. 30).

loved one(s) with HIV or AIDS (Robson, Ansell, Huber, Gould, & Van Blerk, 2006), or where young carers “have often been orphaned by conflict or HIV and AIDS” (Leadbitter, 2006, p. 36), overall the findings are substantially the same. However, no consistent and agreed-upon definition of young carer exists in the literature, with a notable disparity in age ranges used to define this group. For instance, Hamilton and Adamson (2013) define Australian young carers as “children and young people aged 25 or younger who provide substantial unpaid support to a family member with a chronic illness, disability, mental health issue and/or problems with alcohol or other drugs” (p. 101), while Gaffney’s (2007) NZ definition is “children up to 17 years of age who have the sole or significant joint caring responsibility for another person” (p. 5). In 2008, Becker and Becker introduced the term “young adult carer”, which is now widely used to identify individuals aged 18-24, who face distinct challenges compared to their younger counterparts. Consequently, many researchers define young carers as aged under 18 (e.g., Aldridge et al., 2016), with young adult carers encompassing the 18-24-year-old age bracket (e.g., Becker & Sempik, 2019). In addition to Hamilton and Adamson (2013), several studies have extended the upper age of young adult carers beyond 24 years, “to incorporate the transitional period to higher education, work and/or leaving home after finishing school” (McDonald, Dew, & Cumming, 2010, pp. 460-461). In some cases, researchers delineate between ‘primary’ and ‘secondary’ young carers, with primary young carers being the main or largest contributors of care (Moore, 2005). However, differing and subjective understandings of primary young carers amongst researchers and participants, alongside the nature of care to be provided “within complex networks of formal and informal care provision” (Hamilton & Adamson, 2013, p. 112), results in studies often choosing not to differentiate between primary and secondary young carers. The absence of a uniform definition makes synthesising across studies difficult, especially when addressing young carers’ prevalence in a given population. Furthermore, despite substantially similar findings across studies, direct comparisons are difficult because of differences in definitions. Accordingly, I group prevalence data only where definitions align, and discuss the broad similarities across studies. The definition for my study adopts the extended age parameters beyond 24 years used by McDonald et al (2010), and in order to align the study with the age parameters of New Zealand’s Child and Youth Wellbeing Strategy 2019, which is “aimed at to improve the wellbeing of all children and young people under the age of 25” (NZ Government, 2019, p.22). As such my definition is to be broad enough to include the widest possible range of carers: Children, youth, and young adults aged 25 years and under providing significant, ongoing care for someone with a disability, illness, mental illness, substance misuse, or who is elderly.

Some disability researchers have expressed dissatisfaction with the term young carer, perceiving it as stigmatising for people with disabilities (Morris, 2014; Parker & Olsen, 1995). The controversy around the term reflects a key debate that emerged in the 1990s based on research priorities. Some researchers, who investigated and addressed young carers’ experiences, rights and needs, advocated a Children’s Rights philosophy (Aldridge & Becker, 1996). Researchers in Disability Rights suggested that a focus on young carers detracted attention from the rights of parents with disabilities (Keith & Morris, 1995; Parker & Olsen, 1995). Those in the latter group contended that if parents with disabilities were better supported in their parenting roles, their children would not need to provide care (Keith & Morris, 1995; Newman, 2002). Children's Rights researchers defended their emphasis on young carers, stating that a sole focus on parents with disabilities was "an absurd zero-sum argument", which suggested that "research and policy-makers can only solely engage" with young carers or their parents (Aldridge & Becker, 1996, p. 72). While I acknowledge the complications of the term young carer, and recognise that it is not universally embraced, I use it in my research because it is the most widely used across literature, in public policies, and by social service organisations. Furthermore, for young carers, discovering the young carer label is often an "empowering" and "welcome revelation" that acknowledges their familial contributions (Smyth, Blaxland, & Cass, 2011, p. 157). For instance, during a focus group, one Australian young adult stated that identifying as a young carer "made me step back and look at the past few years and go 'Oh my gosh! My schoolmates weren't dealing with this' … it just affirmed that yeah no wonder things have been so hard" (Smyth et al., 2011, p. 151).

Children's and youth's *discovery* of their carer identity, often years after beginning care, highlights another key and contentious theme in the literature: children's agency and informed choice in regard to the role. Numerous researchers, especially those operating from a Children's Rights perspective, argued that children "do not begin caring from their own free choice" (Aldridge, 2018; Fives, Kennan, Canavan, & Brady, 2013, p. 52; Sprung & Laing, 2017). These researchers argued that children are often socialised into the role, resulting in a lack of awareness that they are, in fact, caregivers (Aldridge & Becker, 2003; Hounsell, 2013; Lackey & Gates, 2001; McGibbon, Spratt, & Davidson, 2018). Furthermore, even when children were aware of their young caregiving roles, numerous researchers asserted that children lacked informed choice in undertaking care, as they often saw no alternative (Aldridge, 2018; McDonald et al., 2009; Sprung & Laing, 2017). Children also did not have the perspective to understand the negative outcomes of caring in childhood on their social, educational, vocational, and emotional development (Hanna & Chisnell, 2019; Pakenham & Bursnall, 2006). Sprung and Laing (2017) asserted that rather than making a choice to care, children often undertook caregiving "because they have always done so for the people they care about, and because they believe that the care recipient could not manage without them" (p. 398).

Recent research highlights the importance of extending any examination of children's agency and choice beyond a single instance or relationship at any given point in time (Abebe, 2019; Becker & Sempik, 2019; Evans & Skovdal, 2016). Researchers stress the "dynamic, situated, and contextual" (Abebe, 2019, p. 92) nature of children's agency, which is "negotiated and renegotiated" (Abebe, 2019, p. 92). The continuous renegotiation reflects the fluidity of independence and dependence within any given relationship, alongside the nature of the activity the child is undertaking (Heidbrink, 2018). Agency, therefore, is not static but relative to "the spatial, political, and material factors that shape the lives of children, the 'choices' they might confront, and the types of futures they might expect" (Abebe, 2019, p. 93). An examination of young carer's agency must look beyond tasks undertaken by the child or youth and the appropriateness based on their age and maturity (Leu et al., 2018; Noble-Carr, 2002). Factors underlying children's and youths' 'choices' to undertake care must be taken into account, including the social and fiscal government support offered to families with members with a disability or illness, alongside wider cultural and societal notions of caregiving and childhood and their impact on children's 'choices' to care. The dynamic and contextualised examination of young caring relationships is evidenced in recent research. A consensus appears to have been reached between Children's Rights and Disability Rights researchers, with researchers now advocating for a wider examination of "the circumstances in which caring occurs" (Becker & Sempik, 2019, p. 385; Evans & Skovdal, 2016). Such circumstances are posited to include, for instance, "poverty and exclusion" that generate the need for young carers when their parents have disabilities (Aldridge, 2018; Newman, 2002; Olsen, 2000, p. 393).

The context of Children's Rights in NZ is an essential part of the backdrop to understand the experiences of NZ young carers outlined in this thesis. Whilst children hold the same basic human rights as adults, they have additional rights that arise from the recognition of their need for additional protection (Human Rights Commission, 2010; Ministry of Justice, 2020). The United Nations Convention on the Rights of the Child (UNCROC) is an agreement among 195 countries to protect the human rights of all children and youth aged under 18 (Human Rights Commission, 2010; Ministry of Justice, 2020). On the 6th April 1993, NZ consented to uphold the UNCROC, which would be administered by the Ministry of Social Development (Ministry of Justice, 2020). Since this time, NZ has forged its place as a front-runner in child health and development research (Dunedin Multidisciplinary Health & Development Research Unit, 2020). Nevertheless, NZ's outcomes for its 1.1 million children and youth aged under 18 years "are extraordinarily poor with large equity gaps" (Children's Commissioner, 2020; D'Souza et al., 2012, p. 71). Enduring children's rights inequalities that are of particular concern include significant poverty and child abuse, disproportionately poorer education and social outcomes for Māori and Pacific children, high rates of suicide among young people, and discrimination experienced by children with disabilities (D'Souza et al., 2012; Human Rights Commission, 2010). As a result of ongoing issues, a 2020 UNICEF report regarding the wellbeing of children placed NZ 35th out of 41 developed countries, down two places from 33rd in 2018 (Webb-Liddall, 2020). Consequently, children remain positioned as "one of the most vulnerable groups" in NZ society (Human Rights Commission, 2010, p. 240).

A report by the NZ Human Rights Commission identified persistent gaps in the policy landscape as a key issue underlining childhood inequalities in NZ (Human Rights Commission, 2010). The report specifically highlighted the "absence of a comprehensive strategy or mechanism for incorporating children's rights into policy and legislation", resulting in the protection of children's rights being "ad hoc and inconsistent" (Human Rights Commission, 2010, p. 245). In order to ameliorate this situation, and uphold their commitment to the UNCROC, several initiatives have been implemented in NZ. The most notable of these include the Vulnerable Children's Act 2014 and associated Children's Action Plan, which sought to coordinate NZ children's agencies in order to improve vulnerable child wellbeing (Parliamentary Counsel Office, 2018). Most recently, a central priority of the 2019 Wellbeing Budget was announced as "improving child wellbeing" (NZ Treasury, 2019, p. 2), with NZ$320m targeted to addressing what Prime Minister Jacinda Ardern called "shameful rates of family violence and child poverty" (NZ Treasury, 2019, p. 4). Other key priorities of the Wellbeing Budget aimed at improving the lives of NZ children included supporting the mental wellbeing of under 24-year-olds, addressing inadequate housing, and lifting Māori and Pacific skills and employment opportunities. The

Families Package implemented in July 2018 was another key means of enacting the government's aim to reduce child poverty and improve wellbeing, with an investment of NZ$5.5 billion over four years to increase the incomes of almost 350,000 families with children (NZ Treasury, 2019, p. 24). Prime Minister Ardern hoped that, taken together, these actions would "coordinate and catalyse change and help provide the focus and momentum needed to achieve wellbeing for all our children and young people" (NZ Government, 2019a, p. 3). A key aspect of all NZ child wellbeing initiatives is the government's strong commitment to respect diverse cultural understandings of childhood and family, with a particular focus on protecting indigenous Maori interpretations (NZ Government, 2019a; Parliamentary Counsel Office, 2018). This reflects NZ's commitment in Article Two of the Treaty of Waitangi – NZ's founding document defining Māori and Pākehā relations (O'Malley et al., 2011) – to protect "the collective rights and responsibilities of Māori, as Indigenous people, to live as Māori and to protect and develop their taonga" (Human Rights Commission, 2010, p. 39). In doing so, such initiatives also support Article 30 of the UNCROC regarding children's rights to enjoy and practice their family and cultural customs, regardless of whether such customs are reflected by the majority of people in their country (United Nations Human Rights Office of the High Commissioner, 2020).

Hearing the lived experiences, and responding to the needs of, NZ's diverse young carer population is an essential component of upholding our commitments to the Treaty of Waitangi and the UNCROC. However, any considerations of NZ children's rights, and their capacities for choice and agency, must consider the many different culturally and family/whānau/aiga informed understandings and preferences with regards to childhood. This is particularly pertinent in NZ's diverse cultural landscape (discussed earlier in the chapter), with large populations of Māori and Pacific families (Statistics New Zealand, 2014), and almost 30 percent of the NZ population born overseas (Statistics NZ, 2019b). Due to such diversity, a strong body of national research highlights the importance of "culturally responsive environments" (Lee & Ng, 2020, p. 21), with key themes of cultural connectedness (Sammons, Ali, Noorzai, Glover, & Khoo, 2020) and mana whenua belonging (Lees & Ng, 2020) carrying throughout NZ childhood, education, and care literature. For instance, NZ's Te Whāriki early childhood curriculum states as its aim that children become "competent and confident learners and communicators, healthy in mind, body and spirit, secure in their sense of belonging and in the knowledge that they make a valued contribution to society" (Ministry of Education, 2017, p. 6). With our knowledge of the importance of family/whānau/aiga care among Māori and Pacific families (discussed in full later in the chapter), then examining the different forms that care takes in Aotearoa/NZ, including young caring of which little is known, is pertinent to understanding how childhood plays out in NZ and how we can support children, youth, and their family/whanau/aiga when a child is undertaking care.

The tendency for NZ young carers to miss out on an education (Hanna & Chisnell, 2019), and to experience poor mental health (Ferguson et al., 2001) (discussed later in the chapter), suggests that not all of their rights as children are able to be met while they are undertaking a young caring role. This could jeopardise our capacity to meet UNCROC Article 32 to protect children "from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development" (United

Nations Human Rights Office of the High Commissioner, 2020, p. 9). Here we see the challenge of navigating the interface of the UNCROC articles, for instance, children's right to practice their culture (Article 30) and thus provide care, but also their right to be protected from work that may interfere with their education or wellbeing (Article 32) (United Nations Human Rights Office of the High Commissioner, 2020). How NZ addresses young caring while maintaining their commitment to the UNCROC therefore depends on our definition of young caring. Do we define young caring as work? Or, is young caring a normal part of childhood? A reflection of how childhood is experienced by a particular culture? For instance, Māori often enact a whānau model of care that includes tamariki (children) as key caregivers (Nikora et al., 2004), with caring being integral to enacting key Māori concepts such as aroha (kindness, selflessness, and commitment) (Barlow & Wineti, 1991; Webber, 2019), manaakitanga (nurturing relationships, and respecting and caring for others) (Mead, 2003), and hauora (maintaining one's whole wellbeing including their social needs) (Collins & Willson, 2008). Such individual interpretations of young caring mean that discussing young caring in regards to children's rights is contentious and differs among academics. Achieving balance in the rights of the child under the UNCROC and respect for cultural understandings of childhood, family/whānau/aiga, and care necessitates giving young carers "the opportunity to be heard" (UNCROC, Article 12) and for their opinions to be considered regarding decisions affecting them (United Nations Human Rights Office of the High Commissioner, 2020, p. 4). Certainly, without young carers' voices regarding their caring experiences and needs, the rights outlined in the UNCROC and in The Treaty of Waitangi will not be met (United Nations Human Rights Office of the High Commissioner, 2020). Furthermore, gaining insight into the experiences of young carers is essential to achieve the goal of "wellbeing for all our children and young people" outlined in the Children's Action Plan 2014 and Wellbeing Budget 2019 (NZ Government, 2019a, p. 3). The experiences of current and former NZ young carers outlined in this thesis will add a valuable narrative to the children's rights discussions that are so pertinent and front and centre of the NZ Government agenda right now. In order to address our poor rates of child neglect, poverty, wellbeing, high suicide rates amongst youth, and Māori and pacific inequality, then young carer voices offer a key piece of the child and youth wellbeing puzzle that is currently missing in NZ.

The need to acknowledge NZ young carers' contributions appears to be pertinent, since my examination of NZ literature identified just seven published studies (Ferguson et al., 2001; Gaffney, 2007, 2009; Goodhead & McDonald, 2007; Hanna & Chisnell, 2019; McDonald, Cumming, & Dew, 2009; McDonald, Dew, & Cumming, 2010), and two Master's theses (Loose, 2004; McDonald, 2008). Whilst all nine sources add invaluable context, interpretations, and insights into young caring in NZ, it seems that just four original data sets exist. One is a survey of 20 NZ social services agencies, 14 of which determined that they had come into contact with young carers in the previous year (Ferguson et al., 2001). The second data set emerges from Loose's (2004) Master's thesis, and includes interviews with five former young carers who undertook significant care but had minimal formal support. Gaffney's (2007) Ministry of Health-funded project offers the third data set. In response to a dearth of means of identifying NZ young carers, Gaffney (2007) developed a recording tool to assist social service agencies to identify young carers. Four Otago agencies implemented the tool and identified that between one and 15 percent of their clientele were young carers. This translated to 21 possible young carers identified across 18 families, out of a total of 495 families using these four services. Gaffney (2007) noted that the service identifying just one percent of families with a young carer(s) most likely reflected underreporting of young carers, wherein “people in this group were asked to self identify rather than the agency worker making the judgement or asking the questions” (p. 24). Unfortunately, detailed information of six of the 18 young carers was not provided, as service representatives felt that it was not appropriate to gather such information. In addition, three of the possible young carers were later identified as not meeting the young caring criteria. Overall, information was gathered regarding nine young carers across six families. Finally, McDonald’s (2008) Masters dissertation presents the fourth original dataset, comprising interviews and case studies outlining the caring experiences of nine families, including 13 current young carers aged 26 years and under, and one adult providing a retrospective account, alongside nine other family members. Among the 12 participants who provided information regarding their ethnicity, eight identified as Pākehā, three as Pacific, and one as Māori.

These studies reveal that NZ young carers enact a variety of care tasks and report a range of physical, emotional, educational, vocational, social, and relational impacts on their own lives as a result (Gaffney, 2007; Hanna & Chisnell, 2019). A key theme among NZ studies is the hidden and unsupported nature of young carers (e.g., Loose, 2004), who are described by Hanna and Chisnell (2019) as “a vulnerable, invisible group who require recognition and respect” (p. 7). The difficulty of recruiting NZ young carer participants is another significant theme in the literature (e.g., McDonald et al., 2010), alongside the requirement for additional studies. Gaffney (2009) asserted the need for further young caregiving enquiries in order “to understand the complexity of children’s lives” when they provide care (p. 18), and highlighted the importance of such studies including young carers’ experiences in employment and higher education (Gaffney, 2007). The potential for research to identify the need for, and to inform, policy and service outcomes for young carers is also stressed (Goodhead & McDonald, 2007; Hanna & Chisnell, 2019). McDonald et al. (2010) concluded that greater services for young caregiving families can “increase choice and contribute to balancing life for carers” (p. 459), with one NZ young carer stating that “When the [formal] carer started working, we had less time doing the looking after; it was more shared” (McDonald et al., 2009, p. 125). Gaffney (2009) asserted that “understanding the complexity” (p. 54) of young caring roles will create opportunities to enact effective solutions.

It is important to note that young carers are briefly mentioned in several reports undertaken by government departments, and care and disability organisations, over the previous fifteen years (Kia Piki Ake Welfare Expert Advisory Group, 2019, p. 7; Ministry of Social Development [MSD], 2007, p. 19). In line with the published studies outlined above, these reports identified key gaps in NZ informal carer research, including the prevalence and experiences of NZ young carers. A background paper prepared by the Kia Piki Ake Welfare Expert Advisory Group (2019) identified that NZ young carers’ experiences of providing care are largely unknown, with the prevalence of NZ young carers “likely to be undercounted” because “people under 15 years old providing care would not have been picked up in the Census” (p. 7). The need for funding aimed at further research to guide service and policy implementations for young carers is a key theme across these reports, with a participant in the 2007 MSD report stating, “As a young carer I just wanted to be recognised and heard” (p. 19). The need for further research specifically exploring NZ young caring is stressed, due to the distinct challenges faced by young carers compared to their *adult* carer counterparts. These include young carers’ difficulties attending and achieving in school and university, alongside perceived social exclusion from their peers (MSD, 2007). One young carer stated, “My friends didn’t understand why I couldn’t do things with them, or felt down or tired sometimes” (MSD, 2007, p. 19). In addition, a marked absence of public policies and services addressing young carers’ needs is certainly evident in NZ (e.g., MSD, 2007) (discussed later in this chapter).

Thematically Structured, Cross-Cultural Examination of Young Caring

The small body of NZ young caring scholarship is complemented by the larger corpus of international studies. Researchers suggest that the global and local needs of young carers are largely complementary (Evans & Becker, 2009; Hunt et al., 2005). Thus, themes established in the international literature are also relevant to NZ. From my synthesis of international and national studies I have identified five broad themes – (1) identification, (2) roles and relationships, (3) activities and tasks, (4) impact, and (5) solutions and needs – that outline current knowledge and understandings.

Identification.

Prevalence studies use a wide range of methods, sample sizes, and age ranges, which makes comparisons across and even within countries difficult. However, two attempts to synthesize the results of existing research have estimated that, overall, two to eight percent of all children, youth, and young adults in first-world societies are young carers (Becker, 2007; Day, 2015). Considering the variance in parameters used to ascertain prevalence, I have summarised prevalence data for each country, where available, in Table 1. The studies in Table 1 indicate that the most common estimates were less than five percent (Scotland, Wales, Austria, Italy, USA). Studies in three countries reported between five and 12 percent (Northern Ireland, Switzerland, NZ) and another three (England, Canada, Australia) reported high prevalence percentages of 22 to 40 percent.

From Table 1 it is clear that the prevalence estimates come from primarily large-scale quantitative surveys, including nationwide Census data from Italy, Sweden, and NZ. Excluding Census-based studies, the number of survey participants ranged from 925 (Joseph et al., 2019) to many thousands. Only one study, in the USA, included interviews with young carers, alongside a large survey of 2,000 households (Hunt, Levine, & Naiditch, 2005).

Compared to other research on young caring, the prevalence studies targeted a much more diverse range of participants by age, exacerbating the challenge of comparison. Excluding the studies that used whole-population Census data, several survey-based studies focused on narrow age ranges of only two years, such as 10-11 (Lloyd, 2013), 11-12 (Joseph et al., 2019), and 14-15

Table 1

Young Carer Prevalence Estimates According to Country

Country	Estimated % of young carers	Defined age range of young carers	Number of participants	Method used	Definition of young caring employed in the research	Source
England	22	11-12 and 14-15	925	MACA-YC18[23]	Youth "caring for parents, siblings, or other relatives who have an illness or disability" (Joseph et al., 2019, p. 606).	(Joseph et al., 2019).
Scotland	4	4-15	Representative sample of the general population	The Scottish Health Survey 2012/2013	Youth providing care or support for someone due to disability, illness, a mental health issue, substance misuse, or advancing age, both within and outside the home (Rutherford et al., 2014).	(Rutherford et al., 2014).
Northern Ireland	12	10-11	4,000	Online survey	Youth who "helped look after someone in their household who was sick, elderly or disabled" (Lloyd, 2013, p. 67).	(Lloyd, 2013).
Wales	2.6	5-17	Population	2011 Census	"Young people who provide assistance or support to other family members" (IARS, 2016, p. 12).	(IARS, 2016).
Italy	2.8	15-24	Population	Census	Youth taking on care of adults or older persons experiencing a disability (IARS, 2016).	(ISTAT, 2010, in IARS, 2016, p. 29).
Sweden	33	18 and under	Population	Census	Youth supporting parents with a mental or physical illness or substance misuse (IARS, 2016).	(IARS, 2016).
Austria	4.5	10-14	7,000	Questionnaire	Youth providing "substantial" care "on a regular basis" for a family member with an illness or disability (Nagl-Cupal et al., 2014, p. 2317).	(Nagl-Cupal et al., 2014).

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[23] The Multidimensional Assessment of Caring Activities Checklist for Young Carers (MACA-YC18) is a simple, child-friendly, and accessible questionnaire with an 18-item self-report measure, for the assessment of caring activities carried out by children and youth (Joseph, Becker, & Becker, 2009; Joseph, Becker, Becker, & Regel, 2009).

Country	Estimated % of young carers	Defined age range of young carers	Number of participants	Method used	Definition of young caring employed in the research	Source
Switzerland	7.9	10-15	4,000	Online survey	Youth “caring for ill and disabled family members” (Leu et al., 2019, p. 64).	(Leu et al., 2019).
USA	3.2 of all households	8-18	Study 1: 2,000 households Study 2 stage 1: 600,000 households Study 2 stage 2: 213 young carers 250 non-carers	Survey Questionnaire Phone interviews	Youth providing “unpaid help or care to any person” within and outside the household (Hunt et al., 2005, p. 3).	(Hunt et al., 2005).
	12-18	18-25	2 national surveys: 1002 and 1247	Survey	Young adults providing care “for ill, elderly, or disabled family members or friends” (Levine et al., 2005, p. 2071).	(Levine et al., 2005).
Australia	40	14-15	10,000	Survey	Youth “caring for a person with a long-term health condition, disability or who is elderly” (Warren & Edwards, 2017, p. 116).	(Warren & Edwards, 2017).
NZ	9	15-24	430,000 NZ Carers	Census	Youth caring “for a friend, family, whānau or aiga member with a disability, health condition, illness or injury who needs help with everyday living” (MSD, 2019, p. 5).	(MSD, 2019).

(Joseph et al., 2019; Warren & Edwards, 2017). Two encompassed slightly larger ranges of five to seven years (Leu et al., 2019; Nagl-Cupal et al., 2014) and three included participants across eight or more years, such as Levine et al. (2005, 18-25), Rutherford, Hinchliffe, and Sharp (2014, 4-15), and Hunt et al. (2005, 8-18).

In NZ, no data specifically addresses the prevalence of young carers. However, as outlined in Table 1, Census data offers some information regarding the numbers of youth and young adults aged 15-25 years undertaking care. Reviews of the 2006 Census revealed that approximately 20 percent of 15 to 24-year-olds (Statistics New Zealand, 2007), and 42 percent of 15 to 18-year-olds (McDonald, Cumming, & Dew, 2009), reported caring for a family member(s) with a disability or illness. The most recent NZ Census, which was undertaken in 2013, identified that 40,000 18 to 24-year-olds carried out a care role (MSD, 2019). More recently, the Mahi Aroha Carers' Strategy (MSD, 2019) used 2013 Census data to identify that approximately nine percent of the estimated 430,000 NZ carers were aged between 15-24, and thus were young carers. However, because the Census data only recognises carers over the age of 15, it is possible that many young carers are missing from the Census statistics. Nevertheless, more accurate data pertaining to NZ young carers will become available by 2021, with Action Four in the Mahi Aroha Carers' Strategy (MSD, 2019) outlining a collaboration between the Carers Alliance and MSD to use the MACA-YC18 survey tool previously used in England to identify caring activities undertaken by young carers.

Overall, whilst studies use divergent criterion and methods to identify young carers, the prevalence of young carers appears to range from 2.6 to 40 percent, with the NZ estimate being nine percent of 15-24 year olds (MSD, 2019).

Many studies report that young carers are school-aged (Frank & Slatcher, 2009; Moore et al., 2009; Sempik & Becker, 2013), with some research pinpointing the average starting age to be between nine and 13 years (Lackey & Gates, 2001; Noble-Carr, 2002). Several researchers have found that young carers can begin their roles at very young ages: three years old in the USA (Lackey & Gates, 2001), four years old in Scotland (Barry, 2011), and six years old in Australia (Noble-Carr, 2002). One Swiss female young carer supporting her brother with a disability said, "When I was five, I quickly learned to deal with this [his impairment] … I learned from a young age how to change his nappies, dress him and do the caring, even shower him, if necessary" (Leu et al., 2018, p. 928). The general consensus for the age at which young caring finishes – as the child or young person graduates to being an *adult* carer – is between 18 and 24 years (Banks et al., 2002; Becker & Becker, 2008; Earley, Cushway, & Cassidy, 2007), although some researchers include the transition to adulthood and extend the parameters to include carers aged up to 25 years (Hamilton & Adamson, 2013; McDonald et al., 2010).

Generally, it appears females are more likely to be young carers than males, albeit to varying degrees (Dearden & Becker, 2004; Lakman, Chalmers, & Sexton, 2017; Leu, et al., 2018; Stamatopoulos, 2015). While several studies identify only marginally more female than male young carers (Hunt et al., 2005; McDonald et al., 2009), most studies found higher instances of female young caring (Joseph et al., 2019; Lackey & Gates, 2001; Nagl-Cupal et al., 2014; Shifren & Kachorek, 2003). For instance, Becker and Sempik's (2019) UK survey of 295 young carers identified more females (78%) than males (21%), although the researchers explain that their sample may not accurately reflect the young adult carer demographic because participants were recruited via young adult carer projects. Nevertheless, their findings are supported by several studies that report the margins of difference between female and male young carers as substantially in favour of females (Joseph et al., 2019; Watt, Ibe, Edginton, & Whitehead, 2017).

Several researchers suggest that the higher incidence of female over male young carers could be particularly exaggerated amongst cultural and ethnic minority young carers (Ethnic Disability Advocacy Centre, 2003; Hill et al., 2009). Sahoo and Suar (2010) reported that, in India, "almost in every family, caregiving tasks are regarded as women's or girls' responsibilities. They continue to bear the overwhelming responsibility for ill/sick persons in the home" (p. 324). Similarly, a UK study of black young carers identified that, "where cultural expectations were evident, this related to general assumptions about gender and young people's, particularly girls', involvement in household tasks" (Jones, Jeyasingham, & Rajasooriya, 2002, p. 20). In line with these studies, a NZ parent of a young carer stated, "In [our] culture, it's expected that one of the daughters is to look after the grandparents when they're older. It's never the son for the reason the daughter can do the personal things, and the son is not to" (McDonald et al., 2009, pp. 119-120). Unfortunately, the culture of the participant was not stated. However, because the study included young carers identifying as Pākehā, Pacific, and Māori, then the culture being referred to in the quote could be assumed as one of these three cultures. Researchers extend the influence of culture on care beyond gender, however, pointing out that although the family unit is the focus of caring in almost all societies, the individual who takes on care, and the kinds of caring activities expected of them, is often culturally defined (Laird, 2005; Sahoo & Suar, 2010). As such, situating young carers in their cultural context is critical. Young caring appears to be more common amongst ethnic minority and immigrant populations. Studies in the UK and Europe addressing the experiences of Black, Asian, and Minority Ethnic (BAME) young carers ascertained that they are "twice as likely" to be young carers than their non-BAME peers (Hounsell, 2013; IARS, 2016, p. 14). UK and European studies have also identified higher proportions of refugee or migrant young carers (Frank & Slatcher, 2009; IARS, 2016). Frank and McClarnon (2008) pointed out that refugee and BAME young carers, and those for whom English is an additional language, may struggle to understand information about services, and experience racial discrimination on top of stigma concerning the care recipient's disability or illness. In turn, BAME and refugee or migrant young caregiving families are less likely to access formal supports, and "can find themselves relying on their children to meet their care needs" (Frank & Slatcher, 2009, p. 3). These groups have thus have been pinpointed as a marginalised and neglected group of carers who "remain under the radar of policy, legislation and practical support" (IARS International Institute (IARS), 2017, pp. 13-14). Analogous to BAME research, Australian studies reporting on young carers from Culturally and Linguistically Diverse (CALD) backgrounds recognised indigenous young Australians as being two to three times more likely than their non-indigenous counterparts to be young carers (Bray, 2011; Cass et al., 2011). In addition, Cass et al. (2011) identified that twice as many Australian young carers were born in non-English speaking countries than non-young carers.

Adhering to traditional cultural values appears to be a key reason for young caring. Several researchers describe how in collective cultures, caring for a family member with a disability or illness is likely to be seen as the role of the family, and formal services may not be sought as freely as in an individualist cultures where the care responsibility may be more likely to be given to a service provider (Marote, Pinto, Vieira, Barbiéri-Figueiredo, & Pedrosa, 2012; Sahoo & Suar, 2009, 2010). For example, in India “families having traditional cultural values never prefer external support or help” (Sahoo & Suar, 2009, p. 136). Here, families’ preferences for young carers over outside help is understood as a sign of children and youths’ respect for their elders and as a means of retaining “strong emotional bonds” within the family, so that young caring is a highly valued role (Sahoo & Suar, 2010, p. 324). This aligns with young carers in sub-Saharan Africa, whose care “is underpinned by a value system” emphasising children’s roles “in terms of contributing to the household and providing care during sickness or old age. Failure to fulfil these responsibilities will attract censure and probably penalty both from kin and the wider community” (Laird, 2005, p. 462). However, it is important to consider other key factors in the onset of children undertaking care, such as the high instance of HIV or AIDS, and lack of services available, in Sub-Saharan Africa (Becker, 2007; Robson et al., 2006).

This finding of cultural collective values influencing young caring is particularly interesting in a NZ context, given that numerous collective cultures – such as Pacific, Māori, and Asian – exist within the more individualist NZ society. The Office for Disability (2009) found that Pacific and Māori people were more likely to provide informal care than any other ethnic groups, particularly in the 15-44 age group (MSD, 2008). In line with this, Pacific adults were the most likely to receive support from informal carers (37%) followed by Māori and European adults (both 25%). Outside of cultural preferences, a possible explanation for the high instances of informal caring amongst Pacific and Māori families is their dissatisfaction with culturally insensitive services (Ministry of Health, 2009; Nikora et al., 2004). In particular, an inadequate use of Pacific languages or te reo Māori (Māori language) by service providers is highlighted as a key reason for their lack of services uptake (Office for Disability, 2010). As a result, Pacific and Māori individuals with a disability or illness may choose aiga/whānau carers over accessing culturally insensitive services, and this in turn may suggest the existence of an invisible population of Pacific and Māori young carers. While there is increasing awareness of the cultural context of caring in existing international literature (IARS, 2016; Jones et al., 2002), further NZ research is needed with participants representing a diversity of ethnicities (Marote et al., 2012; Nikora et al., 2004), especially as the most recently published Census results shows an increasingly ethnically diverse NZ population (Statistics New Zealand, 2013).

Roles and relationships.

Secondly, studies have identified that parents, and in particular mothers, may be the most common care recipients (Aldridge et al., 2016; Barry, 2011; Joseph et al., 2019; Leu et al., 2018), although young carers are also reported to care for siblings (McDonald et al., 2010), extended family (Hanna & Chisnell, 2019), and friends (Warren & Edwards, 2017). In a UK survey, care was “most frequently” given to a mother (Joseph et al., 2019, p. 606), and likewise in NZ, Ferguson et al. (2001)

found most of the young carers identified by community social support agencies were caring for parents.

People with a disability are the most common care recipients supported by young carers (Ferguson et al., 2001; Leu, et al., 2018; Noble-Carr, 2002; Robison et al., 2017), followed by individuals with a mental illness (Aldridge, 2006; Cooklin, 2010). Additionally, young carers are cited as caring for people with specific illnesses such as HIV/AIDS (Tisdall et al., 2004), cancer (Gates & Lackey, 1998), motor neurone disease (Clabburn, Knighting, Jack, & O'Brien, 2019), dementia/Alzheimers (Svanberg et al., 2010), and substance misuse (Aeyelts et al., 2016). The need for care due to advancing age is also commonly identified (Lloyd, 2013; Warren & Edwards, 2017). NZ social service agency representatives identified that it was common for services to overlook young carers of people with a mental illness, because of the transient and episodic nature of the illness that can create sizeable periods of wellness, followed by episodic outbreaks, making it "an area of major concern" (Ferguson et al., 2001, p. 17). In light of the finding that 50 percent of people with a mental illness in NZ are parents (Mental Health Commission & KITES, 2005), the prevalence of young carers of parents with mental illness could be significant. I am not suggesting that all children and youth with family/whānau/aiga members or friends with a disability, poor health, or mental illness will become young carers (Aldridge & Becker, 2003). However, it appears from the literature that while young carers support individuals with a range of care needs, people with a disability or mental illness most commonly receive care.

Studies highlight the key motivations for young caring roles as being: a lack of services for individuals with disabilities and illnesses and their families (McDonald et al., 2009); resistance to services due to disability-related stigma and financial barriers (Aldridge, 2018); cultural and familial preferences for within-family care (Leu et al., 2018); and children, youths', and young adults' desires to undertake care (Hanna & Chisnell, 2019). For example, one Australian young adult carer stated that care is "Part of life and honestly if I wasn't caring for my mum I wouldn't know what to do, 'cause it's a part of me" (Smyth et al., 2011, p. 150). In addition, some studies discuss young carers being socialised into their roles either via their progressive introduction to care over time (McGibbon, Spratt, & Davidson, 2018), or by the gradual onset of care (Smyth et al., 2011). One study reported that participants grew "gradually" into their roles, so that "only in cases of a sudden change in their lives or in their family structure did they realise" their care role (Leu et al., 2018, p. 932). For instance, one female young adult carer stated, "I did take care partially of my mum [...], and besides that I did all the household tasks. I was never aware of this. [...] for me, this was part of my life" (Leu et al., 2018, p. 929).

Low socioeconomic status could be an important factor influencing the onset of young caring (Aldridge, 2018; Bray, 2011; Dearden & Becker, 2000; Noble-Carr, 2002). For instance, Pakenham and Bursnall (2006) reported that "children may perceive little or no choice in caregiving as a result of socioeconomic difficulties that restrict the family from receiving outside help" (p. 720). Greater instances of low socioeconomic status for families with young carers is certainly possible, since disability and illness are strongly connected with negative changes in families' financial situations, especially if the person who has a disability or illness is or was the primary income earner (Lackey &

Gates, 2001). Ferguson et al. (2001) noted that a common theme among the NZ young carers identified by services was low socioeconomic backgrounds, although it was not clear if their low-income status was the result of disability or illness in the family.

Children, youth, and young adults appear more likely to take on care if they are the eldest in their family (Banks et al., 2002; Barry, 2011; Lackey & Gates, 2001), or are residing in a sole-parent household (Aldridge, 2018; Dearden & Becker, 2004; Hunt et al., 2005). The sole-parent dynamic can result in not enough *adult* carers in the household, with young carers filling the void (Noble-Carr, 2002). In NZ, children with disabilities are more likely to be in sole-parent households (28%) compared with non-disabled children (18%) (Office for Disability, 2009), suggesting that some children and youth in sole-parent families may be caring for their siblings who have a disability. Nevertheless, even when there are two parents, young carers can still provide care (Leu, et al., 2018).

Activities and tasks.

Thirdly, the key factor distinguishing young carers' roles is most commonly identified as being the regular amount, or significant or substantial level, of tasks carried out (Cooklin, 2010; Evans & Skovdal, 2016; Gray, Robinson, & Seddon, 2008; Leu et al., 2018). Young carers "take on significant, substantial or regular caring tasks and responsibilities" (Becker, Dearden, & Aldridge, 2000, p. 2) that "would usually be associated with an adult" (Leu et al., 2018, p. 1). Indeed, some researchers identify the adult-like nature of young carers' tasks (Becker & Sempik, 2019; Noble-Carr, 2002), oftentimes discussing "the role reversal that occurs" when a child or youth takes on a caregiving role (Aeyelts et al., 2016, p. 77). The impact of caring on the young carer has more recently been identified as a key factor distinguishing young carers from their non-caring counterparts (Aldridge, 2018), because the parameters of regular, substantial, and significant are vague and "open to much interpretation", and thus "can make identification difficult" (Wong, 2016, p. 380). For instance, a recent UK study removed these terms from their young carer definition, and instead stipulated that in cases where families were unsupported, "caring may have an adverse impact on children's health, wellbeing and transitions into adulthood" (Aldridge et al., 2016, p. 7). The extent, nature, and duration of care appear to rely largely on the nature of the care recipient's disability or illness (Aldridge & Becker, 2003; Ferguson et al., 2001; Lackey & Gates, 2001). As a result, tasks carried out by young carers are diverse and can change depending on the level and demand required (Aeyelts et al., 2016; Leu et al., 2018). For instance, family carers are possibly more likely to help adults with a *physical* disability with shopping and heavy housework, and adults with an *intellectual* disability with personal finances (Office for Disability, 2009).

Key care tasks carried out by young carers include, but are not exclusive to: (a) domestic tasks including household chores, managing the family's finances, and grocery shopping (Ferguson et al., 2001; Hunt et al., 2005); (b) emotional support including providing counsel when the care recipient is distressed (Banks et al., 2001; Becker & Sempik, 2019); (c) intimate tasks comprising bathing and toileting (Becker, 2007; Cunningham, Shochet, Smith, & Wurfl, 2017); and (d) medical or nursing support such as changing bandages or administering medication (Aldridge, 2006; Aldridge et al., 2016). For example, an Australian young adult carer said that for his care recipient, he provided

“Constant supervision...I’d wake up, look after her, give her meals, help her to the toilet. Whatever she needed” (McDougall et al., 2018, p. 575), while a Canadian young carer said, “I was doing everything, the groceries, the washing, all the cleaning, all the laundry, all the dishes” (Szafran, Torti, Waugh, & Duerksen, 2016, p. 136). Agencies in Ferguson et al.’s (2001) NZ study identified domestic caring responsibilities, followed by the provision of mobility assistance and companionship, as the most common tasks carried out by young carers. However, Ferguson et al. (2001) asked agency representatives about “relevant” or “important” care tasks (p. 16). Therefore, personal bias concerning which tasks are relevant or important, particularly in terms of one’s culture, and the age of the young carers, could have influenced the results. Nevertheless, internationally, domestic care tasks are often identified as young carers’ primary care activities. For instance, a large UK survey of young carers and their parents identified that almost 80 percent of the participants were “undertaking practical tasks as part of their caring responsibilities, such as cooking, cleaning, doing paperwork or helping with household chores” (Aldridge et al., 2016, p. 7).

Overall, young carers appear to carry out a wide array of care tasks, the level and nature of which are largely influenced by the nature of the care recipient’s disability or illness. Furthermore, the duration spent caring differs as certain disabilities and illnesses require young carers’ roles to extend into adulthood, while others have a shorter care-need lifespan (e.g., terminal illnesses). In both situations, care needs can be episodic (Aldridge & Becker, 2003; Ferguson et al., 2001; Pakenham & Bursnall, 2006). While limited data exists concerning the length of time spent caring, it appears that young carers’ roles can range from one year, and continue into adulthood (Bray, 2011).

Impact.

The fourth key theme is positive outcomes for young carers being increasingly identified by researchers (Aldridge et al., 2016; Hamilton & Cass, 2017; Heyman, 2018; Lackey & Gates, 2001). Young carers may want to carry out their care roles, and enjoy providing care (Noble-Carr, 2002; Shifren & Kachorek, 2003), especially when they gain skills, maturity, and deeper relationships with their care recipients (Aldridge, 2009; McDougall, O’Connor, & Howell, 2018). This was evident as a Scottish 16-year-old young carer commented that care “doesn’t really feel like a chore, because rather than feeling I have to do it, I feel I want to do it” (Barry, 2011, p. 528), and again in a NZ young carer’s comment, “I enjoy it and it gives me a sense of meaning and satisfaction” (McDonald et al., 2009, p. 22). Questionnaires completed by 100 Australian young carers identified their independence, confidence, and personal growth, alongside improved self-efficacy via gaining new skills and understandings (Pakenham et al., 2006). Similarly, the Caring for NZ Carers report identified that young carers “often gain diverse and rich life experiences” as a consequence of their caring role, “which can benefit them later in life” (MSD, 2007, p. 19). Other positive aspects of being a NZ young carer include resilience in the face of adversity, and the development of compassion and empathy (Ferguson et al., 2001; McDonald et al., 2009).

Nevertheless, the research suggested that negative impacts of caring, including poor mental health, missing school, and lower levels of educational achievement and employment, continue to outweigh the benefits that NZ and international young carers receive (Hanna & Chisnell, 2019;

Pakenham & Bursnall, 2006; Stamatopoulos, 2018). Evans and Skovdal (2016) asserted, however, that any impacts of young caregiving must be seen “within a broader context” (p. 11), which several researchers argue would include the family’s socioeconomic standing, availability of “formal support systems”, and experience of disability- or illness-related marginalization and stigma (Aldridge, 2018; Evans & Skovdal, 2016, p. 11; Nagl-Cupal & Hauprich, 2018; Sadler et al., 2018). For instance, reflecting the earlier discussion of the social model of disability, Newman (2002) pointed out that claims made regarding negative outcomes for young carers “have no direct relationship to illness or impairment” and instead “are frequently related to poverty, social exclusion, and unsupported or inadequate parenting” for individuals with disabilities or illnesses (p. 613). Likewise, Becker and Sempik (2019) have highlighted that any “reported mental and physical problems” of young carers “may also represent a general vulnerability of their families and be indicative of the difficulties they have in seeking support” (p. 383).

Numerous studies suggest negative short- and long-term health implications for young carers, including physical injuries, but more commonly poor mental health (Aldridge & Becker, 2003; Becker & Sempik, 2019; Järkestig-Berggren, Bergman, Eriksson, & Priebe, 2019; Pakenham et al., 2006; Watt, Ibe, Edginton, & Whitehead, 2017). Becker et al. (2000) asserted that young carers’ roles “have a negative impact or outcome for their own wellbeing and psycho-social development and transition from childhood to adulthood” (p. 2). One Canadian young carer reported “feeling exhausted at a young age”, while another said that she “went through you know depression, feelings of alienation, destructive behaviours” (Szafran et al., 2016, p. 139). In the UK, young carers were “significantly more depressed, and had lower self-esteem than non-carers” (Banks et al., 2002, p. 237), and likewise in NZ, negative emotional wellbeing was the most commonly cited impact for young carers (Ferguson et al., 2001). Unfortunately, the quantitative nature of Ferguson et al. means the exact emotions being referred to are unclear. Numerous studies point out that young carers supporting someone with a mental illness “face additional challenges” in terms of experiencing negative emotional impacts (Robison et al., 2017; Sadler et al., 2018; Spratt, McGibbon, & Davidson, 2018, p. 2354). Cooklin (2010) identified that negative emotional impacts for young carers supporting an individual with a mental illness included invasion of their thinking and feelings due to exposure to the care recipient’s delusions and hallucinations, fears for their care recipient’s safety, and self-isolation through fear of rejection and stigma from peers.

Restricted opportunities for young carers to socialise and develop friendships, resulting in limited social networks, is also a significant theme in the literature (Dearden & Becker, 2000; Levine et al., 2005; Stamatopoulos, 2018; Szafran et al., 2016; Watt et al., 2017). Hindered chances for friendship development was evident in a UK survey of over 500 young carers, which found that they had “difficulties making friends among peers who might lack empathy towards or not understand their family situation” (Aldridge et al., 2016, p. 57). An Australian male young carer in McDougall et al.’s (2018) study said that his role “Makes it kind of hard to relate to other people, [I] really struggle making friends....at school who kind of understand”. Barry (2011) asserted that young carers “often experience even greater social isolation than other disadvantaged young people because their caring roles leave little time or opportunity for leisure activities or friendship networks” (p. 524), which is evidenced when a Swiss young carer said “I never invited [my friends] home because I was ashamed of our household, because I was ashamed of my mother” (Leu et al., 2018, p. 931). Young carers’ concerns or worries for their care recipient even when they are not physically with them is another influence limiting their socialisation opportunities (Aldridge & Becker, 2003; Noble-Carr, 2002). The research concludes that respite or other services for young carers are important to ensure that children and youth have time to develop and maintain friendships at school and in their communities.

Young caring has also been found to affect educational experiences and attainment (Banks et al., 2002; Lakman, Chalmers, & Sexton, 2017; Moore et al., 2009; Pakenham et al., 2006; Szafran et al., 2016). Of particular concern is young carers’ “higher-than-average absenteeism” (Aldridge et al., 2016; Becker & Sempik, 2019; Hamilton & Cass, 2017; Stamatopoulos, 2018, p. 200) and low educational achievement (Lackey & Gates, 2001; MSD, 2008). For example, a Canadian young carer said that she was “distracted” or would “fall asleep in class or I’ll show up late because I had trouble sleeping or things came up” (Stamatopoulos, 2018, p. 192). Similarly, a Welsh young carer said that struggling with schoolwork caused her “worry”, because “If I don’t go to school and don’t pass my exams, how am I going to support my mum and my family[?]” (Thomas et al., 2003, p. 40). In Becker and Sempik’s (2019) study, 45 percent of the 295 UK young adult carers who had left school “considered that they could have obtained better grades had it not been for their caring role” (p. 382). The researchers emphasised that caregiving responsibilities had “serious effects on the young people’s abilities to get good grades and progress well through education and into appropriate employment” (p. 384). In NZ, Kia Piki Ake (2019) found that at younger ages, carers often held lower qualifications than non-carers of a similar age. Correspondingly, the NZ Carers’ Strategy Action Plan (MSD, 2019) states, “carers have fewer opportunities than people without caring responsibilities to participate in education” (p. 6). Low educational achievement for young carers was reported by over half of the social support agency representatives in Ferguson et al.’s (2001) NZ study.

Research also points to reduced educational completion rates of young carers compared to their non-caring counterparts, with some studies stressing that young adult carers have “a higher likelihood not to be in education, training or employment (NEET) between the critical ages of 16-19” (Becker & Sempik, 2019; IARS, 2016, p. 14). In the USA, four participants reported that they had dropped out of high school because of their care roles (Lackey & Gates, 2001). Similarly, an Australian report identified young carers as being “less likely to have completed” high school (41%) than their non-caring peers (65%) (Hill et al., 2009, p. 57). Carers New South Wales (2003) suggested a discontinuation of education can come about in response to the difficulty of managing simultaneous roles as student, child or youth, and carer, and believe this is exacerbated when the teacher is not aware of their caring role, and thus is unable to accommodate young carers’ requirements for flexible education. This is a worrying finding considering that many young carers choose not to disclose their roles to teachers (Leu et al., 2019; Rose & Cohen, 2010). However, some studies suggest schools may unintentionally permit young carers’ poor attendance, as teachers who are aware of young carers might overlook their nonattendance or poor work standards (Becker & Sempik, 2019; Dearden & Becker, 2000). Bibby and Becker (2000) emphasised the importance of young carers attending school until the legal school leaving age, unless adequate educational alternatives, such as correspondence college or home schooling, have been organised. Researchers highlight the necessity of achieving in education and acquiring qualifications, as these are the key criteria to gaining employment and exiting poverty (Dearden & Becker, 2005; Levine et al., 2005).

Other studies suggest that physical, verbal, and/or emotional bullying of young carers at school as a result of being perceived as 'different' further pushes young carers out of education (Aldridge et al., 2016; Bibby & Becker 2000; Morrow, 2005; Sempik & Becker, 2019). One young carer explained "I was getting bullied very badly at school and so there was no escape" (Szafran et al., 2016, p. 139), while another young carer recalled how she "used to get bashed . . . [due to] my dad being in a wheelchair. I had to stick up for myself so I got in a lot of trouble … up to Year 10 no-one would really talk to me" (Moore et al., 2009, p. 12). In turn, the literature identifies a fear of being teased, seen as an outsider, or misunderstood, as key reasons for young carers' reluctance to draw attention to their caring roles (Banks et al., 2002; Becker & Becker, 2008). For example, an Australian young carer said that opening up about her role meant "You get ditched by your friends … they wouldn't understand", while another young carer stated, "People didn't really understand … so I was a bit of an outsider" (Moore et al., 2009, p. 11). In line with these young carers' assertions, Aldridge et al. (2019) identified that UK young carers aged 11-17 experienced "a higher likelihood of bullying and difficulties making friends" and thus could choose not to disclose their roles amongst peers "who might lack empathy towards or not understand their family situation" (p. 57). This was reflected in Becker and Sempik's (2019) study, where almost 30 percent of the 295 UK young adult carers "reported being bullied at school because of their caring role" (p. 381), a statistic which reduced to six percent for those at university.

Research often highlights young carers' desires to enter higher education (Kettell, 2018), with Sempik and Becker (2013) reporting that 85 percent of young carers in high school planned to go to college or university. Nevertheless, difficulty accessing and maintaining higher education alongside caregiving is a key theme in the literature (Robison et al., 2017). A Canadian young carer described her delay in attending university despite her desire, as she explained "I doubt I can leave [my care recipients] and I don't want anything bad to happen to them so I am thinking about holding back on college and university until they are better ... even if I have to wait until I'm 40 I will" (Stamatopoulos, 2018, p. 194). Young adult carers' capacity to enter and attend higher education settings can be hampered by the: difficulty of "building academic resumes" in light of poor grades and low co-curricular investment (Stamatopoulos, 2018, p. 200), demands of their continuing caregiving roles (Dearden & Becker, 2000), additional stress and distraction during examinations (Becker & Sempik, 2019), and the lack of university-level flexibility to accommodate "alternative transitions and timetables" (Hamilton & Cass, 2017, p. 90). As a result, it is not uncommon for young carers to exit higher education prior to course completion (Becker & Sempik, 2019; Cass et al., 2011), with Kettel (2018) asserting that UK "young adult carers are four times more likely than other students to drop out of higher education" (p. 1). An Australian young carer explained that she "couldn't do" university when her care recipient "went through phases of being.... more difficult. At the more difficult time, I just couldn't study as well" (McDougall et al., 2018, p. 575). The importance of clear and effective identification and support services implemented early on for young adult carers are proposed as a key means of enfranchising their higher education participation (Kettell, 2018). In NZ, the need to focus specifically on Māori and Pacific students is emphasised, as those students “may be particularly likely to have caring responsibilities due to cultural values of responsibility for wider extended family and because they are more likely to be mature-age students with older parents” (University of Auckland Equity Office, 2015, p. 7).

Young carers’ limited educational qualifications can also result in a lack of employment opportunities and vocational success according to the literature (Becker & Sempik, 2019; Bray, 2011; Cass et al., 2011; Levine et al., 2005; Warren & Edwards, 2017). As a result of young carers’ lowered educational achievement and completion, they are negatively placed for participation in the labour market (Noble-Carr, 2002; Stamatopoulos, 2018). Higher rates of unemployment for young carers are evident in Australian data (Australian Bureau of Statistics, 2009), which estimates that 60 percent of young carers aged 15-25 are unemployed or not in the labour force, compared to 38 percent for the general population in the same age group. Although pertaining to informal carers rather than young carers specifically, it is interesting to note that in NZ, unpaid carers aged 25-54 were less likely to have full-time employment (57%) than people of the same age in the general population (66%) (Department of Labour, 2011). For young carers who find work, a career in caring professions appears common (Levine et al., 2005). For example, in Lackey and Gate’s (2001) study, 11 of 51 USA participants reported they were nurses and six that they were teachers. Heyman (2018) explained that “adult professionals do not always recognise intangible gains such as greater self-assertiveness, and may unintentionally steer young adults into care-related training which does not match their inclinations, aspirations and aptitudes” (p. 1209). For instance, one UK young adult carer in Heyman’s (2018) study was “persuaded” that working with children was “the easy option” due to her young caregiving experiences with her sister, “But, hey, it’s not! ... If there’s any children coming in with a disability, I get the pleasure of them, which I’ve had, and scars to prove it” (p. 1205). Whilst being employed in the caring professions is a reputable vocation, Dearden and Becker (2000) stressed that alternative career options should be accessible for young carers whose caring experiences were negative, or for whom their caring outcomes were unfavourable. These findings emphasise the importance of supporting young carers to balance their care roles with their schooling and further education, so that they can attain the required qualifications to be successful in their desired fields outside of their caregiving roles.

Before young carers can be supported, they must first be identified. Identification poses a significant challenge in all parts of the world, due to the hidden or invisible nature of young caring (Gaffney, 2007; Gray et al., 2008; Stamatopoulos, 2018; Szafran et al., 2016). Hanna and Chisnell (2019) have asserted that NZ young carers are a “silent, taken-for-granted, population” (p. 7), and Aldridge and Becker (2003) found UK young carers “were quite literally children who were seen but not heard” (p. 97). Waugh, Szafran, Duerksen, and Torti (2012) believe the reason for this oversight is society’s disassociation of children and youth with primary caring roles, but several other reasons for their hidden nature are also outlined. Firstly, researchers cite a lack of identity among young carers, who (like me) may not even realise that they are carers (Noble-Carr, 2002; Robison et al., 2017). An Australian young carer described discovering her young caring identity several years into her role, when she stumbled upon a carer organisation online; “So that’s how I found out I was a young carer and that I actually had been a carer most of my life . . . Before that it was just you know, normal work, sort of chores almost” (Smyth et al., 2011, p. 149). As evidenced in this young carer’s quote, because of their lack of identity, young carers’ roles are not only concealed from the public, but “can also be hidden from children themselves” (Aldridge & Becker, 2003, p. 56). Lackey and Gates (2001) point out that the invisibility of US young carers extends to former young carers, with several not identifying or recognising themselves as former young carers until they were asked to participate in the research. A second reason for the hidden young carer population may be young carers’ reluctance to draw attention to their caring roles (Aldridge & Becker, 2003; Moore & McArthur, 2007). UK research identified that young carers can intentionally keep their roles hidden due to a fear of judgment or rejection from their peers (Bolas, Wersch, & Flynn, 2007). A Swiss young carer explained “I never spoke about my family situation” with peers (Leu et al., 2018, p. 931), and likewise an Australian young carer said “It’s hard to talk to friends about it … it’s kind of hard for them to understand” (McDougall et al., 2018, p. 576).

Another key reason why young carers and their families might choose not to disclose young caring roles is a fear of child removal or familial disjunction (Frank & Slatcher, 2009; Rose & Cohen, 2010). For instance, Aldridge et al. (2019) identified the “fears that families have about disclosure … and what this means in terms of intervention” (p. 58), which is supported by one Canadian young carer’s assertion that she and her siblings “would’ve lied through our teeth to keep our mom safe … the fear in our minds would’ve been we’re gonna get taken away and Lord knows where we’re gonna go” (Szafran et al., 2016, p. 137). In addition, an Irish study found that young carers were hidden due to “parents/guardians’ fears they will be considered ‘at risk’ if public attention is drawn” (Kennan et al., 2012, p. 276). This fear of removal may not be unwarranted, as Dearden and Becker (2005) reported parental disability or ill health as the third most common reason for children being admitted to state care in England. Likewise, a NZ Families Commission study (Kerslake Hendricks & Stevens, 2012) identified that a parent with an intellectual disability was one of two key groups for notifications of vulnerable infants. Aldridge and Becker (2003) also revealed a connection between parental mental illness and child safety concerns, evident in one parent stating that they were “frightened” of contacting a young carers project, “because I imagined them taking me kids off me for the way I was ... so instead of bringing help in I was pushing them all away” (p. 49). As this testimony illustrates, parents can experience heightened anxieties from an overriding concern about their child being removed. However, studies emphasise that child removal may occur due to broader circumstances related to being a person with a disability or mental illness, for instance poverty or poor health, rather than an individual’s actual ability to care for their child (Becker & Sempik, 2019; Evans & Skovdal, 2016; Kerslake Hendricks & Stevens, 2012; Nagl-Cupal & Hauprich, 2018; Newman, 2002).

Solutions and needs.

The final key theme is that despite a growth in international young carer projects over the last few decades, Banks et al. (2002) argue that “for the majority little has changed” (p. 230). Researchers highlighted inconsistencies in services both within and between countries (Aldridge, 2018; Hanna &

Chisnell, 2019), varying from “support for the young people in policy and legislation through to a total lack of recognition and no support” (Leu & Becker, 2017, p. 759). For instance, in the UK “support services are available and many young carers attend support ‘projects’” (Becker & Sempik, 2019, pp. 377-378), yet services in the US are described as “woefully behind in addressing young carers” (Kavanaugh, Noh, & Studer, 2015, p. 13). However, Aldridge et al. (2016) state that even when policy change is implemented to meet the needs of young carers, turning policy into action is slow. Researchers propose that such inaction and oversight results from “the broader systemic impact of austerity on contracting social care budgets” (Hanna & Chisnell, 2019, p. 15), resulting in “cuts to youth services” (Aldridge, 2018, p. 155). Aldridge (2018) added further context by describing the difficulty of enacting “lobbying and campaign work with and on behalf of young carers” in order to “provide support for them”, while Stamatopoulos (2015a) explained that funding for young carer programs is often precarious, relying largely on grants and philanthropy. Nevertheless, it is important to keep in mind the difficulty of delivering age-appropriate services to the largely unrecognised population of young carers (Banks et al., 2002; Kennan et al., 2012).

The national and international literature suggested key practical services required by young carers as being: (a) age-appropriate information pertaining to their care recipient’s disability or illness (Kavanaugh et al., 2019), (b) information outlining possible services for young carers and their care recipients (Gaffney, 2009; Morrow, 2005), (c) impartial and trustworthy people for young carers to talk to (Noble-Carr, 2002), (d) increased school staff awareness in order to recognize and support young caring students (Lakman et al., 2017; Leu et al., 2019), and (e) acknowledgement of young caring through their inclusion in needs assessments (Gaffney, 2009; Joseph et al., 2019; McDonald et al., 2010). The requirement for holistic support is highlighted by Pakenham and Bursnall (2006), who argued that “all family members are likely to be affected” when one member experiences ill health, “hence support for the whole family is recommended” (p. 721). Young carers in a UK study also stressed the need for holistic support, explaining the inadequacy of services that “were really concentrating on my mum” and “never how are you [the child]” (Jones, Jeyasingham, & Rajasooriya, 2002, p. 19). Other researchers contend that the traditional centre-based medium of services may need to be supported with modern technology (e.g., cell-phone applications and social networks) if young carers’ needs are to be met (Bibby & Becker, 2000; Kennan et al., 2012). This is emphasised by an Australian young adult carer, who stated that “online [services] would probably be easier accessible” (McDougall et al., 2018, p. 577). However, it will be important to ascertain the most effective and ethical ways to use web-based, mobile, and social media technologies in order to safely engage a widespread group of largely unrecognised young carers.

Since the 1990s, policy and legislative changes have been carried out in the UK to address the invisibility of young carers in service delivery (Aldridge & Becker, 2003). This includes legislation that has led to UK young carers having legal rights as carers, which has opened up their access to dedicated information, respite, education, and counselling-based young carer programs, alongside financial support (Aldridge, 2018; Becker et al., 2000; Leu & Becker, 2017). A UK young carer identified the benefits of such services, as he explained that he had become more assertive through attending a young carer service; “They gave me that much extra to speak my mind” (Heyman, 2018,

p. 1206). Recently, the Children and Families Act 2014 and Care Act 2014 came into effect, both of which require all local authorities to carry out an assessment “when it appears that a child is involved in providing care” (Joseph et al., 2019, p. 609). The desired starting point for the legislation is the implementation of a Whole Family Approach when assessment is undertaken and services are provided to a person with support needs. The purpose of the Whole Family Approach is for local authorities to adopt a holistic understanding of the individual’s needs, taking into consideration their wider support network (Frank & Thompson, 2015). Specifically, Frank and Thompson (2015) asserted that “the adult’s assessment and eligibility for support should take into account their parenting responsibilities and functioning of the family” (p. 5). A key focus is why the child, youth, or young adult is caring, and what can be done in order to prevent adverse outcomes for the young carer’s education, welfare, and development (Frank & Thompson, 2015).

Similar to the UK, supports for Australian young carers have grown in the last decade. Carers Australia (2019) advocates for carers on a wide range of issues, and manages the implementation of national programs, support, and services for carers. It has worked with young and *adult* carers, carer organisations, the Government, and key stakeholders to develop and deliver counselling, advice, and information services for young carers. The Young Carers Program, run by Carers Australia (2019), specifically addresses young carers’ needs, by offering information, advice, and support. One Australian young carer described the benefits of the service as knowing that you are “not alone … and there’s things that you can [do to] just get away” (Moore et al., 2009, p. 10). Carers Australia also offers information packs and a website[24], and since 2014, a federal Young Carer Bursary Programme, which offers financial support aimed at helping young carers to combine education with their caring responsibilities (Young Carers Network, 2019). More than 300 annual bursaries of AUS$3,000 each are provided for young carers aged 12 to 25 who are in secondary school or higher education (Young Carers Network, 2019). Carer Payments, Youth Allowances, and Student Start-up Loans are also available for young carers.

In NZ, limited public policies and a marked absence of services addressing young carers’ needs is evident. This section adds further detail to the brief outline of the policy and service initiatives undertaken in NZ in Chapter One, such as the re-establishment of YCNZ and the Young Carer Advisory Group in 2014. The Carers’ Strategy Action Plan 2014-2018 (MSD, 2014) was the first time that young carers had been included in NZ policy. Young carers’ addition came in response to NZ research calling for greater support for young carers (Gaffney, 2009; McDonald et al., 2010), and lobbying by Carers NZ. Young carers were addressed in Action 5.2 of the Strategy, which aimed to “better understand the needs of younger carers” (MSD, 2014, p. 25). The outcome was a focus on addressing NZ young carers’ information needs, through young carer and educator booklets. Additionally, the MSD contributed funding for the development of a Facebook page for young carers. By December 2014, the Facebook page had over 2,000 ‘likes’, and remains active today.

Since then, the MSD (2019) has released the “Mahi Aroha: Caring for the Carers” discussion document to inform the third proposed Carers’ Strategy Action Plan 2019-2023. Once again, younger carers aged 25 years and under have been highlighted as a key target group. Mahi Aroha appears to

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[24] https://youngcarersnetwork.com.au

be a significant step forward in terms of policy inclusion for young carers, going beyond their information-related needs to include a young carer research grant, the reestablishment of the Young Carer Advisory Group, and a prevalence survey (MSD, 2019). With the 2019 Strategy being updated alongside key work in other related areas central to young carers' experiences – including the NZ Disability Strategy[25], He Korowai Oranga: Māori Health Strategy[26], and the Child and Youth Wellbeing Strategy[27] – policy implementations for young carers and their family/whānau/aiga are entering a promising phase.

Importance of the Study

This literature review has established young carers as a significant but largely invisible population, who experience challenges as a result of providing care (Becker & Sempik, 2019; Gaffney, 2009; Hanna & Chisnell, 2019; Moore et al., 2009; Pakenham et al., 2006). However, the topic and experiences of NZ young carers remains understudied. Several fundamental gaps and limitations exist in NZ research to date, which I outline in this section. Firstly, limited research has been carried out with young carers representing all NZ's major population groups, including Pākehā, Māori, Pacific, and Asian, which affords them agency and power by accessing their own conceptions of their caring experiences, and which encourages their self-identification prior to participating in research (i.e., sampling without using gatekeepers). Secondly, a scarcity of research exists exploring young carers' conceptions of their role(s) that extends to the larger social and institutional care and disability milieu, including research examining young carers' interactions with external environments (e.g., disability services) over the course of their caring role(s). Thirdly, limited research exists that examines young carers' perceptions of their caring experiences during and after transition to adulthood, including their understandings of the impacts of care specifically relating to health, education, socialisation, and vocation developments, both during and after their caring role(s). Fourthly, lacking in NZ literature is research examining the effect of public policies and practices on the wellbeing of young carers, research accessing young carers' conceptions of their own identified needs and requirements related to their caring role(s), and their considerations regarding how these could effectively be met. My study addresses these identified limitations. Specifically, I recruited young carers from Pākehā, Māori, Pacific, and Asian populations from across NZ, without using gatekeepers, and including both current young carers and those who had transitioned into adulthood, to gather young carers' own perceptions of their experiences and needs and the effects of care over time. My research also aimed to address the dearth of NZ research concerning the effects of wider social and institutional environments on young caring from two directions, first by examining young carers' experiences with disability and care related government and social services organisations, and second by gaining the perspectives of those involved in delivery of services relevant to young carers. Indeed, my research has already informed, and has the capacity to further effect, changes in care and disability policies and services for young carers in NZ.

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[25] https://www.odi.govt.nz/nz-disability-strategy/

[26] https://www.health.govt.nz/system/files/documents/publications/mhs-english.pdf

[27] https://dpmc.govt.nz/our-programmes/child-and-youth-wellbeing-strategy

Research Questions

Therefore, the overarching research question for this project was: What does it mean to be a young carer in Aotearoa/NZ? The six sub-questions were:

1. What circumstances create and maintain young caring roles?
2. How do young carers perceive and make sense of their carer identity?
3. What is the nature and extent of care tasks carried out by young carers?
4. What are the ongoing health, education, vocation, and social effects of being a carer in childhood and adolescence, especially as young carers transition to adulthood?
5. How do current public policies, services, and practices affect young carers’ access to and use of external supports?
6. In what ways can young carers’ insights inform care and disability policies and services?

CHAPTER THREE

Theory and Methodology

The methodology chapter details the research process undertaken to address the research questions. The chapter opens with the theoretical framework using Bronfenbrenner's (2001) Bioecological Systems Theory (BST), including key ontological and epistemological assumptions that guided the thesis. The phenomenographic methodology will then be introduced, alongside an examination of the phenomenographic interviews and autoethnographic vignettes, and Whole of Transcript analysis. The chapter then justifies their use in order to answer the research questions. Thereafter, ethical considerations will be explored, followed by the key limitations and how I managed those areas of concern.

Theoretical Framework: Bioecological Systems Theory

To answer the research questions, I adopted Urie Bronfenbrenner's Bioecological Systems Theory (BST). Bronfenbrenner is widely recognised as a leading scholar in child development. He advocated for research carried out in authentic and real-life settings, a notion distinctly different to the historical developmental research convention of the study of what he described as "the strange behaviour of children in strange situations with strange adults for the briefest period of time" (Bronfenbrenner, 1977, p. 513). Bronfenbrenner's (1979) book, *Ecology of Human Development*, established the setting for his envisioned authentic research, initially called Ecological Systems Theory (EST), and extended the notion of the environment beyond the immediate situation, to examine:

> the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded (p. 21).

In subsequent work, Bronfenbrenner (2005) acknowledged the key limitation of Ecological Systems Theory as the focus on context (the environment) and the absence of biological influences on physiological development. Consequently, he added parameters enabling the consideration of genetic propensities on development, and Ecological Systems Theory henceforth became known as Bioecological Systems Theory (BST) (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994). Despite the terminology shifting, there is a "continuity of themes and arguments" throughout Bronfenbrenner's evolving conceptions of his theory (Bronfenbrenner, 2005, p. 1). Since the makeup of, and ontological and epistemological assumptions inherent in, both models remain largely consistent, literature pertaining to the original Ecological Systems Theory (e.g., Bronfenbrenner, 1979) remains highly relevant, and will be incorporated throughout the ensuing discussion.

BST has two key defining properties, the first of which is its "evolving" nature, reflecting changes occurring to the model itself over time (Bronfenbrenner, 2001, p. 4). Since the breadth of Bronfenbrenner's work reflects "the bases and development" of his evolving BST, my thesis draws

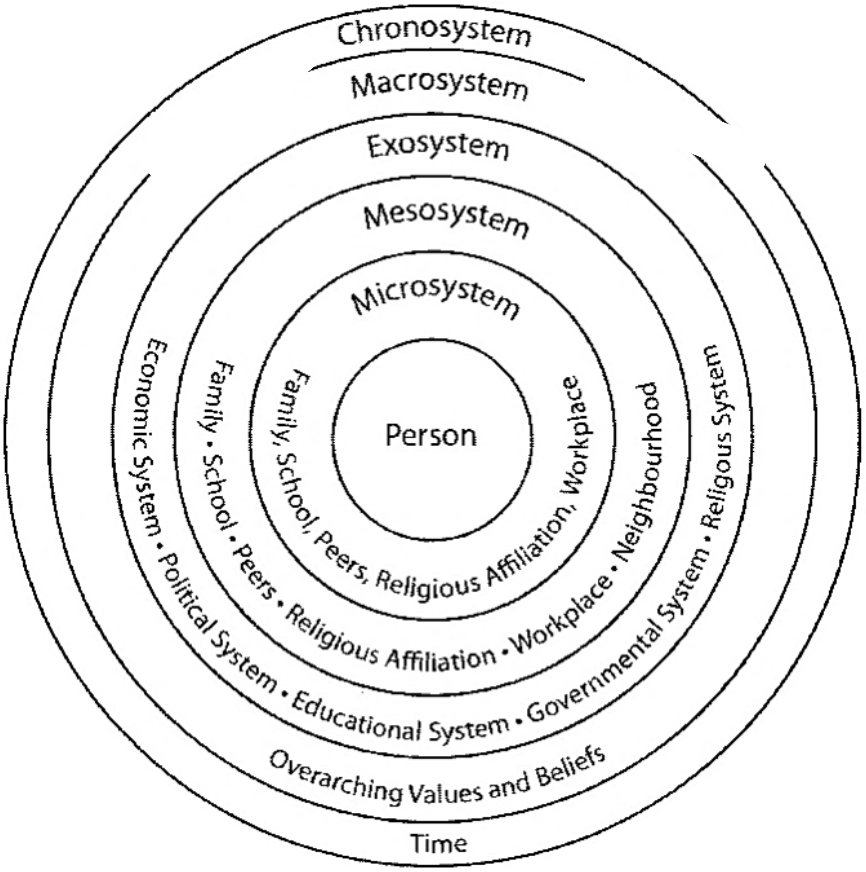

Figure 4. Bronfenbrenner's Bioecological Systems Theory (Berger, 2007, Adapted by Stanger, 2011, p. 169).

on a diversity of his published work over time (Lerner, 2005, p. xx). The second defining property of BST is "that it deals with two closely related but nevertheless fundamentally different developmental processes, each taking place over time" (Bronfenbrenner, 2001, p. 4). These are, on the one hand, the phenomenon "of continuity and change in the biopsychological characteristics of human beings" that is being investigated and, on the other hand, a focus on the "scientific tools" – both the theoretical underpinnings and design of the research – that enable a thorough assessment of this continuity and change (Bronfenbrenner, 2001, p. 4). Because the two tasks "are the joint product of emerging and converging ideas, based on both theoretical and empirical grounds", addressing either task in isolation is not possible (Bronfenbrenner, 2001, p. 4). As such, studies underpinned by BST enact "developmental science in the discovery mode" (Bronfenbrenner & Evans, 2000, pp. 999-1000), and accordingly are guided by two interrelated aims. Firstly, the objective of research moves beyond the traditional verification of existing findings under new conditions to verify their continued relevance, by instead "devising new alternative hypotheses and corresponding research designs" that have the capacity to discover innovative and relevant knowledge (Bronfenbrenner, 2001, p. 4). Secondly, a fundamental aim of BST research in the discovery mode is to influence relevant policy and practice that has the capacity to "counteract newly emerging developmentally disruptive influences" (Bronfenbrenner, 2001, p. 4).

Nested systems.

BST defines development as the “phenomenon of continuity and change in the biopsychological characteristics of human beings both as individuals and as groups. The phenomenon extends over the life course across successive generations and through historical time, both past and present” (Bronfenbrenner, 2001, p. 3). BST includes the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, arranged as a set of concentric structures, each nested within the next (Bronfenbrenner, 1979, 2005). At the innermost level is the microsystem, which is the immediate setting comprising the young carer (Bronfenbrenner, 1979). Here, face-to-face interactions are readily engaged in – for example, at home or in the classroom. At the microsystem level, I sought young carers’ experiences of the activities, roles, interpersonal relations, and symbolic features in any of their given microsystem settings (known as the elements of the microsystem), in order to decipher the nature and influence of their interconnections with others physically present in the immediate setting; for instance, with their care recipient(s) or parent(s) (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 1998). Dyads, or two-person systems (e.g., young carer and care recipient) are the essential units of analysis at this level (Bronfenbrenner, 2005). The second level is the mesosystem, which is essentially “a system of microsystems” (Bronfenbrenner, 1979, p. 25). Here I looked beyond single settings to the interconnections between settings in which a young carer actively participates. An example of a mesosystem is the interaction between a young carer’s home, school, and community groups. When the young carer moves into a new setting, the mesosystem is either extended or reformed. The mesosystem extends beyond the dyad in its unit of analysis, as it accords importance to “N+2 systems”, which can be triads, tetrads, and other interpersonal structures outside of the dyad, for example, young carers’ interactions with relatives, friends, or neighbours (Bronfenbrenner, 1979, p. 25).

The third level is the exosystem, where settings are examined that do not include the young carer “as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing” the young carer (Bronfenbrenner, 1979, p. 25). Thus, a young carer’s exosystem might include parents’ workplaces or the actions of the local school’s Board of Trustees. The principle of interconnectedness applies with equal force and consequence within and between settings, so that settings within a level (e.g., the workplaces of the young carer’s mother and/or father in the exosystem) can influence one another to the same extent as settings between levels (e.g., the young carer’s home in the microsystem and the mother’s workplace in the exosystem) (Bronfenbrenner, 1979).

At the macrosystem level, examination is carried out regarding a particular setting’s “blueprint” (Bronfenbrenner, 1979, p. 26). The blueprint refers to uniformity that does or could exist in the form and content of microsystems, mesosystems, and exosystems in a particular subculture or culture as a whole, alongside the underlying belief systems and ideologies (Bronfenbrenner, 1979). Examination is carried out both within (“intrasocietal”) a given setting – for instance by examining the beliefs and ideologies existing regarding caregiving within a young carer’s home – and between (“intersocietal”) particular settings – for instance, by comparing the beliefs and ideologies existing regarding caregiving in the young carer’s home with other NZ households’ conceptions of care (Bronfenbrenner, 1979, p. 26).

Finally, at the outermost BST level is the chronosystem, where the dimension of Time is housed and environmental changes occurring over the life course are examined (Bronfenbrenner, 2001). The chronosystem moves beyond previous considerations of time “taken into account only as it applied to constancy and change in the characteristics of the person” so that the environment was essentially seen as static and only examined at a particular point (e.g., information gathering regarding young caring carried out in the home over a two-week period) (Bronfenbrenner, 1992, p. 119). Instead, time regards “constancy and change” in both the young carer and their environment; for instance, information gathered via former young carers reflecting back on their diverse care experiences over time (Bronfenbrenner, 1992, p. 119). At the chronosystem level, a particular focus is placed on “developmental changes triggered by life events or experiences”, (e.g., young caring as a result of the onset of parental illness). Such events have their origins in either the external environment (e.g., beginning caregiving or school), or within the individual themselves (e.g., puberty or illness). The key feature of such events is their capacity to change the previous relationship between the young carer and their environment, “thus creating a dynamic that may instigate developmental change” (Bronfenbrenner, 1992, p. 119). The chronosystem has a key focus on interactions between systems, and how these systems impact each other over time (Bronfenbrenner, 2001). For instance, a child hiding their young caring role from their teachers is a microsystem-macrosystem interaction, because while teachers are members of the microsystem, the hiding of the young carer’s role is shaped by their understanding of beliefs (or blueprints) held at the macrosystem level, regarding the appropriateness of children providing care. The assumption might be that their teacher will react poorly to the child’s ‘inappropriate’ caregiving role.

Process-Person-Context-Time (PPCT).

The BST model has four interrelated components, being the Process, Person, Context, and Time (or PPCT) (Bronfenbrenner, 1979, 2001). Bronfenbrenner (2001) asserted that all four PPCT components must be examined in any given study for the accurate representation of the child or youth’s development. Looking more deeply into each component, *Process* regards the developmental processes occurring due to interactions between an individual and their environment – termed proximal processes. These “operate over time and are posited as the primary mechanism producing human development” (Bronfenbrenner & Morris, 1998, p. 994). An example of a proximal process is a child caring for their unwell parent.

The characteristics of the developing Person (young carer) are understood to significantly impact the capacity of proximal processes to affect their development (Bronfenbrenner & Morris, 1998). That is because young carers bring to interactions their unique “biological, cognitive, emotional, and behavioural characteristics” (Lerner, 2005, p. xv). Three types of Person characteristics are identified as being the most influential on the course of a child or youth’s development (Bronfenbrenner & Morris, 1998, p. 995). Firstly, *force characteristics* refer to young carers’ dispositions, which “can set proximal processes in motion in a particular developmental domain and continue to sustain their operation" (Bronfenbrenner & Morris, 1998, p. 995). Continuing with the example of a child providing care outlined above, then the child's motivated, persistent, and compassionate disposition may result in their uptake and maintenance of care. Secondly, *resource characteristics* are needed for the "effective functioning of proximal processes" throughout development. Resource characteristics include mental and emotional resources (e.g., ability, experience, knowledge, and mental wellbeing) and material and social resources (e.g., educational opportunities and housing). Here, the child's level of understanding of their parent's illness and unique care needs, coupled with familial financial means, would impact the child's capacity to effectively enact care (Bronfenbrenner & Morris, 1998, p. 995). Thirdly, *demand characteristics*, for instance, age, gender, and physical appearance, "invite or discourage reactions from the social environment" that in turn "foster or disrupt the operation of proximal processes" (Bronfenbrenner & Morris, 1998, p. 995). So, the child's caring role may become challenging if their parent experiences physical changes as a result of their illness or disability, drawing unwanted and/or negative societal attention. The ultimate combinations of the three characteristics in an individual account for "differences in the direction and power" of proximal processes and their effect on development (Bronfenbrenner & Morris, 1998, p. 995).

From this detailed consideration of the Person, then a "richer understanding" of the Context is achieved. For instance, the three characteristics of Person also apply to others residing in a young carer's microsystem – who interact with that individual "on a fairly regular basis over extended periods of time" (Bronfenbrenner & Morris, 1998, p. 995) – including care recipients, parents, relatives, teachers, and peers. The Context for a young carer's development is the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, and as such, an examination of the child's caring would consider all five levels.

The final component of PPCT is *Time*, which moderates change across the young carer's life (Bronfenbrenner, 2001; Lerner, 2005). This final defining property of BST "moves it farthest beyond its predecessor", the Ecological Systems Theory (EST) (Bronfenbrenner & Morris, 1998, p. 995). Bronfenbrenner and Morris identified time as comprising three key facets. Firstly, micro-time refers to "continuity versus discontinuity within ongoing episodes of proximal processes", for instance, how individual care tasks play out (Bronfenbrenner & Morris, 1998, p. 995). Secondly meso-time represents "the periodicity of these episodes across broader time intervals"; for example, the instance of children's care provision over weeks, months, and years (Bronfenbrenner & Morris, 1998, p. 995). Thirdly, macro-time (the chronosystem) focuses on the young carer's entire lifetime, and identifies "the changing expectations and events in the larger society, both within and across generations" (Bronfenbrenner & Morris, 1998, p. 995); for instance, shifting societal expectancies with regards to children providing care.

Overall, BST recognises the integral place of the young carer in their individual development, occurring within a wider system "of interacting contexts over time" (Hamilton & Ceci, 2005, p. 284). BST thus enabled me to examine "the forces that promote or undermine" young carers' development (Hamilton & Ceci, 2005, p. 284).

Ontological assumptions.

A key challenge inherent in BST is the future-focus required when initiating new hypothesis and research designs in the face of inevitable "historical change" (Bronfenbrenner, 2001, p. 4). With this in mind, Bronfenbrenner (1979, 2001) identified several consistent elements of BST expressed as nine propositions. These nine propositions house the key ontological assumptions concerning the nature of human development underpinning BST, with correlating epistemological derivations for my research.

Firstly, human nature is plural and diverse. As such, BST embraces a holistic view of human existence, with the young carer being one element in the wider system. Therefore, my research focused on young carers' understandings of their roles, which change in response to their "exposure to and interaction with the environment" (Bronfenbrenner, 1979, p. 9). Secondly, equal emphasis is placed on experiential and objective views, as external influences truly affecting human behaviour and development cannot be explained in terms of either their objective or subjective elements alone (Bronfenbrenner, 2005). Accordingly, a young carer's "evolving construction of reality cannot be observed directly" (Bronfenbrenner, 2005, p. 11), but can only be inferred from qualitative information gathered via verbal and non-verbal behaviour in relation to the activities, roles, and relations in which they engage, involving the young carers themselves. Thirdly, Bronfenbrenner proposed that perception is reality, and development is thus a young carer's "evolving conception of the ecological environment, and his [sic] relation to it" (1979, p. 9). Central to behaviour and development is "the environment as it is perceived rather than as it may exist in 'objective' reality" (Bronfenbrenner, 1979, p. 4). In this way, if young carers "define situations as real they are real in their consequences" (Thomas & Thomas, 1929, p. 572). My research thus focused on what young carers "perceived, desired, feared, thought about, or acquired as knowledge" rather than solely on that which could be objectively confirmed (Bronfenbrenner, 1979, p. 9).

Fourthly, Bronfenbrenner regarded the developing child as "a growing dynamic entity that progressively moves into and restructures the milieu in which it resides" (1979, p. 21). In this way, the child actively influences his or her development, "shaping environments, evoking responses from them, and reacting to them" (Darling, 2007, p. 204). Subsequently, my research afforded agency to young carers by actively soliciting their views, recommendations, and examples of how their actions shaped their caring environments. Fifthly, Bronfenbrenner (1979) critiqued the hypertrophy of "development-out-of-context" (p. 21) research, which uses "dichotomous" and "value-laden labels" (p. 14), and locates the developing person only in terms of his/her immediate setting (or "social address") (p. 16). Instead, Bronfenbrenner (1979) called for "development-in-context" (p. 21) research carried out in authentic environments in which human beings exist. My interviews thus aimed to develop a deeper understanding of young carers' behaviour both across and within various settings as affected by the relations between settings. Accordingly, in order to make participants feel comfortable, where possible young carers and service representatives chose the interview locations, often being places that they had commonly visited. Sixth, Bronfenbrenner proposed the environment as dynamic and extending beyond the immediate situation to encompass "interconnections between ... settings as well as to external influences emanating from the larger surroundings" (1979, pp. 21-22). Therefore, a young carer's development can be influenced by events occurring in locations in which they are not present. My research thus gathered information about young carers' wider environmental contexts, including those of which they might not have even be aware, such as government, health, community, care, and family organisations, via speaking with service and agency representatives. Furthermore, Bronfenbrenner proposed that central to BST research is amending, improving, and implementing public policies that improve living conditions for, and influence the wellbeing and development of participants. Bronfenbrenner (2001) asserted that research framed by BST "can advance understanding of the bases of the challenges, indeed the disarray, confronting contemporary families and, in turn, can offer ideas for policies and programs that can actualise humans' self-constructive potential for positive development" (p. 185). In this way, BST endorsed collaboration between young carers and myself to enact real-world change, by soliciting young carers' own views about theirs' and their family/whānau/aiga's needs.

Seventh, Bronfenbrenner proposed that human beings develop in interaction with their environment, and as such, he defined human development as "the process through which the growing person acquires a more extended, differentiated, and valid conception of the ecological environment" (1979, pp. 9-10). So, while young carers may initially be cognisant only of their microsystem, their perceived reality will temporally evolve, extending to interests and capacities to engage in activities at the mesosystem, exosystem, and macrosystem levels. Consequently, I accorded equal importance to the young carer and their environment, for instance by probing to gain deeper insights into their interactions with their wider environments (e.g., their conceptions of the impact of their parents' workplaces at the exosystem level, on their caregiving roles in the microsystem). Furthermore, the interaction between person and environment is reciprocal, with human beings producing the environments that form the progress of their development more than any other species (Bronfenbrenner, 1979, 2005). My research thus had a definite focus on the interaction between the young carers and their environment, for instance, by probing to encourage young carers to consider how their caregiving roles and actions might have affected the environments that they chose to discuss, and vice versa (e.g., how their young caring role effected their schooling experiences, and vice versa). Eighth, the interaction between humans is reciprocal and power-laden. Dyad members coordinate activities, because each dyad member's behaviour and actions will affect the other. Dyadic coordination with another person facilitates a child's acquisition of interactive skills and a concept of interdependence, although one participant can hold greater influence than the other. Dyads investigated in my study were largely young carer-care recipient. However, because knowledge is socially created, and examination of a young carer's development could not be carried out in isolation from their relationships with others, information was gathered relating to both parts of dyads, and took into consideration any influential N+2 systems, for instance, the influence of the young carer's school teacher(s). Finally, the ninth ontological assumption is Bronfenbrenner's (1979) proposal that human development is dynamic and multifaceted, with "enduring changes that carry over to other places at other times" (p. 14). Bronfenbrenner (1979) understood the impossibility of meeting the carry-over qualification within the constraints of short-term research projects, and explained that analysing "a short-lived adaptation to the immediate situation" (p. 14) suffices, provided the researcher identifies and discloses that this qualification has not been met. Therefore, I was mindful of, and signalled in my research limitations, the ecological criteria that I could not meet.

Overall, Bronfenbrenner's BST was chosen for its capacity to empower young carers to share their own interpretations of their caregiving experiences, examined in their immediate and wider contexts, and with the aim of enacting social and policy change for young caregivers and their families.

A "curriculum of care".

In several of his publications, Bronfenbrenner (1985, 2005) outlined the failing of society's efforts in making human beings human, which was a key theme underlying his body of work. He felt that society was "breaking down" due to "a turning away from concern with the problems of others" (1985, p. 258). He outlined a key issue resulting from this type of disconnect, being that:

> It is possible for a young person, female as well as male, to graduate from high school, college, or university without ever having held a baby in his or her arms for longer than a few seconds, without ever having had to comfort or assist another human being who really needed help. Yet all of us, sooner or later, will desperately require such comfort and care, and no society can sustain itself unless its members have learned the motivations, sensitivities, and skills that such caring demands (Bronfenbrenner, 1985, p. 254).

Such an absence of caring was in contradiction with Bronfenbrenner's earlier (1979) conceptualisation of the worth of any society as "the concern of one generation for the next" (p. 216). Consequently, he called for a "change in our present way of life" (Bronfenbrenner, 1985, p. 254) in order to "revitalize the human bonds essential to sustaining the wellbeing and development of both present and future generations" (Bronfenbrenner, 1985, p. 258). Henceforth, Bronfenbrenner's (1985) "curriculum of care" was born, in which "the young caregivers" (p. 255) would take "responsibility for spending time with and caring for others – old people, younger children, the sick, and the lonely" (p. 254), at school and in the community. The outcome of such a curriculum was deemed to be capable and empathetic citizens, who had the capacity to "reweave the unravelling social fabric" and once again make human beings human (Bronfenbrenner, 1985, p. 258). Bronfenbrenner's curriculum of care informed my study by offering a macrosystem level societal viewpoint on young caring and its benefits. In addition, the young carers' own descriptions of their roles echoed Bronfenbrenner's conception of a curriculum of care (discussed in Chapter Four).

In the following section, I will outline the study's interpretivist research paradigm and phenomenographic methodology, which were chosen for their capacity to address the research aims and questions and their fit with Bronfenbrenner's BST.

Methodology

Social science research seeks answers to questions in order to understand the social world (Neuman, 1997). The term paradigm is used to "describe an entire way of looking at the (social) world" (Davidson & Tolich, 1999, p. 26). Neuman (1997) describes two competing social science paradigms: positivism, which places emphasis on deduction and causal laws, and interpretivism, which concentrates on an inductive understanding of the meanings people bring to situations and behaviour (O'Donoghue, 2007; Punch, 2009). The interpretivist paradigm considers knowledge as “not simply imprinted on individuals but ... formed through interactions with others”, so that a person’s perceived reality is always ingrained in their experiences and culture (Creswell, 2003, p. 8). The interpretive paradigm has a key focus on the viewpoint of the person experiencing the phenomenon being studied, and also considers the viewpoints of external agents such as parents and teachers (Denzin, 2001). Therefore, I adopted an interpretivist paradigm in order to understand young carers’ own perceptions of their caring experiences, as well as agency representatives’ conceptions of young caring.

Certain methods are better suited to investigating and understanding particular social phenomena than others. The two major approaches to choose from are quantitative and qualitative. Bronfenbrenner’s (1979) BST, which guided the study, advocates for the qualitative approach. Qualitative research is generally undertaken with smaller numbers of participants and enables adults or children to be positioned as the direct and primary unit of study (Punch, 2009). According to Rossman and Rallis (2003), qualitative research has five defining features. Firstly, it draws on the interpretivist paradigm (Rossman & Rallis, 2003), which concerns the way in which people interpret and give meanings to phenomena (Liamputtong & Ezzy, 2005). Qualitative researchers capture participants’ “lived experiences of the social world and the meanings [they] give to these experiences from their own perspectives” (Corti & Thompson, 2004, p. 326). As the focus of the research was to access young carers’ perceptions of their caregiving experiences rather than its incidence, and because Bronfenbrenner (2005) states perceptions can only be inferred from qualitative information, then qualitative methods assisted in addressing the research questions. Secondly, qualitative research has a strong focus on context (Rossman & Rallis, 2003). The qualitative researcher aims to understand the “contextualised nature of experience and action, and attempts to generate analysis that is detailed, ‘thick’”, and integrates participants’ individual interpretations of events and experiences within “larger meaning systems and patterns” (Liamputtong & Ezzy, 2005, p. 2). The strong focus of qualitative research on context that extends beyond participants’ immediate environment to wider structures and forms is key to BST research (Bronfenbrenner, 1979, 2005). Thirdly, qualitative research occurs “in the natural world” (Rossman & Rallis, 2003, pp. 8-9), thus supporting Bronfenbrenner’s (1979) assertion that research should be authentic and carried out in the real-life settings of the participants. I did not do this, however, due to the sensitive nature of interviews undertaken in current young carers’ homes – their authentic environments where caregiving occurred, and because the majority of the participants were former young carers. Instead, where possible, participants chose their own interview locations, often being familiar places to them such as a café or local library, in order to facilitate their comfort. Fourth, qualitative research employs multiple methods in any given study, such as combining interviews and observations (Rossman & Rallis, 2003). As a qualitative BST researcher, I used two methods. The first and most important was in-depth interviews employed with participants, to gather information regarding young carers’ microsystem, mesosystem, exosystem, macrosystem, and chronosystem environments (Bronfenbrenner, 1979, 2001). The second method was autoethnography employed by the researcher as part of researcher self-reflexivity. Fifth, qualitative research is “emergent rather than tightly prefigured” (Rossman & Rallis, 2003, pp. 8-9), and thus is “more likely to delay conceptualizing and structuring of the data until later in the research” (Punch, 2009, p. 117). According to McDonald and Daly (1992), qualitative research is pertinent to studies in which researchers have limited knowledge of the area under investigation. The fundamentally emergent nature of qualitative research befitted this exploratory study of the relatively “little known phenomena” of young caring (Stebbins, 2001, p. 7) in NZ.

Phenomenography.

The key method that enabled me to answer the research questions was phenomenography. Developed in the early 1970s in Sweden by the initial Gothenburg group, phenomenography was created to “collect respondents’ verbal descriptions of their understanding of a particular study text” (Van Rossum & Hamer, 2010, p. 34). Phenomenography was originally developed from “a strongly empirical rather than theoretical or philosophical basis” (Åkerlind, 2012, p. 115). However, over time a theoretical basis has been developed, alongside epistemological and ontological assumptions, and methodological requirements (Bowden, 2000; Bowden & Green, 2005). Phenomenography today investigates “qualitatively different ways in which people understand a particular phenomenon or an aspect of the world around them” (Marton & Pong, 2005, p. 335).

Seven key assumptions inherent in phenomenography drove the research methods. Firstly, phenomenography embraces a non-dualistic ontology, which proposes that there is no objective worldview (Svensson, 1997). Instead, and in line with Bronfenbrenner (1979), it understands the experienced world as created in interaction between individuals and their environments (Marton & Booth, 1997). Also comparable with Bronfenbrenner, phenomenography posits knowledge as social, interrelated, and contingent upon context and perspective (Svensson, 1997). Secondly, phenomenography focuses on participants’ experiential reality. A key distinction is made between first- and second-order perspectives, which respectively aim at “describing various aspects of the world” (first order), and “describing people’s experience of various aspects of the world” (second order) (Marton, 1981, p. 177). Whilst phenomenography advocates the use of both perspectives, the emphasis is placed largely on second-order perspectives (Marton, 1981). Hence, rather than aiming to describe reality itself, which Bronfenbrenner (2005) asserted cannot be done, phenomenographic researchers use a second-order perspective to orient themselves towards and then analyse participants’ ideas and experiences of the world (Marton, 1981, 1986; Ornek, 2008). The focus on second-order “experience-as-described” (Ashworth & Lucas, 1998, p. 415) supports research questions about conceptions of reality relating to a specific phenomenon, dominant in a particular time, culture, or society.

Thirdly, the notion of conceptions – ways of experiencing, seeing, or understanding – is central to phenomenography, and is the basic unit of description (Marton & Pong, 2005). Conceptions are also central in BST and interpretivist research, as researchers focus on participants’ conceptions rather than objective reality (Bronfenbrenner, 1979). The second-order phenomenographic perspective posits conceptions as dynamic, embedded in relations between individuals, and dependent on the specific activity and setting in which they are being examined (Prosser, Trigwell, &

Taylor, 1994; Säljö, 1997). Fourth, phenomenographic researchers are interested in variation relating to both the similarities and differences inherent in people's conceptions of particular phenomenon (Marton, 1981). Marton (1981) highlighted that different conceptions of certain phenomena are found not only between individuals, but also within individuals. Furthermore, phenomenography supposes that only a limited number of conceptions exist about a given phenomenon, and that these conceptions can be identified and described (Marton, 1981, 1986). Phenomenographic research thus aims to identify and describe qualitative variation within and between participants' experiences (Dortins, 2002).

Fifth, in order to ascertain variations in participants' experiences, the context-bound nature of conceptions is vital (Marton, 1981). Furthermore, context-oriented research enables an examination of participants' conceptions extending beyond their immediate settings (microsystems), to their relations to and understandings of their wider settings (mesosystems, exosystems, macrosystems, and chronosystems) (Bronfenbrenner, 1979), supporting an examination of relations between young carers and their immediate and wider environments (Marton, 1981, 1986; Prosser et al., 1994). Sixth, the aim of phenomenographic information collection is experiential descriptions concerning participants' perceptions of a given phenomenon (Marton, 1981; Svensson, 1997). Because participants' descriptions characterize how a given phenomenon is experienced or perceived, "phenomenography cannot be other than a fundamentally qualitative research method" (Marton, 1986, p. 33). As such, phenomenographic information is qualitative and explorative in nature. Whilst participant descriptions of conceptions can be conveyed in varying qualitative forms, such as written surveys (Holmström, Halford, & Rosenqvist, 2003), they are most available via language. Consequently, the most common phenomenographic method is interviews (Marton, 1986).

Finally, like other interpretive and BST researchers, phenomenographers assume it is not possible to be an objective and politically neutral researcher carrying out a value-free interpretive study (Bronfenbrenner, 1979; Denzin, 2001). Instead, "a gendered, historical self" is brought to the research process (Denzin, 2001, p. 3). Thus, "systematically reflecting" on who I am, and my prior preconceptions and interpretations in relation to the research, was imperative (Rossman & Rallis, 2003, p. 9). Phenomenography uses the term "bracketing"[28] to describe the "need for the researcher to set aside his or her own assumptions" (Van Rossum & Hamer, 2010, p. 45) in order to access participants' perceptions and understandings (Ashworth & Lucas, 2000). Bracketing relates particularly to the effect that previous findings and theories may have on the researcher (Van Rossum & Hamer, 2010). My examination of literature deepened my understanding of existing knowledge about the young caring experience. Additionally, as I was a young carer for 11 years, I brought to my study experiential, historically embedded, and continuously developing preconceptions and interpretations. As such, I had to be particularly mindful to bracket my presuppositions (e.g., concerning the key impacts of caring as a child), whilst still maintaining enough prior knowledge to "recognize when to prompt respondents" (Van Rossum & Hamer, 2010, p. 46). I achieved this by

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[28] Phenomenographic bracketing, discussed in the text, is distinct from Denzin's (2001) interpretive interactionist bracketing, in which "the researcher holds phenomenon up for serious inspection, taking it out of the world where it occurs" (p. 75).

using open interviews principally led by participants' notions of what was relevant, and autoethnographic writing to bracket out my own assumptions (discussed later in this chapter). Phenomenography also required constant reflection on my positionality as a researcher, as perceptions are dynamic and ever-changing.

Recruitment

Sampling facilitated the development of effective recruitment strategies for my study. Three broad sampling approaches can be used for qualitative research: convenience, theoretical, or judgement (Marshall, 1996). Due to the significant overlap between categories, qualitative research generally draws on all three sampling techniques to some extent (Marshall, 1996). However, in most cases, one of the three approaches is chosen by researchers as their main sampling method. Convenience sampling is the least rigorous and least costly in terms of time, money, and effort, involving the selection of the most accessible participants (Marshall, 1996). However, "a more thoughtful approach to selection of a sample is usually required" (Marshall, 1996. p. 523), and as such, convenience sampling was not the main sampling technique in my study. Theoretical sampling involves the researcher iteratively building interpretative theories as new information emerges throughout the research process, and as a result, selecting a new sample to develop their theory (Marshall, 1996). As the intention of my study was not to build theory, I did not adopt theoretical sampling as my main sampling technique. Finally, in judgement (or purposeful) sampling, "the researcher actively selects the most productive sample" to answer their research questions, based on "practical knowledge of the research area, the available literature and evidence from the study itself" (Marshall, 1996. p. 523). Judgement sampling was used as the main sampling technique in my study, as it enabled my purposeful selection of diverse participants within the young carer population – where a need for further research with diverse participants (e.g., of diverse ethnicities) was identified in the literature (e.g., Lackey & Gates, 2001) – to assist in a holistic understanding of the phenomenon.

The number of participants required for any given study is "less important than the richness of the data" and as such, a sample is large enough "when the researcher is satisfied that the data are rich enough and cover enough of the dimensions they are interested in" (Liamputtong & Ezzy, 2005, p. 49). The number of participants chosen should take into consideration the time necessary to manage and analyse large quantities of transcribed information, and the financial resources available (Liamputtong & Ezzy, 2005). Following the lead of participant numbers used by qualitative young caring studies within the body of existing research – generally ranging from nine to 24 participants per study (Gaffney, 2007; McDonald, 2008; Moore, McArthur, & Noble-Carr, 2011) – I initially considered up to 20 participants as feasible for my research. I continued sampling until the "categories of description" (Marton, 1986, p. 43) (discussed later in this chapter) had become stable, and existing information was being confirmed rather than new young caring interpretations being found, a concept described as saturation (Fusch & Ness, 2015). According to Fusch and Ness (2015), "data saturation is reached" when "the ability to obtain additional new information" has been exhausted (p. 1408).

Due to a paucity of existing NZ research, the key priority of my study was to collect material from diverse participants across the NZ young carer population. Refining the research further to focus on any single sub-group was not plausible. As such, sampling aimed to recruit three populations: current young carers (≤25 years), who were immersed in and thus could provide their perspective on the present-day reality of being a carer; former young carers, who could provide valuable retrospective perspectives on their caring roles; and service and agency representatives, who could offer background information pertaining to young carers' exosystem and macrosystem environments.

Initial selection criteria for young carer participants was broad to allow for the likely scarcity of respondents identified in previous studies (Gaffney, 2007; Hanna & Chisnell, 2019; McDonald, 2008), but purposive sampling could have been employed if the response rate was high. Selection was made on all of the following criteria – currently provides or previously provided care when they were ≤25 years and for at least one year. I aimed to select young carer participants who were diverse in their: (a) ages when starting and ending caring; (b) gender; (c) ethnicity; (d) disability or illness of care recipient; (e) relationship to care recipient, for instance sibling or parent; (f) level and variety of care tasks undertaken; and (g) geographical locale. In order to increase my possible pool of respondents, participants' ages and care statuses at the time of the research were not a deciding factor for their participation in the study.

Bronfenbrenner (1979) asserted it "is not the size but the structure of the design that is critical" (p. 39). Consequently, as a starting point – see later discussion of "treatment in depth" (Van Rossum & Hamer, 2010, p. 38) – I proposed to interview approximately 10 current young carers aged 25 and under (the age range accounts for transition to adulthood), 10 former young carers aged 26 and over, and up to 10 agency representatives across care and disability organizations and services. Ethical approval was sought from the University of Auckland Human Participants Ethics Committee in May 2014, and was granted on the 29th July 2014 for three years (reference number 01238).

Recruiting any NZ young carers at all for the study proved to be a challenge, however. Difficulty recruiting young carer participants for research is commonly identified in this field, due to the hidden nature of young carers (Barry, 2011; Gaffney, 2007; Kennan et al., 2012). Existing studies have used gatekeepers and poster advertisements in order to gain access to young carer participants (e.g., Gaffney 2009). I aimed to recruit young carers without using gatekeepers, as the scope of the study could have been "limited by the degree of cooperation achieved" with service providers or as a result of "wary gatekeepers" due to the "sensitive nature of the study" (Stevens, Lord, Proctor, Nagy, & O'Riordan, 2010, p. 504). In addition, previous research identifies that parents/caregivers and young carers do not always disclose their roles to services, due to a fear of familial disjunction (Aldridge et al., 2016; Kennan et al., 2012; Szafran et al., 2016). Consequently, I initially attempted to recruit participants through four different posters targeting diverse age groups of young carers, and also service representatives [Appendix A]. The posters were displayed at universities, youth and disability organisations, and in the community. I extended my sampling to disseminating the posters via the University of Auckland student portal Cecil. I also tapped into pre-established networks (e.g., Auckland Carers Alliance) to identify organisations and subsequent agency representatives who may be interested in participating in the study. Two months passed with no young carers and just two service representative responses.

Reflecting Butler et al.'s (2019) sentiment that "overly cautious" recruitment procedures "may exclude entire groups of potential participants, inhibiting their autonomy" (p. 226), I realised that I needed to step outside the bounds of traditional young carer participant sampling. I soon recognised that one issue lay in young carers' lack of awareness of their own young caregiving identities, so that even where individuals fitting the parameters of the term 'young carer' saw the poster headlines, they were unlikely to be aware that they were in fact young carers and eligible to participate in the study. Essentially, recruiting participants appeared difficult because young carers seemed unaware that they were young carers.

Reflecting on my own self-identification gained through reading another young carer's experiences, I concluded that in order to encourage young carers to self-identify so that they could come forward for my study, I needed to share my own experience of being a young carer. Several opportunities emerged to share my story and the research, which I accepted and adapted to become part of the recruitment process. Three amendments were made to the research Ethics to factor in the new recruitment strategies. Written and oral storytelling were employed for recruitment, with written storytelling involving a monthly autobiographical column in a widely distributed (75,000 person readership) NZ family caregiving magazine [Appendix A]. In addition, regular calls for participants were published in several family-, caregiving-, and disability-related magazines and newsletters, including the *NZ Down Syndrome Association* magazine, and *Parent and Family Resource Centre* newsletter [Appendix A]. One-off pieces were also included in a major printed and online newspaper, the NZ *Sunday Star Times* (Dennett, 2014), the Radio NZ *Wireless* news website (Enoka, 2015), and the University of Auckland *Ingenio* alumni magazine (Wilford, 2015). The platforms covered print and electronic or online media, and reached diverse audiences. In each piece, I wrote about my own life as a young carer – often accompanied by photos – and included the call for research participants. Secondly, oral storytelling was employed through sharing my young caring experience and call for participants via: presenting in person to university cohorts; at key disability, caregiving, and youth organisation meetings, workshops, and conferences; and on NZ's national radio station, Radio New Zealand. However, once again reflecting the well-documented difficulties of recruiting young carers, these methods too were largely unsuccessful in recruiting young carers for the study. Only one current and two former young carers responded to the storytelling calls for participants – alongside one service representative – over a four-month period. As such, after six months of recruitment, just three young carers and three service representatives came forward.

Ultimately, the most successful recruitment method was visual storytelling via the release of a 5-minute video, which was the result of serendipity. University of Auckland videographer Michelle Vergel de Dios approached me after hearing my presentation in the University's Three Minute Thesis finals in 2014. Michelle produced and edited the video, which she initially proposed as a means of raising awareness of young carers via a film festival. However, with Michelle's permission, it became the primary recruitment strategy. In the video, I spoke informally about my own experience of young caring and of the research aims, accompanied by animations created by Michelle in order to appeal to the young target audience and facilitate their understanding of young caregiving and the research project. The video was disseminated via social media platform Facebook. Initially, Michelle and I posted the video to our personal pages. The video was then shared by our family and friend networks, and by over 20 care, disability and illness, child and youth, and family/whānau/aiga organisations (e.g., YCNZ, IHC Foundation). In total, the video was shared by over 100 people and organisations, and thus reached a large audience. Within just eight weeks, a further 25 young carers – including three current and 22 former young carers – came forward to be part of the research. The use of a video and social media appeared to be more reflective of the age and stage of participants in the study who, in most cases, viewed the video via Facebook on their mobile phones or laptops. Social media also appeared to bridge the gap between information about the research, and current young carers and former young carers who were current *adult* carers, both of whom primarily remained in the home providing care (Aldridge, 2009; Leu et al., 2018). Their home-based lives may help to explain the ineffectiveness of posters and presentations. Furthermore, social media opened up the research to geographically diverse young carers throughout NZ, and former young carers who had since left NZ and were residing overseas.

Finally, in order to embed NZ young carers' experiences into the wider services context, I also recruited service representatives at several conferences. In the end, one international and three NZ service representatives were recruited. The UK service representative was chosen for their ability to add context regarding possible services solutions that might benefit NZ young carers – based on participants' own expressed needs – from their knowledge base as a key player in the young caring field, both in the UK and internationally. Overall, 32 participants took part in my study, including four current and 24 former NZ young carers, and three NZ and one UK service and agency representatives.

Sources of Information

The sources of information reflect the ontological and epistemological foundations of BST framing the study, and aimed to capture the experiences and understandings of young carers in their own voices. The main focus was young carers' experiences, but the same principles applied to interviews with representatives of services and agencies who had responsibility for interacting with young carers. In order to answer the research questions, and in line with a qualitative BST approach, the study used one primary and one secondary qualitative sources of information that together elicited stories and experiences of young caring in immediate and wider environments, being phenomenographic interviews with participants, and autoethnography by the researcher (Bronfenbrenner, 1979; Rossman & Rallis, 2003).

Phenomenographic interviews.

The primary source of information about young caring was in-depth interviews. According to Thomson (2008), interest in methods that bring children's and youths' "previously unheard voices into scholarly ... conversations" is growing (p. 1). Because children and young people have agency (Bronfenbrenner, 1979), it is imperative to involve young carers themselves in research that concerns them (Kennan et al., 2012). The study regarded young carers as active social agents with important contributions to make to public and political discourses, and with perceptions and understandings that were worth exploring (Aldridge, 2009). Since perceptions cannot be directly observed (Bronfenbrenner, 1979), phenomenographic interviews were adopted as the primary source of information.

Contact with young carers and service representatives prior to their interviews was participant led, and mirrored the form of communication by which the individual had chosen to initially make contact with the researcher following the call for participants. While forms of communication included phone calls, Facebook Messenger and, in one instance, a posted letter, most often email and text messaging were employed. Each person expressing interest was sent an information sheet and consent form, tailored to their age or position [Appendix B]. Four versions of consent forms and information sheets accounted for current and former young carers – as children (including information for their parents), adolescents, and adults – and the service or agency representatives. Information sheets were a jargon-free summary of the research, including details of the interview process, issues of confidentiality, and the intended use of the information, and used imagery to facilitate understanding for young children. Possible participants could then ask questions, with most taking the opportunity to clarify details of the study. Once individuals felt fully informed, and comfortable with their involvement, they completed consent forms. Written consent was obtained from adult research participants. Written assent was given by participants aged 16 years and under, together with written consent from parents/caregivers.

Whilst Bronfenbrenner (1979) states the importance of real-life settings for BST research, he does not designate any specific guidelines around appropriate research locations. Instead, he emphasises selecting the information collection locale in response to the problem being investigated, and points out that "certain real life environments may be highly inappropriate" (Bronfenbrenner, 1979, p. 34). In line with this, locations were decided in collaboration with the participant. Suggested options were tailored to each participant based on their location on the day (for instance, near work or home). Options for Auckland-based participants always included a local library or café, or a private room at the University of Auckland. When former young carers lived overseas, or when participants were geographically dispersed throughout NZ, then video calls were used via Skype. Video calls were also offered to participants who were still providing care, in order to account for the possible difficulty of leaving their care recipient for a face-to-face interview. However, in all such cases participants were able to attend their interviews in person. Video rather than phone calls were preferred, as video facilitated audio-recording of the interviews, and note-taking regarding non-verbal behaviour such as body language, which were integral to and undertaken across all interviews. The interviews were sometimes re-scheduled several times by participants in order to cater to changes in their schedules and responsibilities, and I remained open and available to such changes.

Fifteen minutes of unrecorded informal conversation took place at the beginning of all meetings, prior to any interviews commencing. Through such casual dialogue, the interview space was set up so that the participants and I could get to know one another and establish the ebb and flow of the conversation. Furthermore, the time spent simply being in one another's company gave participants the opportunity to divulge any fears or anxieties about their interviews, which largely centred around worries that their role was not significant enough to be classed as young caring, or that they would have nothing valuable to share. Such fears were addressed with the reassurance that participants could end the interview at any point and without explanation, even though in all cases participant concerns appeared to be alleviated once the interviews commenced. Informal conversation prior to the interview was worthwhile, because asking participants to arrive and begin interviewing immediately could have been overwhelming or confronting, or reinforced their uncertainty. Furthermore, such a hurried approach would not have given time for the development of "a strong rapport with participants so that they feel comfortable discussing intimate details of their lives" (Butler et al., 2019, p. 229), which was necessary given the nature of the topic. In this initial discussion, key points outlined in the assent/consent forms and information sheets were re-summarised, and any further questions that participants had regarding the research and their involvement in it were answered.

Phenomenography is exploratory in nature; therefore, phenomenographic interviews have no fixed protocol (Van Rossum & Hamer, 2010). The only prearranged element of the interviews was several questions asked to open the discussion of young caring (Van Rossum & Hamer, 2010), and used throughout the interviews in order to bring attention back to the topic when participants strayed too far outside the bounds of young caring. Open-ended questions and prompts were used to gain participants' perceptions of: (a) their involvement in activities, roles, and relations (the elements of the microsystem); (b) their immediate care dyads (microsystem); (c) the existence and nature of N+2 systems and other dyadic relationships with third parties (mesosystem); (d) their understandings of wider issues effecting their caregiving roles, for instance, service protocols and occurrences at their parents' workplaces (exosystem); (e) macrosystem level influences on their care roles, such as their culture's beliefs concerning young caring; and (f) as they occurred within the continually changing individual and their ever-evolving environments, including key life events and experiences (chronosystem) (Bronfenbrenner, 1979, 1992, 2001). With regards to service representatives, open-ended start and prompt questions concerning the mesosystem, exosystem, and macrosystems as outlined above (points c, d, and e) were employed. Consequently, the open and explorative nature of phenomenographic interviews enabled the gathering of young carers' experiential descriptions about their perceptions of their caregiving roles and experiences (Marton, 1986; Svensson, 1997) at the microsystem, mesosystem, exosystem, macrosystem, and chronosystem levels (Bronfenbrenner, 1979), with context added via service representatives' perceptions regarding the mesosystem, exosystem, and macrosystem environments. In turn, the insights gained into the reality of young carers' lives offered potential to inform care policies and services (Kennan et al., 2012).

Interviews centred on the participants' voices, and I was mindful to ask "neutral questions" and exhibit "no judgmental statements (or body language)" (Bowden & Green, 2010, p. 8). Open-ended questions allow participants to "choose the dimensions of the question they want to answer" (Marton, 1986, p. 42). The dimensions participants selected were a critical information source as they revealed information about their "relevance structure" (Marton, 1986, p. 42). The actual route of the interviews and the sequence of themes discussed were inevitably dependent on the dimensions that the young carers chose, so that interviews with different participants followed different courses (Marton, 1986). The aim was to keep interviews focused on the particular ways that the respondents understood young caring. The primary purpose of the interviews was to "establish the phenomenon as experienced and to explore its different aspects jointly and as fully as possible" (Ashworth & Lucas, 1998, p. 417). As such, prompts were used to request clarification or elicit further elaborations on key points decided by the interviewees, without guiding them towards a particular outcome (Van Rossum & Hamer, 2010). Effective prompts included: "What do you mean when you say…?" "Can you explain that further?" or "Can you think of a time when that was not the case?" (Van Rossum & Hamer, 2010, p. 38). As a consequence of participants' organic descriptions of their experiences, the path through interviews was not linear. Instead, participants often revisited ideas several times, adding new meanings and greater context each time, so that numerous interpretations for any given young caring concept were embedded throughout each interview. Such a lack of linearity was essential in order to enable participants to fully explore the range of avenues, meanings, and interpretations they assigned to their experiences. I was careful to remain aware of when a certain topic had been "treated in depth", and to subsequently introduce a new theme, or end the interview (Van Rossum & Hamer, 2010, p. 38).

Nevertheless, treating a topic "in depth" could be challenging (Van Rossum & Hamer, 2010, p. 38). For example, in some cases, the emotionally overwhelming nature of a topic meant that probing for further information was not appropriate. In such cases, I moved on to a new topic for the participants' wellbeing. In some instances, participants chose to return to the topic later in their interviews, whilst in other instances, the topic was left untouched because it appeared that the memory was too painful to share. In all cases, participants' decisions were respected. Participants' inability to speak about a topic or their emotional responses did, however, provide a depth of understanding in itself that the issue was pertinent (discussed later in this chapter).

Although I initially requested up to 60 minutes per interview, all took longer due to how much each interviewee shared. For many of the young carers, it was the first time that they had talked about their experiences in-depth with anyone. As such, interviews often lasted two hours and up to three hours in several cases. Participants were alerted to the time around the 50-minute mark, and then again every 30 minutes thereafter, and interviews only continued if the participant agreed and appeared willing to do so. In turn, it became essential to put aside at least three hours for each interview in order to give participants time to fully explore young caring in the depth that they desired. If the interviews appeared likely to go over the three-hour mark, conversations were ended at a point that felt natural.

Sensitive research.

Whilst some debate exists regarding the precise meaning of "sensitive" research (e.g., Elmir, Schmied, Jackson, & Wilkes, 2011), the seminal definition provided by Lee and Renzetti (1990) remains pertinent. These authors stated "a sensitive topic is one which potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched" (Lee & Renzetti, 1990, p. 512). The complex nature of interviews with vulnerable or disadvantaged young carers exploring an emotive and relatively taboo topic meant that becoming familiar with enacting sensitive interviews with children and youth (current young carers) and adults (former young carers) was essential (Butler et al., 2019; Ellis, 2007; Hall & Sikes, 2017). Although just three participants were aged under 18 years at the time of the interviews, the previously unaddressed nature of most interviewees' young caregiving meant that reflecting back on childhood and adolescent experiences tapped into some difficult memories, representing "a wound that remains fresh" even decades later (Bray, 2019, p. 203). The emotional nature of interviews was intensified when the interview elicited new meanings and interpretations of their experiences – often as an adult looking back on their time caring as a child or adolescent – that could be painful and "haunting" (Bruce & Schultz, 2001, p. 8). Participants were not only unearthing but also discussing and adding new meanings to an experience that had been deeply buried, so that many untouched vulnerabilities, desires, fears, and worries resurfaced (Bronfenbrenner, 1979; Bruce & Schultz, 2001). By unlocking these raw emotions, participants were sitting in pain that had snowballed over many years, and was evident in the tears rolling down their faces, the pain in their eyes, and their expressed disbelief in what their experiences in fact meant. As the reality of the effect of the interviews on participants became evident, I realised that even with adults whose caring roles had ended many years prior, at times in the interview, they were speaking as 'current' young carers as they fully re-experienced moments from the past. In order for such sensitive interviews to "be safely conducted", preparation needed to be "thorough" (Stevens et al., 2010, p. 504). Deeply engaging with the literature regarding interviews into taboo, sensitive, un-tellable, or difficult topics, and enacting two pilot interviews with feedback given concerning my actions and reactions as an interviewer, were thus vital (Butler et al., 2019; Dickson-Swift et al., 2006; Johnson, 2009). Such preparation prior to interviews facilitated adherence to "relational ethics" by enabling me to "take responsibility for actions and their consequences" (Ellis, 2007, p. 3), and supported the undertaking of interviews that would "respect and disseminate" the participants' rich accounts (Hall & Sikes, 2017, p. 1203).

Sharing my own young caring experiences not only in the recruitment phase but during interviews was a key decision made prior to undertaking information gathering, which facilitated the enactment of sensitive interviews. An examination of studies outlining researchers' experiences of investigating sensitive and close to home topics highlighted the benefits of "self-disclosure" (Butler et al., 2019, p. 229), in order to establish openness and trust between the interviewer and interviewees (Renzetti & Lee, 1993), and allow researchers to gain deeper insights whilst helping participants to "feel more comfortable" because the researcher "might comprehend what they had been through" (Johnson, 2009, p. 31). Johnson highlighted the additional facilitation of relationships "as one of being-with", where researchers are seen as "a member of" participants' communities through their self-disclosure (2009, p. 31). Furthermore, several researchers conceived that it is unfair for researchers to expect their participants to be open if they themselves are not willing to do the same (Dowling, 2006; Johnson, 2009). As such, I made an informed decision to share my own young caring experiences with participants during the interviews, when asked, or as appropriate. In turn, participants expressed their gratitude at hearing a story similar to their own, and appeared to dive more deeply into their own experiences as a consequence of feeling understood and accepted.

The sharing of my own experiences, alongside the intimate nature of the interviews, required careful maintenance of clear boundaries with participants (Dickson-Swift et al., 2006; Johnson, 2009). I continually traversed the tightrope so common amongst researchers examining sensitive topics, of developing “enough rapport to encourage open and comfortable discussion, without crossing into the realm of friendship or therapy” (Butler et al., 2019, p. 229). So, whilst the sharing of my own young caring experiences was “beneficial in fostering” relationships (Johnson, 2009, p. 31), I remained particularly mindful to sustain “the boundaries of the relationship within the confines of researcher and participant” (Butler et al., 2019, p. 230). One research strategy that I used to speak about and work through my own remembered and rewoven memories was to seek regular counselling. The university counsellor was not only able to support me, but was used to counselling other counsellors, which enabled me to gain strategies for maintaining boundaries whilst still supporting my participants.

One key strategy that I learnt via counselling was to give participants space and time to unpack their experiences. Oftentimes, when participants asked questions, I had to exercise judgement to ascertain when the young carer was in fact seeking an answer. Sometimes participants were pursuing reassurance in the form of a story of my similar experience, while at other times they were asking a reciprocal question as part of their own narratives. As such, I learned during counselling and through subsequent interviews to be comfortable to let a question sit for some time without giving an answer. In other cases, participants’ stories reminded me of aspects of my own young caring experiences that I had not considered in such a light, or that I had forgotten. Whilst the power of the interviews lay in the collective young caring discoveries and meaning-making occurring for the participants and myself, I remained mindful “to create sufficient space to enable participants to fully tell their story” (Stevens et al., 2010, p. 504), because the interviews aimed to access *their* unique understandings of young caring. In many cases, when my memories were triggered by their stories, I jotted down a few words in my notebook, including a timestamp, so that I could revisit the memory later, and in the meantime remain fully present in the interview [my process of autoethnography is discussed in the next section]. The decision to often withhold my own memories was integral to maintaining the participants’ storytelling space.

The silences were not simply a moment to gauge whether participants required a response. Instead, what was ‘said’ in the silences was incredibly powerful. Mazzei (2007) describes this as “the voice of silence” (p. ix), and claims that the “valorising of speech, voices heard and recorded” (p. 1) can overlook “silent speech” (p. 1) and “what is spoken … between words” (p. 2). Such silent speech was embodied in the time participants took to ruminate on an experience, which could reveal a great deal about the weight of an aspect of young caregiving for that participant. For instance, in some cases the sharing of a story required silence in order to give time and space to process the memory. In other cases, participants’ time spent thinking could result in new meanings being assigned to their young caring experiences, from vantage points that they had not previously considered. Sometimes I wrote autoethnographic entries to give participants space to reflect and remain lost in their thoughts without feeling hurried or uncomfortable. When they were ready to move on, participants simply started speaking aloud again and I would put down my pen.

The silence also contained a great deal of communication, or silent speech between the participants and I. Young carers would share looks or gestures in order to convey an idea, emphasise key points, or to suggest what the incident meant to them; perhaps a determined stare or a nod. When words were not available or young carers felt unable to talk due to the emotional nature of a given topic or memory, such looks and gestures were essential to gain insight into how participants were feeling, thus guiding me on when to probe and when to let an idea sit. The most significant gesture was the moment – which came at some point in almost every interview – when participants realised that they *were* in fact a young carer. So, whilst participants came forward for the study with a hunch that they were young carers, the interview process often confirmed their fit with a young carer identity through their own storytelling and meaning-making. This moment is best described as an expression of shock, mixed with delight, and a sudden deep understanding of one's life, behaviours, emotions, and decisions to that point. Such powerful moments often resulted in tears, perhaps of both joy and sorrow, shared by the participant and myself. These gestures, looks, and displays of emotion meant that thorough and time-stamped field notes were essential in order to capture the rich meanings held in the silences that would not be housed in the interview audio-recording, but which were so integral to later interpretation of the information. Field notes extended to include my own emotions and memories (via time-stamped notes) that were triggered during interviews.

Concluding the interviews, many young carers described their dialogues as being "cathartic" or akin to receiving "counselling". This was interesting given that no intentional counselling was provided. Instead, I simply listened, at times added my own young caring experiences, and comforted when participants became upset, via physical contact such as a hug or hand holding, or through offering a tissue or glass of water. Instead, and aligning with existing studies examining sensitive topics, participants described the cathartic nature of interviews in terms of the chance to speak about their young caring experiences in depth (Dickson-Swift et al., 2006), receive recognition for their roles (Johnson & Macleod Clarke, 2003), gain greater understanding of their young caring experiences (Orb et al., 2000), and meet another young carer – the researcher – thus realising that they were not alone (Johnson, 2009). However, the most powerful reason for the cathartic nature of interviews expressed by many participants was their capacity to "help others" and bring about change via sharing their own experiences (Bronfenbrenner, 2001; Butler et al., 2019; Johnson, 2009).

Despite participants highlighting positive elements of their interviews, I was aware of the possible enduring impacts of not only sharing such intimate stories, but also of adding new meanings to their past experiences. Participants were not simply giving several hours of their time, but in addition the many hours that they might spend afterwards reconsidering their experiences and relationships. As such, each individual was provided with information to take home at the conclusion of their interviews, outlining possible counselling and support services to contact if they felt distressed, alongside further information and reading about young caring and their loved one's specific disability or illness if they were interested [Appendix C]. Additionally, I went back over the interviews in the days following our meetings and compiled another list of possible services and supports based on the specific topics discussed and the issues highlighted during the participants' narratives. Such services could include advocacy support to push for a required service for their unwell loved ones, websites outlining university scholarships if a participant was struggling to afford their studies, or social groups in their area that may alleviate their need for connection when they felt isolated. I also remained available via text message or email if participants wanted to follow up on anything or ask further questions, which 11 participants did. Directing participants to the YCNZ Facebook page and website was another avenue through which they could access information and identify and pursue supports. The establishment of the Young Carers Advisory Group in late 2014 provided participants with an additional way to add their voices to the policy and services milieus if desired. Participants could make submissions regarding their ideas or requests for service or policy implementations, anonymously or otherwise, so that their voices could be added to young caring conversations at the government level. I also kept in touch via emails to each interviewee, outlining updates in the actions that had been taken to meet the needs of young carers, drawing on what they shared in their interviews. The emails aimed to facilitate participants' understandings that sharing their story was contributing to wider changes and supports for NZ young carers, which had been a driving force behind many young carers' participation in the study. Overall, the young carers themselves led the interviews, tapping into difficult memories and vulnerabilities in order to share powerful stories and insights that have added new interpretations and given greater context to what it means to be a young carer in Aotearoa/NZ.

Autoethnography.

Autoethnography was the second source of information for the study. Autoethnography is a form of current or retrospective observation that occurs when "researchers conduct and write ethnographies of their own experience" (Denzin & Lincoln, 2003, p. 19). More specifically, autoethnography involves researchers writing themselves into their own work (Reed-Danahay, 1997) to "connect the autobiographical and personal to the cultural, social and political" (Ellis, 2004, p. xix). In doing so, researchers "enact the worlds we study" (Denzin, 2006, p. 423). Autoethnography positions research as a socially just and conscious undertaking (Adams & Holman Jones, 2008). As such, it aligns with Bronfenbrenner's (2001) assertion of the importance of social justice-oriented research. Autoethnographic text is generally written in first person, and features dialogue, emotions, and self-awareness as the researcher is affected by history, society, and culture (Ellis & Bochner, 2000). Autoethnographers can vary in the emphasis placed on graphy (the research process), ethos (culture), or auto (person/self) (Reed-Danahay, 1997). Regardless of the particular emphasis, however, the fundamental researcher objective is to "write meaningfully and evocatively about topics that matter" (Ellis, 2004, p. 46). Despite criticism directed towards autoethnography – reflected in the title of Ceglowski's (1997) article "That's a Good Story, but is it Research?" – it is becoming increasingly commonplace as a valuable source of information for qualitative inquiry (Hemmingson, 2008; Ngunjiri, Hernandez, & Chang, 2010).

Sikes and Hall (2019) have proposed that autoethnography is particularly encouraged in sensitive studies, akin to this thesis, in which cases "the emotionally difficult nature of the research" (p. 3) can lead to "emotional and psychological discomfort" for the researcher (p. 2). When a study explores a topic that is personal to the researcher, then "vicarious traumatization" (Pennebaker, 1990,

p. 118) can be exacerbated as the investigation may feel too close for comfort (Sikes & Potts, 2008). As such, researchers are encouraged to reflect upon how the research is impacting them, and vice versa, even prior to any emotional distress occurring (Ngunjiri et al., 2010; Sikes & Hall, 2019). After all, "we cannot always anticipate" how our lives might connect with the research that we are undertaking (Sikes & Hall, 2019, p. 8). Autoethnography is thus positioned as a key means of enacting such reflection.

Throughout the thesis process I wrote a series of autoethnographic vignettes examining my own caring experiences across my microsystem, mesosystem, exosystem, macrosystem, and chronosystem environments. The vignettes were retrospective writings about my young carer role throughout adolescence and into adulthood, and my experience of losing my mother when I was 14, which resulted in my young caring role [Appendix D]. The vignettes were written in response to triggers from what I was reading, and experiencing in the research interviews. As such, my research drove my autoethnographic writing, and was a way to maintain my self-reflective positioning. I documented the link between the catalyst/prompt and my remembering of an instance by writing the: (a) event/item, (b) catalyst, and (c) date in my daily field notes. For example: (a) interview 1, (b) hard finding time for extra-curricular activities, (c) 26.09.2014. I maintained several autoethnographic journals containing elaborations of my remembered experiences, together with the associated trigger. The many different journals stored in my car, office, handbag, and on my bedside table, enabled me to write down entries as I was triggered. The additional use of voice recordings on my cell phone meant that I could address memories when I was driving following interviews – a time when thoughts often came to me – and also allowed me to record my counselling sessions, which I later transcribed. Ultimately, I wrote over 50,000 autoethnographic words. While such vignettes were intended to be limited to the information gathering process, instead my writing continued through the analysis and writing up stages. This was because at each stage, new meanings were being added to the information and I found myself re-interpreting my own experiences.

Despite the autoethnographic vignettes originally being intended for inclusion in the thesis, I decided not to include them, for two key reasons. Firstly, because so many included stories involving my brother and family, I realised I could not ensure their confidentiality as I could my participants. Caroline Ellis (2009) describes such a choice as my consideration of "the ethics of representation", being "the ethics of writing about others in ethnographic and autoethnographic tales" (p. 3), a position supported by Bruce (2010) who highlighted the risk of "hurting the other person while attempting to tell [our] truth" (p. 201). Essentially, I had to consider "whose truth" I was telling (Bruce, 2010, p. 202). I enacted Ellis's call for "open dialogue about the ethical quandaries" (2009, p. 3) that researchers face, by discussing with my family the inclusion of the autoethnographic vignettes in the research. In turn, I respected my family's "desire for privacy, positive representation, and control over the stories of their lives" (Ellis, 2009, p. 3), in their request not to include the vignettes. Secondly, I made this decision based on the depth of detail from the 39 participants, which reduced the need for additional stories.

Despite not including vignettes as evidence in the thesis, autoethnographic writing played a pivotal role in the research. Autoethnography was a deeply important and personal part of the thesis process, giving me insights into young caring that I would not have gained otherwise, and encouraging me to remain reflective about my own experiences and underlying biases. Additionally, autoethnographic writing aided in my processing of the emotional content described in interviews that, more often than not, related to my own experiences, as well as providing a space that I felt “safe to be vulnerable” (Sikes & Hall, 2019, p. 5). Having such a safe space was important because almost every interview had personal relevance for me. Aspects of participants’ narratives were often “projections of my own” life experiences (Tillmann-Healy & Kiesinger, 2001, p. 100), and their impact was thus “all the more salient” (Sikes & Hall, 2019, p. 4). This was especially pertinent when young carers touched upon situations that also occurred in my own life, but which I had not yet considered were part of my young caregiving experience. As a result, at some points during interviews I felt confronted and anxious. Writing my autoethnographic vignettes meant that I knew I would be able to reflect on my reactions later, thus enabling me to remain present during interviews. In addition, being able to address my emotions as they arose meant that I could recognise when I was struggling, and take time out from research to connect with friends and family, and to identify when I felt capable to continue with the project. I also found sharing my writing with the university counsellor beneficial, in that my prose guided our sessions as we worked through my thoughts, fears, and anxieties. When my own caregiving role felt overwhelming, autoethnography became integral to processing the emotions associated with my continuing role. In these times I felt as though “there was little let up”, because my life seemed to be constructed around caregiving: reading about it, researching the experiences of those living it, and enacting it myself (Sikes & Hall, 2019, p. 6). I was constantly traversing the line between being an academic and a caregiver myself, as I faced the reality that I was still very much caring for my brother, whilst also trying to pursue my own career.

Phenomenographic Whole of Transcript Analysis

Audio-recorded interviews were transcribed verbatim (Åkerlind, 2012). Because of the important focus on voice in the interviews, it was imperative that transcription was full and accurate (Bowden & Green, 2010; Van Rossum & Hamer, 2010). Included in transcription were field notes about variations in tone of voice, body language, silences or pauses, and emotional responses such as crying (Ashworth & Lucas, 2000). Transcriptions also included time stamped autoethnographic entries. Due to the unexpectedly large response to the call for participants (n=39) that exceeded my originally planned 20 interviews, I transcribed 20 interviews, and employed a University of Auckland approved transcriber for the remaining 19 interviews. Participants’ permission was gained prior to their interviews being transcribed by the University transcriber. I then read the transcripts alongside the audio recordings, making any necessary amendments and adding the integral field notes and autoethnographic vignettes. Once transcription was complete, the interview transcripts – minus the field notes and autoethnographic vignettes – were emailed to the participants, with a plain-language summary of the transcript being sent to the younger participants alongside their full scripts. Participants had the opportunity to read and respond to their transcripts, highlighting any issues or areas that they would like to add or remove, or withdrawing their experience from the study altogether. All participants approved their transcripts, in some cases after minor amendments were made, and no one withdrew.

Analysis had a key focus on both describing young caring in depth and comparing interviews "to identify the conditions on which" the differences existed (Flick, 2013, pp. 5-6). As such, an exploratory qualitative analysis approach was used, as it "privile[dged] … the perspectives of the participants" and was "attentive to the unanticipated" (Mihas, 2019, p. 2). Here, qualitative interpretive analysis facilitated enquiry beyond simply describing details, to explore more deeply "the how and why" of young caring in NZ, through "conceptual thinking", with themes acting as "conceptual patterns" rather than simple descriptions (Mihas, 2019, p. 4). Mihas (2019) asserted that a conceptual theme "casts the information in a certain light so one sees beyond surfaces to synthesized understandings" (p. 4), which allowed me to think "incrementally with" the information "rather than imposing expectations upon" young carers' narratives (p. 5).

An array of tools can be employed to generate conceptual themes (Saldaña, 2015), but two key approaches are identified as useful for analysing phenomenographic information, representing variation in the amount of the transcript that is considered. First, the "pool of meanings" approach extracts quotes from the contexts in which they are said (Åkerlind, 2012, p. 121). Secondly, the whole of transcript approach deals with the whole information of each interviewee, rather than selecting and removing particular utterances, so that so that any quote is looked at "in the context of what is said in the rest of the transcript" (Bowden & Walsh, 2000, p. 12). Because phenomenographic interviews focus on the exploration of conceptions (Marton, 1986), which are context-bound and relational by nature (Bronfenbrenner, 1979), "the exploration of the whole has to be in focus and the exploration of parts has to be done within the whole" (Svensson, 1997, p. 170). As such, analysis is not simply gathering specific information with loosely assigned interpretations, but "a delimitation of specific data related to each other as referring to parts of the same phenomena" (Svensson, 1997, p. 170). The phenomenographic whole of transcript approach was thus used for analysis, as it aligned with Bronfenbrenner's (1979) focus on the context-bound nature of research, and reflected the circular nature of many interviews in which participants revisited and sometimes reinterpreted specific experiences.

Whole of transcript analysis was performed as I moved backwards and forwards through entire transcripts, "seeking clarification of the utterances in context" (Van Rossum & Hamer, 2010, p. 42). Throughout iterative readings of transcripts, I grouped similar conceptions of the phenomenon held by participants into "categories of description" (Marton, 1986, p. 43). The categories of description were the "outcome space" of the research (Orgill, 2007, p. 136) – with one outcome space developed for each emerging topic – that enabled me to describe key conceptions held by young carers (Marton, 1986). NVivo software was employed to organize, manage, and continually re-analyse the categories of description as new interviews were considered and existing interviews were constantly reflected upon. NVivo was invaluable for enacting the whole of transcript approach, as similar conceptions were placed into "nodes" that emerged through reading and interpreting the interviews. Despite placing utterances within nodes, the statements were still examined "in the context of what [was] … said in the rest of the transcript" (Bowden & Walsh, 2000, p. 12), because a key feature of NVivo is the expansion of a given quote when clicked upon so that the conversation – and in this case the interview context – surrounding the utterance can be seen. As such, I was able to preserve the context of each utterance as quotes remained embedded within their interviews despite being housed within nodes (Åkerlind, 2012). NVivo also enabled me to dive deeply into and make connections across interviews beyond the creation of nodes, via using queries to search for text and analyse word frequency.

I continued to draft and redraft categories of description, until an initial stable system encompassing all interviews had been established (Van Rossum & Hamer, 2010). Once the initial categories had been defined, transcripts were re-examined to resolve whether the categories were "sufficiently descriptive and indicative of the data" (Orgill, 2007, p. 136). Categories of description were modified, adjusted, and deleted as I tested category definitions against the interviews (Marton, 1986). As the process was carried out, there was "a decreasing rate of change, and eventually the whole system of meanings [was] … stabilized" (Marton, 1986, p. 43). Throughout the process, phenomenographic interjudge reliability was employed, in which my supervisors carried out the role of devil's advocate, constantly requiring me to justify my emerging categories of description (Van Rossum & Hamer, 2010). Once again, NVivo was pertinent as I was able to share the findings with my supervisors between face-to-face meetings. The final categories of descriptions represented the "interpretation of the collective voice derived from the contextualized individual voices" (Bowden & Green, 2005, p. 10). Whilst a whole of transcript approach presented real challenges in terms of the time taken to continually address the whole of 39 interviews, the capacity to compare and contrast participants' experiences – whilst retaining the context in which each statement was said – resulted in unique findings that might not have been achieved otherwise.

Overall, phenomenographic interviews were central to the collection of rich young carer experiences throughout the thesis. This was because the interviews not only permitted young carers a voice, but enhanced their authority on the topic by empowering participants to choose the parameters of young caring that held meaning, and to unravel their experiences in a way that felt natural to them. As such, participants' own ideas, understandings, and ways of knowing regarding being a young carer led the interviews, rather than the narrative being confined by prescribed researcher-led questions that could limit the meanings of their experiences. The allowance of time and space for participants to make and remake meaning of their experiences was particularly important given the hidden nature of young caring in NZ (e.g., Hanna & Chisnell, 2019) and, thus, the previously unaddressed nature of most participants' experiences. Through accessing participants' authentic understandings regarding their young caregiving "relevance structure" (Marton, 1986, p. 153), young carers' own voices led the interviews. This was important because vulnerable populations are often "exposed to research that is driven by dominant worldviews, research methodologies and sociocultural lenses that can exacerbate their vulnerability, negating their sociocultural reality and inadvertently 'trampling' on their mana[29]" (Webber, 2019, p. 129). In short, phenomenographic interviews allowed me to gather an in-depth, nuanced picture of young caring in Aotearoa/NZ as interpreted by young carers themselves, and with context added by service representatives.

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[29] Described by Durie (1985) as "a state of spiritual authority and power" (p. 484).

Ethical Considerations

While ethical issues are always involved in research with people, they are often amplified when the research is with children and youth (Punch, 2009). Furthermore, significant ethical and methodological challenges often arise from research into sensitive topics (Butler et al., 2019), with hard to reach populations (Kennan et al., 2012), and especially with participants who might be perceived to "lack resources or autonomy" (Morse, 1994, p. 348). My research encompassed several categories of sensitivity, being carried out with adults and children from the hidden and vulnerable young carer population, who could describe possibly taboo or often-untouched issues (Butler et al., 2019). As such, identification and careful consideration of ethical issues was paramount (Davidson & Tolich, 1999; Punch, 2009). I felt an "increased ethical responsibility" that required continued reflexivity in order to achieve "meaningful and inclusive participation" for the participants (Canosa, Graham, & Wilson, 2018, p. 400). I became well-versed in the ethical tensions of research exploring sensitive topics with vulnerable populations, and specifically young carers. For instance, respecting the agency of young carers by placing them at the centre of research (Kennan, Fives, & Canavan, 2012) could in fact be "distressing" for participants sharing difficult experiences (Robson, 2001, p. 136). I also emailed and met with three young caregiving researchers, in order to probe further the possible ethical challenges. The ensuing frank conversations and their willingness to share information aided my understanding of effective means of ethically researching with my participants.

Butler et al. (2019) highlighted the need for "a unified approach" to ethical considerations, with a researcher's obligation being "to identify all areas in their research that may present a risk to participants and themselves and ensure that appropriate plans are in place to manage" those risks (p. 225). The consideration of my own emotional responses has been discussed above. Next, I outline six key ethical considerations for participants during and beyond the information-gathering process.

First, informed consent was obtained through participant information sheets and consent/assent forms tailored to the respective age ranges of my participants (discussed earlier in this chapter). A summary of the nature of the research was reiterated to each participant at the beginning of the interviews. Second, the voluntary nature of participation at all times was a priority throughout my research. I made it transparent to participants their right to withdraw from the research without consequence at any point up until the specified and agreed-upon cut-off date (Davidson & Tolich, 1999), which was once they had read and responded to their complete transcripts, or to a summary of their transcripts for younger participants. Third, I acknowledged that the use of the young carer participants' time was a possible ethical issue. As such, I faced "tension between the underlying purpose of the research and the 'harms versus benefits' dilemma" (Canosa et al., 2018, p. 408). I hoped that the aim of my research – to understand their experiences and use participants' insights to provide input into care and disability policies and services in NZ as opportunities arose to enact social change throughout the thesis – would be a constructive and effective use of their time.

Fourth, the confidentiality of participants was placed at the forefront of each phase of my research (Davidson & Tolich, 1999). Assurances of participants' confidentiality rather than anonymity were given because the study used interviews, which can never be truly anonymous (Davidson & Tolich, 1999). I assured participants that their information would be safeguarded in a locked cabinet for six years, after which time it would be destroyed. Fifth, all identifying information from transcripts was removed and participants' identities were anonymised in the thesis by the use of pseudonyms – often chosen by participants – for themselves, their family/whānau/aiga, friends, teachers, other persons, schools, and local organisations. Their locations were only generally identified by region except for Auckland, which is NZ's largest city with over 1.6 million residents. The anonymising of participants, their wider networks, and locations was particularly important due to the relatively small sample of participants, the uniqueness of their circumstances, and the sensitivity of the subject matter, and it will be applied across all subsequent researcher presentations and publications. Sixth, the use of pseudonyms addressed the common principle of prevention of harm to participants, by ensuring the public could not make connections between participants and their responses (Davidson & Tolich, 1999). The prevention of harm to participants also applied to consideration of the risks to participants taking part in my research, especially given the real possibility that speaking about young caring experiences could conjure negative and upsetting feelings and emotions that may endure for some time. Attention given to the propensity for physically or emotionally high-risk scenarios being shared by participants – including abuse or suicide ideation – was also imperative, as was establishing a plan if these issues arose (Butler et al., 2019; Liamputtong, 2007). In response, I familiarised myself with and shared information about various organisations and agencies that could advise and assist young carers, for those participants who expressed concerns or requested information and/or support over the course of the research process (discussed earlier in this chapter).

Limitations of the Study

Five potential limitations were inherent in my study. Firstly, Bronfenbrenner's carry-over qualification in which research examines "enduring changes that carry over to other places at other times" (1979, p. 14) could not be achieved within the constraints of a PhD. However, by speaking to current and former young carers about their caregiving experiences over time, and with regards to various contexts and influences, I was able to analyse "a short-lived adaptation to the immediate situation" (1979, p. 14), which Bronfenbrenner (1979) asserted is a suitable alternative. Secondly, phenomenography has been criticised for selecting and detaching particular utterances from interview transcripts (Bowden & Walsh, 2000). To counteract this critique, I used whole of transcript analysis, so that the pool of information was a collection of complete interview transcripts, which were compared and organized in their entirety (Van Rossum & Hamer, 2010). In addition, throughout the thesis I have presented edited individual stories in more detail and wholeness to retain the importance of the complexity and nuance of individual's experiences. Thirdly, I addressed the issue of how my own experiences as a young carer could have influenced how I interpreted the findings in two ways: firstly via autoethnography and counselling to continually reflect on and retell my own story as new ideas and memories emerged in response to what young carers said, and secondly by using phenomenographic interviews whereby young carers lead the narrative. An additional solution was what phenomenographers called interjudge reliability, which involved my supervisory team acting as devil's advocate, asking me to continually justify my emerging categories of description (Van Rossum & Hamer, 2010). Fourthly, any interpretations related to culture may have reflected my identity as a

Pākehā New Zealander with limited involvement and knowledge of Māori, Pacific, and Asian cultures, so that contextualising those responses in wider reading about cultural perspectives on care, disability and illness, childhood, and family, was imperative. Finally, my decision not to include my autoethnographic vignettes was a possible limitation, but it was a decision made for ethical reasons in order to respect my family's need for privacy and control of their own stories (Ellis, 2009).

Numerous possible constraints also emerged during my research. The amount of interest expressed in my work, including an invitation to directly contribute to policy and action during my research, had to be carefully negotiated. Given the ontological commitment to social justice and grassroots change inherent in my theoretical approach (Bronfenbrenner, 2001), I decided to accept these opportunities, while using autoethnography and reflection to maintain boundaries between researching young caring, and working on solutions to meet young carers' needs. A further possible constraint was the requirement to speak English to participate in the study. While none of my participants wanted to be interviewed in another language, this is a possible limitation for future studies if recruitment is only done in one language, especially in countries where substantive groups may not speak English as a first or preferred language. Finally, the unexpected extent of the emotional impact on myself was a possible constraint, with interviews being emotionally draining. I addressed this issue via autoethnographic writing, and by seeking regular counselling myself, that also helped me learn strategies to support my participants.

Despite the limitations and constraints in the study, this research provides up-to-date information on the experiences and needs of NZ young carers and fills in many of the gaps in existing NZ research by: including diverse NZ young carer participants; affording agency to young carers by accessing their own conceptions of their roles and support needs; including young carers' conceptions of their transition to adulthood; and contributing to relevant public policies and practices. What it means to be a young carer in Aotearoa/NZ will be teased out in the ensuing four findings and discussion chapters, as expressed by the young carers themselves. Young carers' own voices will be used as much as possible to facilitate the reader's understanding of their experiences and needs, with key findings being embedded within existing young caregiving research and the wider bodies of literature on caregiving, disability and illness, Māori and Pacific, childhood and family, and loss and grief. When participant quotes are used, they will be primarily from NZ young carers, although some evidence will be used from the three NZ and one UK service and agency representatives, and identified explicitly. To aid the reader, given the number and diversity of young carer participants, in the first findings and discussion chapter I will regularly indicate their current caring status (current, former, or continuing as adult), age at time of interview, ethnicity, care recipient and care recipient's condition, in text or parentheses; for example (Current, 17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness) or (Former, 27, Hong Kong Chinese, mother with stroke/dementia) or (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability). This information will be repeated on first reference in each ensuing chapter. In this thesis, it was impossible to do complete justice to the depth of nuance, complexity, and emotionality that infused every interview, due to the word limitation. I have addressed this in part by presenting a story of one of the participants at the start of each findings and discussion chapter, and judiciously chosen representative examples throughout. In order to embed participants’ experiences in BST, I have interrogated their narratives to identify the layers, whilst still maintaining their context in line with whole of transcript analysis. In addition, the participant story presented at the start of each chapter retains the importance of wholeness. To begin the findings and discussion chapters, I will now introduce the participants.

Introducing the Participants

Overall, despite taking eight months to achieve the interview cohort, 32 participants took part in the research, including four current young carers, aged 25 years and under at the time of interview, and 24 former young carers: 13 aged 26 years or over, but who provided care for a loved one when they were aged under 26, and 11 aged under 26 at the time of interview, but whose care role had ended (e.g., their care recipient had died). Eight NZ former young carers continued their caring roles after the age of 25, making them current *adult* carers at the time of their interviews. In addition, three NZ and one international service or agency representatives took part in the research.

Tables 2, 3, and 4 provide details of all participants, including their pseudonym, age at the time of their interview and during young caring, care recipient relationship and disability or illness, and location of care. The tables are a guide to which the reader can refer throughout the findings and discussion chapters, to clarify details of participants as needed. An overview of participants accompanies the tables, to outline the breadth of the participant sample, highlight nuances, and explore how the participants varied in each of the categories included in the tables.

Overview of Participants

Gender. Females dominated the carer participant sample (n=25, 89%). All current young carers (n=4) were female. There were three male carers (11%). The majority of the service and agency representatives were male (75%, 3); only one was female. In this way, the participants reflect the existing research which finds females are more commonly young carers than males (Becker & Sempik, 2019; Joseph et al., 2019; Watt et al., 2017).

Ethnicity. Although all agency/service representatives and most young carer participants identified with white ethnicities, the attempt to ensure ethnic diversity was somewhat achieved. The current and former young carers represented six ethnicities and at least one carer identified with each of the four major ethnicities, including Pākehā (n=20, 71%), Māori (n=6, 21%) and Pacific heritages (14%), comprising two carers who identified as Tongan, one as Niuean, and one as having Tongan and Samoan heritage. One carer identified as Asian (Hong Kong Chinese). For the two young carers who identified with more than one ethnicity, each ethnicity was counted once. With the literature identifying that young caring appears more common amongst indigenous, ethnic minority, and immigrant populations (Bray, 2011; Hounsell, 2013; IARS, 2016), including amongst the NZ Pacific and Māori populations (Ministry of Health, 2009; Nikora et al., 2004), then this ethnic diversity was particularly valuable.

Care status at interview. Although the 28 young carer participants were in a range of current or former caring roles at the time of their interviews, only four (14%) were current young carers. Participants were primarily former young carers (86%). In addition, nine former young carers were currently in adult caring roles (32%). The difficulty of recruiting current young carers reflects a common trend in the literature (Barry, 2011; Kennan et al., 2012), which is particularly highlighted in existing NZ studies due to the widespread dearth of young carer awareness and service-support (Gaffney, 2007; Hanna & Chisnell, 2019; Loose, 2004; McDonald, 2008).

Table 2

NZ Current Young Carers

#	Pseudonym	Sex	Ethnicity	Age at interview	Age during care	Years spent caring	Care recipient	Care recipient disability or illness	Primary location of care
1	Atalanta	F	Pākehā	12	7 - 12	5	Mother	Chronic illness	Auckland
2	Grace	F	Pākehā	21	6 - 21	15	Sister	Physical and intellectual disability	Auckland
3	Leah	F	Pākehā	17	3 - 17	14	Brother	Autism, intellectual disability	Auckland
							Mother	Undiagnosed mental illness	
4	Phoebe	F	Māori/ Pākehā	16	10 - 16	6	Mother	Bipolar	Canterbury
							Brother	Due to mother’s bipolar	
							Grandmother	Cancer, arthritis	

Table 3

NZ Former Young Carers

#	Pseudonym	Sex	Ethnicity	Age at interview	Age during care	Years spent caring	Care recipient	Care recipient disability or illness	Primary location of care
5	Alice	F	Pākehā	25	15 - 25	10	Brother	Cerebral palsy	Wellington
6	Amelia	F	Tongan	36	6 - 25	19	Grandmother Aunty	Elderly Paraplegia	Auckland
7	Anna	F	Pākehā	27	22 - 24	2	Boyfriend's father	Substance misuse, cancer	Auckland
8	Chloe	F	Pākehā	25	12 - 15	3	Mother	Multiple sclerosis	Taranaki
9	Chun	F	Hong Kong Chinese	27	21 - 25	4	Mother Father	Stroke, dementia, cancer Undiagnosed mental illness	Auckland
10	Claire	F	Pākehā	43	5 - 19	14	Mother Sister	Mental illness, undiagnosed mental illness Intellectual disability	Otago
11	Dan	M	Pākehā	53	9 - 14	5	Mother	Paranoid schizophrenia	Auckland
12	Fleur	F	Pākehā	39	6 - 25	19	Mother Brother	Multiple sclerosis Due to mother's illness	Waikato
13	Greg	M	Pākehā	28	17 - 21	4	Father	Cancer, heart attack	Auckland

#	Pseudonym	Sex	Ethnicity	Age at interview	Age during care	Years spent caring	Care recipient	Care recipient disability or illness	Primary location of care
14	Kahurangi	F	Māori	51	13 - 25	12	Father Mother Sister Brother	Cancer, depression Cancer Schizophrenia Schizophrenia, substance misuse	Auckland
15	Kelly	F	Māori	23	11 - 17	6	Grandfather Mother Brother	Elderly Bipolar Due to mother's bipolar	Waikato
16	Lola	F	Pākehā	23	19 - 22	3	Fiancé	Brain tumour	Auckland
17	Louise	F	Māori	25	5 - 21	16	Mother Father	Chronic illness, stroke Arthritis, stroke	Bay of Plenty
18	Lucy	F	Pākehā	25	15 - 19	4	Mother	Cancer	Auckland
19	Mary	F	Pākehā	27	19 - 25	6	Mother Father	Cancer Substance misuse, acquired brain injury	Auckland
20	Melanie	F	Pākehā	31	19 - 21	2	Friend	Schizophrenia	Auckland
21	Mele	F	Tongan	24	18 - 24	6	Grandmother	Dementia, arthritis	Auckland
22	Miharo	F	Māori/ Pākehā/ Samoan	41	9 - 16	7	Mother	Physical disability, Schizophrenia	Otago
23	Ngākau	F	Māori	49	14 - 17	3	Brother and Sister	Due to mother's undiagnosed mental illness and parents working	Auckland

#	Pseudonym	Sex	Ethnicity	Age at interview	Age during care	Years spent caring	Care recipient	Care recipient disability or illness	Primary location of care
24	Rachel	F	Pākehā	59	13 - 21	8	Mother Brother	Depression Muscular dystrophy	Otago
25	Sally	F	Pākehā	32	11 - 25	14	Mother Brother Husband	Cancer, bipolar, depression ADHD Substance misuse, undiagnosed mental illness	Canterbury
26	Terrence	M	Niuean	27	22 - 25	3	Mother	Encephalitis, intellectual and physical disability	Auckland
27	Tilly	F	Pākehā	44	18 - 25	7	Sister (twin)	Tetraplegia	Canterbury
28	Wyn	F	Pākehā	67	8 - 14	6	Mother	Diabetes, stroke, dementia, undiagnosed mental illness	Southland

Table 4

Service and Agency Representatives

#	Pseudonym	Sex	Ethnicity	Organisation Description	Role	Location of Work
29	Jodie	F	White English	A UK University.	Lecturer in Social Work	England
30	Kyle	M	White English	A NZ organisation supporting family/whānau/aiga to become connected to their communities and independent of social services long term. Previously started a UK young carer organisation.	Service Manager	Auckland (previously UK)
31	Tim	M	Pākehā	A NZ national charity dedicated to the integration of people with disabilities in the community.	Family/Whānau Support	Auckland
32	Peter	M	Pākehā	A NZ community-based organisation initiating new ways to solve challenging social issues and providing services to families in need, including people with disabilities.	Project Coordinator	Auckland

Age at interview. Young carers ranged in age from 12-67 at the time of their interviews, with an average of 36 years. The four current young carers ranged in age from 12-21, with most being between 16 and 20 (n=3, 75%). Most former young carers were in their 20s (n=12, 43%), 30s (n=4, 14%) or 40s (n=4, 14%) at the time of interview. Almost 30 percent (n=8) were 40 or over. Seven (25%) were still under the age of 26 but their care roles had ended – most often due to the death of their care recipient. All the service or agency representatives were experienced and in their 30s or 40s.

Age during care. The average age of young carer participants at the start of care was 13, ranging from 3-22 years. Current young carers (n=4) ranged in age at the start of care from 3-10 (average=6.5), and former young carers (n=24) began caring between the ages of five and 22 (average=13.5). This pattern reflected existing research, which reports that young carers are most often school-aged (Frank & Slatcher, 2009; Moore, et al., 2009; Sempik & Becker, 2013). The average age of finishing young caring was 21.5, ranging from 14-25 years. One-third (n=9) of the former young carers continued to care after they reached 25 and thus transitioned into *adult* carer roles.

Years spent caring. Most young carers provided care for eight years. On average, current young carers (n=4) had spent 10 years caring at the time of interview, ranging from 5-15 years. Former young carers (n=24) had spent on average eight years young caring, ranging from 2-19 years. It is important to keep in mind that the statistics only include years spent as a young carer. Thus, additional years as an *adult* carer for the 38 percent of former young carers are not included. These findings echo existing research, which identifies that the length of young caring can range from one year through to adulthood (Bray, 2011).

Care recipient. Participants cared for a wide range of people, the most common being a parent (82%, n=20), particularly a mother (64%, n=18), which reflects prior research (Aldridge et al., 2019; Barry, 2011; Joseph et al., 2019; Leu et al., 2018). The next most common was a sibling (50%, n=14), with brothers (32%, n=9) being almost twice as common as sisters (18%, n=5). It was only participants who identified with Māori or Tongan heritage who cared for grandparents (14%, n=4), more often a grandmother (11%, n=3), perhaps reflecting the wider understanding of family in Māori and Pacific cultures. One person supported an aunt, one a friend, and one a boyfriend's father (n=3, 11%). Almost half the current and former young carers (46%, n=13) supported more than one care recipient, with most supporting two (32%, n=9) or three (11%, n=3) care recipients. One former young carer supported four care recipients.

Care recipient disability or illness. Most young carers (89%, n=25) identified that a care recipient had one disability or illness, with some participants identifying two (54%, n=15), three (7%, n=2), or four (4%, n=1) diagnoses. The most common care need reported by young carers was mental illness (64%, n=18), followed by chronic illnesses (43%, n=12), and physical or intellectual disability (29%, n=8). Current young carers were supporting care recipients with one or two diagnoses (50%, n=3 each), most commonly being a disability (100%, n=4) or chronic illness (75%, n=3). These findings reflect existing research, which found people with disabilities as the most common care recipients supported by young carers (Ferguson et al., 2001; Leu, et al., 2018; Noble-Carr, 2002;

Robison et al., 2017), followed by individuals with a mental illness (Aldridge, 2006; Cooklin, 2010). Overall, young carers supported care recipients with 24 different disabilities or illnesses, including: diagnosed (43%, n=12) and perceived undiagnosed (29%, n=8) mental illness; cancer (32%, n=9); intellectual disability (21%, n=6); substance misuse or stroke (both 14%, n=4); dementia or arthritis (both 11%, n=3); physical disability (7%, n=2); a chronic illness (specific illness not specified), multiple sclerosis, or being elderly (7%, n=2 for each); or due to cerebral palsy, heart attack, autism, brain tumour, acquired brain injury, muscular dystrophy, ADHD, encephalitis, and diabetes (4%, n=1 for each). In addition, 14 percent (n=4) of young carers were caring for one or more healthy siblings due to parental/caregiver disability/illness or employment.

CHAPTER FOUR

The Visible and Invisible Dimensions of Care: Holistic Support and Nonfinite Loss

This chapter seeks to establish the nature and extent of young carers' roles. The chapter is divided into three sections, the first of which explores participants' conceptualisations of care as enacting a variety of tasks that together address their care recipients' holistic physical, emotional, social, and spiritual needs. In the second section, the difficulty of ascertaining the true nature and extent of participants' caregiving roles is unpacked, followed by the third section, which explores the nonfinite loss underlying care tasks. Overall, the chapter argues that young carers provide holistic care to meet multiple aspects of their care recipient's wellbeing, and explores the invisibility but importance of nonfinite loss underlying children's, youths', and young adults' care roles. I will begin the chapter with Terrence's story, which highlights many of the key themes addressed in this chapter, but which shows them in the context of Terrence's whole caring experience. While this chapter focuses on the what and why of young carers' roles, the emotional impacts of young caring – such as the powerful motivations for enacting care tasks demonstrated in Terrence's story – will be revealed and explored in greater depth later in the present and ensuing chapters.

Terrence's Story

> *Terrence is a former young carer who began supporting his mother when he was 22 years old, and who continues to care as an adult. Terrence provided care in a sole-parent household in Auckland with some support from his older sister, due to a sudden illness that resulted in his mother's permanent intellectual and physical disability. Terrence identifies as Niuean and was 27 at the time of his interview.*

Caring alongside services. When I was 22, my mum got really sick with a brain infection that permanently damaged parts of her frontal lobe. She was in a coma, and when she woke up she was pretty much a lemon. She couldn't walk, she couldn't talk, she was dribbling: she really wasn't alive. It was just me and mum living together at the time, so I had to move out and figure out where to put all our stuff. Mum was in hospital for eight months, [and] the doctors were telling us that she was not going to improve, that this is her now. They said we needed to think about putting her into care, but we were like, "no". Someone else wouldn't be able to take care of her how we would because we actually love her. We want to care and will really care because she is our own (hands cross over heart)[30]. She couldn't come home until she was fit enough, so we pushed for OT (Occupational Therapy) and third time lucky, she got funding. She was in rehab full-time for a year and had to learn how to walk and talk all over again.

For that whole time in hospital and rehab I was there with mum everyday 'cause they didn't care for her properly. I remember at hospital at one o'clock in the afternoon she would be in her bed

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[30] Bracketed words add detail regarding the way in which a word or phrase was said, such as (said quietly), or denotes the participant's physical response, such as (smiling widely).

wet ‘cause there was no one there to change her. I thought, “Piss off, leave her alone, we’ll do it ourselves”. But really there was no one else willing to give up their time for my mum. I do have older brothers but one’s in Aus[tralia] and another brother lives in Christchurch, and my older sister, like everyone [else], was working. I mean she would come every other week to visit mum, and she was supporting me money wise. But it was *my*[31] whole life that changed.

Moving to home-based care. Then one day, when mum was medically stable, [services were] like, “Here’s the door, go” (hand waves dismissively). So, we suddenly had to make the whole transition from rehabilitation to home. And there was no follow up. I wish that they could put in place something for mum, like even just a companionship group or people to take her out, but there’s nothing. [Mum and I] both moved into my sister’s house so that [my sister and I] could do her care together. We’ve been there ever since. At the start, there were a lot of sleepless nights because mum just wouldn’t sleep. For two years, I’d sleep with her in the same damn bed so I could get some sleep. I wouldn’t say that to my friends though. [Over time] my sister and I worked out a routine, so I would work during the day and my sister [worked] night shifts. [That way] I was with my mum during the night and then my sister was with mum during the day. And [mum would] stay at my auntie’s house for like a week sometimes just to give us a break.

Me and my sister shower mum, wash her hair, change her nappies, put her in clothes. It’s awkward; even now I still don’t look. When I have to shower her, I make her face the wall, I cover her bottom and stuff. [It’s] just how I try and cope (laughs). We do her hair, put some lipstick on, earrings and stuff because we always want to keep that sense of my mum. Right up until this day before she goes out, we do her hair and change her into nice clothes. And I take her out. I buy her clothes and stuff – I know that she likes a lot of colour – but it’s weird, a grown man walking around the women’s section! And we do all the cooking, laundry, vacuuming. My mum’s a hoarder now, too. No matter how much we clean her room she has all this stuff on top of rubbish [and] food from last week underneath her bed.

The hardest part was definitely seeing how much my mum changed though. Before she got sick, she was so independent; she practically lived at work. She was very loud, very loving, really funny, too. She was just my mum (hugs himself): a real person that I could rely on and talk to about practically anything. But now everything has changed. She’s got the personality of a child and she can’t think for herself. My niece talks to my mum as if she’s a friend now. Like she’s kind of lost the respect for her grandma, you know, as someone older. So I’m really strict on that. If we go out, mum gets lost. You have to hold her hand because she’ll just cross the road [without looking]. Basically, she needs assistance with everything. It’s weird because my mum is there but it’s not my *real* mum at home; I so miss my mum (said in a sincere, hushed voice). I miss her ‘cause I know the person she was, her spirit.

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[31] When a word(s) within a participant quote is in italics, then it is a word(s) that the participant placed emphasis on.

Transition to adulthood. I grew up too fast, I reckon. It sucks ‘cause I missed just normal stuff like drinking with mates [and] traveling. And I didn’t date; who the hell would want to come and stay with me while I’m still changing my mum? I kind of shut myself away. It was all too hard. I felt like I was in a dead end. I’ve always been an active person [but] I put on over 100kg in those first years and I was really depressed. I think I was too busy taking care and being there for everyone else that I didn’t pay attention to myself for anything, so things just kind of built up. Then one day I looked at myself and I was like, “What the hell happened to me?”

I don’t like saying it, but I’m stuck; there’s not a lot what I can do right now. I’m a dancer, but I’m not a dancer; I didn’t get to finish my degree. I had spent two years at performing arts school and then I was doing a bachelors [when mum got sick]. I wanted to keep going but it was just so hard for me to *think*. I guess I could have stayed at uni but it wouldn’t have been the same for my mum [being cared for by someone else] so I had to leave; I wouldn’t know how to live with myself if I tried to put myself first (hand to heart).

[Today] my dancing is on and off, but it’s harder. Like if I’d had my degree, I would be dancing for a company. I need to get more training [but] I’ve had to work a day job and care for mum all night. I guess my plans have changed on me [so] I’m just learning how to accept this is my life now. But I do want to move out next year. Hopefully my sister can accept that. I’m suffocating a bit – I want my own life. I’d like to become a dance teacher [and] help people get to where they need to be. A lot of people say that I’ll be a good teacher, if it’s not too late (head in hands).

Support needs while caring. It’s a pretty intense time. You ask yourself, “How the hell do I do it?” But then I think, “Man, I’m so lucky”. It’s given me appreciation for just living because I know time is precious, and you need to make the most of what you have. And I’m stronger too.

But there *needs* to be more support because honestly, I was *burnt*. There just wasn’t any assistance for me, and I have a life too! And especially financial support because it’s a whole life change and sacrifice, and you have to transition with no support moneywise. And I was lonely, man. I just keep thinking, “Where were you [Lauren] five years ago?” I’m so pleased to do this [interview] ‘cause it feels good. The only people I ever talk to are my sister and my brothers. Even today, I still wouldn’t tell my friends.

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Holistic Care Provision

In the first section, I provide context for understanding the tangible physical, and intangible emotional, social, and spiritual support that young carers provided to their loved ones. The section begins with a brief exploration of the connections between participants’ conceptualisations of their caregiving and Bronfenbrenner’s (1985) “curriculum of care” (p. 254), the Māori notion of hauora, and Durie’s (1994) Te Whare Tapa Whā model of health and wellbeing, all outlined earlier in the thesis. Thereafter, the four key areas of care undertaken by participants will be examined within Durie’s (1994) Te Whare Tapa Whā health framework with which they so closely aligned.

Participants' conceptualisations of care mirrored Bronfenbrenner's (1985) espousing of a "curriculum of care" (p. 254). Despite care being an integral component of all communities, Bronfenbrenner (1985) observed the increasing individualism of society and the propensity for students to leave school "without ever having had to comfort or assist another human being" in need (p. 254). In response, he proposed a curriculum of care, enabling students to care for others who were unwell, elderly, or had a disability. Bronfenbrenner's curriculum of care aligns closely with participants' conceptualizations of their caregiving experiences, and specifically, to young carers' enactment of holistic care tasks aimed at supporting their care recipient's wellbeing.

Participants' understanding of care as meeting their loved one's holistic needs also echoes the Māori concept of Hauora (Durie, 2004), which is "the driving force" behind individuals' acts "for and with others" (Kohere, 2003, p. 23). Such driving forces in the young caring context refer to participants' understandings of their roles as achieving holistic wellbeing for their loved ones. This view is markedly different from the bulk of existing literature that, whilst outlining "a broad range of caring activities" (Nagl-Cupal & Hauprich, 2018, p. 532) undertaken by young carers, overwhelmingly describes physical and emotional aspects of care but often overlooks the social and particularly spiritual elements (e.g., Aldridge et al., 2016). In this way, participants' understandings of the four-dimensional holisticity of care is reflective of the Māori health philosophy of Hauora, which is reflected in existing healthcare models relevant to NZ. For instance, the Fonofale Pacific health model uses the metaphor of a Samoan meeting house to highlight the holistic nature of care (Agnew et al., 2004) (outlined in Chapter Two), and is akin to participants' own perceptions of care as multidimensional expressions. In particular, Mason Durie's (1994) Te Whare Tapa Whā Māori health model (discussed in Chapter Two) echoes participants' understandings of care as comprising four elements, as it outlines an individuals' health as incorporating: Taha Tinana (physical wellbeing), Taha Hinengaro (mental and emotional wellbeing), Taha Whānau (social wellbeing), and Taha Wairua (spiritual wellbeing). Due to the alignment of participants' understandings of care and Durie's framework, and the widespread recognition of the model among NZ caregiving stakeholders (Egan & Timmins, 2019), the ensuing discussion of care undertaken by participants will be embedded within the Te Whare Tapa Whā framework.

Māori concepts have received increasing attention and acceptance in NZ society, facilitating an individual's enactments and understandings of their roles and relationships. Several concepts are particularly relevant to the young caring context. Aroha, for example, is "expressed as kindness, generosity and commitment" (Webber, 2019, p. 129). Barlow and Wineti (1991) state that enactments of aroha can be seen when an individual "expresses genuine concern towards" another person, "and acts with their welfare in mind, no matter what their state of health or wealth" (p. 8). This view is evident in Terrence's statement that "Someone else wouldn't be able to take care of [mum] how we would because we actually love her. We want to care and will really care because she is our own" (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability). The notion of manaakitanga is also a “highly valued principle in te ao Māori[32]” (Webber, 2019, p. 130) that emphasises “nurturing relationships, looking after people, and being careful about how others are treated” (Mead, 2003, p. 29). Webber (2019) asserted that underlying manaakitanga is to “akiaki (cherish/nurture) the mana of others” (p. 130), which denotes the importance of respecting others’ capacities to continue to “impact upon, affect and transform the lives of others” (Dell, 2017, p. 89, in Dell, Staniland, & Nicholson, 2018, p. 54). Terrence’s akiaki for his mother was evident in his efforts to protect his mother’s maintained position as a family elder, as he stated, “My niece talks to my mum as if she’s a friend now. Like she’s kind of lost the respect for her grandma, you know, as someone older. So I’m really strict on that”. Overall, young carers’ protection of their care recipients’ physical, emotional, social, and spiritual wellbeing reflects their capacities to akiaki the mana of their loved ones, and demonstrates aroha and manaakitanga. As such, NZ Māori concepts appear to reflect young carers’ enactment of holistic care.

Taha Tinana: Physical Care

Similar to prior research (Aldridge et al., 2016; Ferguson et al., 2001), tangible, physical care encompassing “the more familiar aspects of bodily health” (Durie, 2011, p. 30) dominated participants’ understandings of care. Mirroring the range of physical care activities outlined in existing studies (McDougall et al., 2018; Szafran et al., 2016), participants conceived that they undertook seven care tasks that addressed their loved ones’ Taha Tinana physical welfare, being: (1) domestic, (2) intimate, (3) nursing, (4) mobility, (5) supervision and childcare, (6) financial, and (7) service coordination and translation.

Firstly, all participants carried out **domestic care** encompassing cooking, cleaning, and food shopping. Young carers conceived domestic tasks as “the day-to-day” (Grace) or “housework” (Anna) related activities, as demonstrated by Chun who explained “I was in charge of ensuring all the necessity in the family is done [by] doing the housework and cooking and everything” (Adult, 27, Hong Kong Chinese, mother with stroke/dementia/cancer, father with undiagnosed mental illness). Male and female participants undertook domestic care, which could encompass a large portion of their roles. For instance, current young carer Leah said “I got to the point where I was cooking like four or five times a week [for my family] and doing the food shop [and] all the cleaning … and it was just kind of relentless” (17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness). Many young carers conceived that domestic chores signalled the commencement of caregiving, as Grace said “My care started when I’d help mum with cooking dinner while she did the cares for [my sister]” (Current, 21, Pākehā, sister with physical and intellectual disability). Likewise, Louise remembered her

> first time doing caring was when I was five … dragging the washing out and standing on a chair to hang it up for dad ‘cause he couldn’t do it … you felt quite like, “ooh, I’m a little bit of

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[32] Te ao Māori denotes the Māori world, including Māori language, customs, and the Treaty of Waitangi (University of Otago, 2019) – NZ’s founding document defining Māori and Pākehā relations (O'Malley et al., 2011).

> the head of the house" (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke).

Domestic care is a particularly common task identified in the literature, with several researchers positing domestic activities as foundational to the commencement of young caring, especially when roles gradually onset (Aldridge et al., 2016; Noble-Carr, 2002). All young carers' roles soon extended beyond domestic care tasks, however, often into intimate care activities.

Secondly, **intimate care** was carried out by 86 percent (n=24) of young carers. Intimate care was conceptualised as the "practical" (Lola) or "basic tasks for daily functions" (Chun). Akin to existing literature (Leu et al., 2018), it included toileting, bathing, dressing, and grooming. Toileting-related tasks were undertaken by over 70 percent (n=22) of participants, who described helping their care recipients with catheterising (Anna, Miharo), changing children's or adult's "nappies" (Amelia), and supporting their loved one "on and off the toilet" (Louise). Current young carer Grace addressed intimate care as she explained,

> I probably started doing it around 6 or 7 [years old]. We call it the "poo parties". [My sister] gets into her nappies and will just get it everywhere. And I would actually just clean it up while mum's sleeping. It was horrible (laughs softly) but [my sister] thinks it's hilarious; she's mischievous! (21, Pākehā, sister with physical and intellectual disability).

Toileting care ranged from an everyday task for 14 participants, to one-off care required for the remaining ten young carers when an "accident" (Tilly) or "emergencies" (Greg, Wyn) happened. All participants whose loved ones had a physical disability undertook regular toileting care, while care recipients with a mental illness were the least likely to receive such support. Toileting could continue overnight, as Miharo recalled that when her mother

> started to become incontinent with number two, she would poo and not know that was what she had done, and there would be a mess during the night. So whoever was sleeping with her would have to then wake up, help her clean the mess, and then go back to bed, and I think that happened at least you know twice a night.

Bathing was described by 79 percent (n=22) of young carers, and once again included all participants whose loved one had a physical disability. Care recipients who were bedbound most often received sponge baths in bed, whilst those who were mobile were more commonly supported to shower or bath. Mele described bathing her grandmother due to her dementia and arthritis:

> She was quite heavy … 'cause she had a really big tummy 'cause she's not mobile [and] anyway like lifting her up she'll be uncomfortable. So we'd just actually bring a tin of water and basically just bathe her on the bed with a towel every day – that happened every morning and then every night (Former, 24, Tongan).

Bathing for Terrence, on the other hand, meant "me and my sister shower mum … It's awkward; even now I still don't look. When I have to shower her, I make her face the wall, I cover her bottom and stuff. [It's] just how I try and cope (laughs)" (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability).

Dressing and grooming care encompassing brushing and styling hair, applying makeup and shaving, and was enacted by almost 90 percent (n=25) of young carers. Current young carer Grace stressed the importance of “shaving her [sister’s] legs and having her hair nice [because] we want her to have dignity and femininity when she goes out in shorts and stuff” (21, Pākehā, sister with physical and intellectual disability). Likewise, former young carer Terrence said “We do [mum’s] hair, put some lipstick on, earrings and stuff, because we always want to keep that sense of my mum. Right up until this day before she goes out, we do her hair and change her into nice clothes” (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability).

Toileting and bathing were often described as “difficult” (Lola) or “embarrassing” (Terrence) tasks for young carers and their care recipients, especially in the many cases when unwell family members were older than the young carers themselves. For instance, current young carer Leah said that her brother with autism and an intellectual disability

> doesn't have particularly regular bowel movements and so it’s quite a big deal going to the bathroom; it involves putting him straight back into the shower because that’s the appropriate way to deal with it now. And … you have to unblock the toilet and that kind of stuff, which is always fantastically fun” (said sarcastically) (17, Pākehā).

Louise recalled how helping her father toilet “was awkward [because] you don’t normally see those things or want to know about those things of your parents … I think he was uncomfortable” (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). Existing studies highlighted the challenges of intimate care for young carers and care recipients (Bjorgvinsdottir & Halldorsdottir, 2014; Cunningham et al., 2017), which could be “difficult for both sides” with “feelings of shame or embarrassment” being common (Chikhradze, Knecht, & Metzing, 2017, p. 10). Overall, most young carers supported their loved ones with toileting, bathing, and/or dressing and grooming, with these forms of intimate care often being described as embarrassing.

The third category of physical support was **nursing care**, undertaken by 71 percent (n=20) of participants. Nursing tasks ranged from applying dressings to pressure- or bed-sores and wounds, to spoon-feeding, administering or injecting medications, and checking vital signs. Louise explained that due to her father’s arthritis, he had “big ulcers that took nine years to heal … so I helped do all of dad’s dressings and stuff to try and get the ulcers to heal” (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). Likewise, Tilly remembered that for her twin sister with tetraplegia, “there’d be lots of … adjusting things and checking pressure sores [and] pressure relief [and] rearranging [her] in bed” (Adult, 44, Pākehā). Nursing support appeared to intensify during palliative care. Both Mary and Lucy described an increase in nursing support for their terminally ill mothers, as Mary recalled giving “injections every morning” to ease her pain (Former, 27, Pākehā), and Lucy remembering she had to “constantly change the syringe on [mum’s] pain pump”, and “taking her blood pressure, which I really wasn’t qualified to do” (Former, 25, Pākehā).

As shown in Lucy’s quote, young carers could feel unqualified to carry out nursing care. This was because no participants were formally trained or supported to enact such care. Instead they learned via paying attention during hospital or specialist visits, shadowing formal care staff, or being guided by their family members or unwell loved ones. For instance, Louise explained that her mother’s district nurses were “all really influential for me to know how to do her cares” as she observed them carrying out tasks. Chloe recalled her mother’s nurses installing “a speaker system in the bathroom … They showed us how to [care] and if anything happened, we could talk to [the nurses]. But unfortunately, there were a couple of times we should have used it, but we didn't (laughs a little)" (Adult, 25, Pākehā, mother with multiple sclerosis). Participants' experiences of nursing care are reflected in existing research (Aldridge, 2006; Aldridge et al., 2016; Dearden & Becker, 2004). Over a third of the 96 US young carers in Kavanaugh et al.'s (2019) study undertook nursing care, which they learned via guidance from their care recipients, observing others, or using their initiative. Overall, the many participants undertaking nursing care in this study often felt underqualified to enact these forms of specialist care.

Mobility care marked the fourth type of physical support, with over 65 percent (n=19) of young carers describing lifting care recipients in and out of wheelchairs or mobility vehicles, turning or rolling them in bed, or assisting with transferring from one setting to another. Wyn recalled helping her mother to walk following her stroke, explaining that "It was not just a two-minute process as I'm sure you know. It took a long time to get her from wherever she was to the toilet, and I would be supporting one side and encouraging the poor woman to walk" (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness). Amelia (Adult, 36, Tongan) also described undertaking mobility care for her aunty with paraplegia, explaining

> I can't change auntie when she sits, so she has to lie down on bed … So there is the bed there and her wheelchair there (indicates that the bed is next to the wheelchair) and it's more like sliding her over. So I do that all the time [for] removing her bottom clothes.

For four young adult carers, mobility care extended to providing transportation. Sally said,

> When I turned 18 … I had this lovely experience of getting my driver's licence thinking, 'this is great!' And then getting phone calls [from mum], 'Sally, I'm going to kill myself if you don't come over, I've got the knife, this is what I'm going to do' ... So she became really *needy* all of a sudden (Adult, 32, Pākehā, mother with cancer/bipolar/depression, brother with ADHD, husband with substance misuse/undiagnosed mental illness).

Likewise, Mary explained that her father

> Became quite a severe alcoholic, and that became quite prevalent towards the end of 7th form[33]. And it became a real issue when he was banned from driving 'cause he lost his licence … and I had to drive him everywhere and take him to AA [Alcoholics Anonymous] meetings (Former, 27, Pākehā).

Mobility care was most commonly undertaken by participants supporting loved ones with a physical disability or serious illness, a trend mirrored in existing research (Kavanaugh et al., 2019; Szafran et al., 2016).

Young carers' mobility tasks seemed to be predicated on the care recipient's illness or disability, rather than being related to participants' gender or size. Most participants carrying out mobility care were females – reflecting the wider trend of caring being female-dominated – with the youngest being six years old. An absence of support outlined in existing research (e.g., Nagl-Cupal et

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[33] 7th Form is equivalent to Year 13, and refers to the final year of high school, when students are generally aged 17 to 18 (https://www.nzqa.govt.nz/studying-in-new-zealand/secondary-school-and-ncea/).

al., 2014) was reflected in this study, with a lack of equipment and training requiring participants to use trial and error or creativity to ascertain the most effective means of supporting their loved ones. Kahurangi explained that aged 14 and 13 respectively, “My brother and I would carry [mum] out of the car, and we would do what’s called the fireman’s lift (her arms cross over and she indicates her hands hold another person’s hands), because she couldn’t walk” (Adult, 51, Māori, father and mother with cancer, brother and sister with schizophrenia). Similarly, Miharo said that because her mother with a physical disability

> Didn’t have a wheelchair … the kids somehow had to transport her from her bed, and she was a big woman. They did it by putting her on a sheet, lifting her off her bed, putting her on the skateboard, and carting her around like that.

Other young carers used the help of others when out. For instance, Rachel stated that when she was out with her brother with muscular dystrophy, “I’d just make sure there were a couple of burly young men there … and they would pick him up because he was very thin and very light. I probably could have just about carried him myself!” (Former, 59, Pākehā). Likewise, Louise recalled that when she and her father, a wheelchair user, went

> to the stock-cars, we kind of had a place where we parked … and then often I would grab one of the other people that were already there to help me get him out [because] the ground at the track was a bit hard, in the mud on my own (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke).

Fifth, mirroring prior research (Becker & Dearden, 2004; Cass, Smyth, Hill, Blaxland, & Hamilton, 2009), participants also undertook **supervision and childcare**. Supervision care was described by all participants, and involved what several young carers described as “watching over” their care recipients. For instance, Wyn said she “never left mum alone [because] she could easily fall” (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness). Leaving the house appeared to increase the need for supervision. For example, Claire said that her role as “protector” was cemented after a “scary” incident on the school bus when she and her sister were in Years One and Two [aged five and six] respectively:

> Because of her motor skills, she had to sit on the back step and shuffle her bum down to the next step [to] get off the bus. But the driver didn’t see that she was still on the bus, and [he] took off. I had to run after the bus and grab her hand and pull her off (Former, 43, Pākehā, mother with mental illness, sister with intellectual disability).

Supervision also appeared to intensify for young carers of loved ones with a mental illness or substance misuse, who had to remain “constantly vigilant” (Sally) about their care recipient’s safety. For instance, Melanie said that “the biggest aspect of caring” for her friend with paranoid schizophrenia was

> always watching for self-harm or expressing that he wanted to hurt people … I knew at any point if he showed signs of wanting to hurt himself or other people, then he would have had to go to hospital – that was made very clear (Former, 31, Pākehā).

This is reflected in Moore et al.'s (2011) finding that for young carers supporting family members with substance misuse, "responsibility for monitoring their … wellness and safety was always significant" (p. 167).

Also reflecting the findings of existing studies (Leu et al., 2018; Stamatopoulos, 2015), the second form of supervision was childcare for healthy siblings. Childcare was undertaken by over 30 percent (n=9) of participants, and in most cases, was necessitated due to parental illness or disability, especially in sole-parent households. Fleur recalled how because her mother "wasn't very well" with multiple sclerosis, "I would do things like get up in the morning and look after my little brother, you know, I was six years old and changing nappies and making bottles and doing quite a lot around the house" (Adult, 39, Pākehā). In one instance, childcare was necessitated in a sole-parent household where the mother was working evenings and nights to provide for the family. Ngākau explained that her caring role largely consisted of

> having to look after two kids through the night [and do] things that I'd imagine mothers do … unpacking the school bags, [doing] homework with them, cook the dinner … then doing the dishes after that, preparing the table [by] resetting it for the morning, and getting them ready for bed … I always felt like the black sheep: I was always different. I couldn't just be their friend because if I was then nothing would get done (shakes head). They wouldn't go to bed, they wouldn't eat their dinner, they'd make a mess and spill things on the floor and then I'd have to clean it up. So I did kind of get into that role of overseer, tough on them … at that age I didn't have enough resilience to get through the routines of the evening with extras like cleaning up spills or dealing with broken plates or anything like that. It was too much (Former, 49, Māori, brother and sister due to parental employment and mother's undiagnosed mental illness).

As such, all participants enacted some form of supervision care, the nature or amount of which could be exacerbated when care recipients had a mental illness or substance misuse, or when participants lived in sole-parent households.

The penultimate category of physical support, carried out by 68 percent (n=19) of young carers, was **financial care**. Financial care involved participants managing the family's finances by paying bills and organising and collecting government subsidies. Dan said that at 11 years old, he would "go to the post office to pay bills, collect the benefit[34], [and] pay the mortgage" (Former, 53, Pākehā, mother with paranoid schizophrenia), while Chloe "did a lot of writing out cheques [and] balancing out the chequebook" (Adult, 25, Pākehā, mother with multiple sclerosis). Oftentimes participants received support from their unwell loved ones to manage the family's finances, with Chloe explaining that her mother "was able to tell us what to do". For 10 participants as young as 12 years old, financial care extended to gaining employment. While being employed during high school and young adulthood is a common occurrence, participants' income functioning as a "financial contribution" (Ngākau) to their families rather than as personal spending money or career progression cemented their employment as an integral component of participants' caregiving roles. Ngākau

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[34] The benefit is a term that covers a variety of financial support offered by the NZ government for low socioeconomic individuals and families (https://www.workandincome.govt.nz/eligibility/).

explained that from age 14; "I was working in a dairy [shop] after school and all weekend and all that money went as a financial contribution to our household. So I was, in effect, supporting our family from a really young age" (Former, 49, Māori, brother and sister due to parental employment and mother's undiagnosed mental illness). Likewise, Amelia said that for "two years we didn't have any income at all, so [I] weave and make the handicraft and we sell it [to] pay the food, help with the petrol, and stuff like that" (Adult, 36, Tongan, elderly grandmother, aunty with paraplegia). Young carers working to support their families is reflected in existing research (Aldridge et al., 2016), with Leu et al. (2018) reporting that "supporting the family financially by taking on paid work" is particularly common for young adult carers (p. 931).

Low socio-economic status appeared to increase the need for, and difficulty of carrying out, financial care. Despite not asking for information regarding participants' socio-economic situations, household finance was spoken about by all young carers. Over 80 percent (n=23) of participants described their family as financially "struggling" or being "poor". For example, Grace explained,

> Growing up I've never seen mum work. Well of course not, [caring is] a full-time job. [So] we were really tight. *Really* tight, yeah. I was constantly in hand-me-downs, so that was a little embarrassing, [and] we had really really basic lunches. I mean like basic. [Mum] would get like food grants from WINZ[35], certain uniform grants, you know all these sort of grants and stuff (Current, 21, Pākehā, sister with physical and intellectual disability).

Due to this financial strain, many participants struggled with financial care because it "was never straightforward" (Dan). For example, Lucy explained that

> if there wasn't money to direct debit the mortgage, then I would have to go and talk to [the bank] … Even now I have anxiety issues around paying for things because it was such a big deal when I was a teenager: we were going to get kicked out of our home [and] I had to carry that (Former, 25, Pākehā, mother with cancer).

Overall, financial care was a complex but integral task undertaken by most participants, who often supported their family/whānau/aiga to cope with the loss of, or decrease in, income.

The final physical task outlined by many young carers was **service coordination and translation**. In terms of service coordination, 68 percent (n=19) of participants accessed, coordinated, and oversaw the myriad of services required for their loved ones' health and wellbeing. For example, Chun said that a key part of her role was "being a broker" for her mother following her stroke and the onset of dementia, by "helping her with referrals [and] maintaining all of the medical records and managing her case" (Adult, 27, Hong Kong Chinese). Chun went on to explain that this role

> was primarily my responsibility because there was nobody else to do that. I can't expect my father to do that because he didn't really understand the health system and the language would have been a problem … He speaks Chinese but [his] English is ok conversational; it's not deeper than that.

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[35] Work and Income NZ (WINZ) is a government agency that offers financial support to low income or unemployed individuals (https://www.workandincome.govt.nz).

For Chun, and five additional participants, advocacy care extended to translating during appointments as unwell loved ones or wider family/whānau/aiga did not speak or understand English, and/or the medical terminology used. Some young carers described the difficulty of translating, because of the intimate nature of content being discussed, the significant workload, or due to their concerns to correctly translate such key information. Tongan Amelia said that services having translators would be helpful, as

> each appointment or each person coming in that are not Tongan or not coming with the translator I had to sit there and translate. So, I'm like translate doctors, the physiotherapy, most of the services that comes in … I'm sitting there and translating everything! … My little English study in the [Pacific] islands [was] very helpful when I comes over here … and if I don't understand anything what they saying, I just Google what they are talking about (Adult, 36, elderly grandmother, aunty with paraplegia).

Participants' concerns to translate correctly are echoed in existing literature, with researchers highlighting the risk of "translation errors", the inappropriateness of children and youth hearing intimate information, and young carers feeling anxious or uncomfortable when interpreting for their family members (Cline, Crafter, de Abreu, & O'Dell, 2017, p. 281; Morales & Hanson, 2005). Translating and coordinating services for their loved ones was thus a key component of many participants' roles.

Overall, young carers carried out a range of care tasks to maintain their loved one's Taha Tinana or physical wellbeing. However, whilst physical care initially dominated participants' discussions, interviews revealed a further three categories of care that were integral to young carers' roles, being their provision of emotional, social, and spiritual support, each of which will be discussed in turn.

Taha Hinengaro: Emotional Care

All young carers undertook emotional care regarding their loved ones' "thinking, feeling, and behaving" (Durie, 2011, p. 30), through providing comfort, counsel, advice, and a listening ear. Participants conceived that emotional support was instrumental to their loved one's capacity to "get through" (Mary) difficult periods in their health journeys, as well as providing "an outlet" (Grace) for the strong emotions tied to experiences of ill health or disability. For instance, Kahurangi recalled the difficulty for her sister undergoing new treatments for schizophrenia, at which times "just being there to guide her [and] keep her on task and keep her spirit up" was important (Adult, 51, Māori). Emotional care continued even when young carers were away from their loved ones. Greg described often calling his father, explaining that his caregiving role "was basically a lot of communicating, a lot of just keeping tabs on how [dad] is, me letting him know what I'm doing, where I'm going, and when I'm going to be back, and about my day" (Former, 28, Pākehā, cancer/heart attack). Likewise, Mary described how when she was at work, her mother with cancer

> would email me constantly throughout the day … [and] I was always texting her actually (laughs a little), [to] make sure she was okay, giving her a call at lunchtime. Yeah it was juggling between work and trying to manage from a far, making sure she's okay (Former, 27, Pākehā).

Emotional support extended beyond care recipients to other family/whānau/aiga members, and particularly to well parents when another parent had become unwell. Chun said that she “talked to dad a lot ‘cause I could see that he wasn’t coping [and] was in a very dark place” following her mother’s stroke and onset of dementia (Adult, 27, Hong Kong Chinese, mother with stroke/dementia/cancer, father with undiagnosed mental illness). Similarly, Mary described providing emotional support for her mother when her father’s alcoholism worsened, that “empowered her to leave dad as well in a way, ‘cause she felt safe that she wasn’t going to be alone and that you know, essentially it was kind of like her and me” (Former, 27, Pākehā, mother with cancer, father with substance misuse/acquired brain injury).

Young carers’ emotional support is also recognised in existing research (Banks et al., 2001; Becker & Sempik, 2019; Joseph et al., 2019). Two large-scale quantitative UK studies found that over half the young carers undertook emotional care (Aldridge et al., 2016; Becker & Sempik, 2019). Studies particularly highlight the intensity of emotional care when care recipients have a mental illness or substance misuse (Aeyelts et al., 2016; Aldridge, 2006). For example, Noble-Carr, Moore, and McArthur (2009) found that some children and youth supporting a parent with a mental illness or substance misuse were “listening to their parent’s problems” and keeping their mother or father “calm” in order “to avoid parental self-harm” (p. 49). This trend was echoed in the present study, where a key stressor for participants supporting loved ones with a mental illness was the need to continually “mediate” (Melanie) their care recipients’ “erratic” (Kahurangi) dispositions. Participants described “picking up on” (Sally) subtle changes to their loved ones’ behaviours in order to “avoid” (Phoebe) or “de-escalate” (Melanie) emotionally-fraught scenarios. Sally described her mother as “a self-harmer” due to her bipolar disorder, explaining that “over the years we’ve had many many many many suicide attempts … [so] we learnt lots of things over the years around how to kind of manage that” (Adult, 32, Pākehā). For many of these young carers, emotional support also meant holding in or concealing their own emotions. For instance, Kahurangi explained

> a situation where one of our sisters chose to go to an equestrian event and then came home and gave us all a telling off because we hadn’t made the sandwiches right (laughs), and [we] had a big family fight. It nearly turned into a punch up! And [my sister with schizophrenia] went out the front and took some newspaper and set it on fire and said she was going to burn us all down (hands holding torch) … because she could not cope with the fighting. It made us really aware of our own selfishness, about our own emotions … I’m so conscious about keeping it together that now [even when] I want to break out I’m too programmed (hands to head) (Adult, 51, Māori).

Overall, a key aspect of participants’ roles was the provision of emotional support for their care recipients and wider family/whānau/aiga members, with young carers of loved ones with a mental illness often experiencing particularly difficult emotional care loads. [Young carers’ emotional wellbeing is discussed in Chapter Seven].

Taha Whānau: Social Care

The third layer of caregiving was the social or “family aspect” of care undertaken by all young carers (Durie, 2011, p. 30). Participants here spoke about keeping their loved ones company and maintaining their link to their immediate and wider social worlds, via telling stories, sharing details of school or university experiences, hosting family/whānau/aiga and friends, and doing fun or distracting activities. Louise explained that, “to me, young caring means … being someone to talk with. Like when dad was isolated, being his company and his friendship” (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). Similarly, Greg described the importance of “never [being] far away so [dad] knew that if he needed company I was there” (Former, 28, Pākehā, father with cancer/heart attack). A key aspect of Taha Whānau for all participants was maintaining the embeddedness of care recipients within their family/whānau/aiga units and wider communities. For instance, Māori Louise said that she would drive her father to the stockcars “so he can go out and feel like a normal dad to some point … like any father with his daughter”. Tongan Mele also addressed Taha Whānau as she explained that caregiving alongside her siblings “was also us trying to protect our grandma … ‘cause we didn’t want [other] people talking [grandma] down at all. You’d only talk with family members [about grandma’s illness]: that’s a safe forum” (Former, 24, dementia/arthritis). Social care also extended to other family members and in particular primary *adult* carers and siblings. For example, Wyn said that once her mother became unwell, “dad didn’t do anything outside of work and home [so] I’d make sure we’d to go to the [movies] every week” (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness). Participants’ provision of social care is echoed in some existing studies (Joseph, Becker, Becker, & Regal, 2009; Warren & Edwards, 2017), with one Scottish study of 153 young carers reporting that “the most common tasks falling on young carers were [those] related to spending time with the person, such as taking them out, keeping an eye on their wellbeing and keeping them company” (Watt et al., 2017, p. 15).

Five factors appeared to increase the amount of Taha Whānau care provided by young carers in the present study. Firstly, social care was particularly commonplace for care recipients who had limited social networks. Terrence said, “I take [mum] out [but] I wish [services] could like put in place something for her to do (hand to heart strongly), or that there were some kind of groups for her to go to” (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability). Likewise, Rachel explained that for her brother with muscular dystrophy, “socially he was with me practically everywhere I went … because I knew if I didn’t do that he [would] have … a very lonely, isolated life” (Former, 59, Pākehā). Secondly, social care appeared to increase when care recipients were largely housebound. Kelly recalled how her elderly grandfather “was lonely, ‘cause when I was two years old my Nan passed away, so although he lived by himself, he kind of needed people around all of the time … to talk to him” (Former, 23, Māori). Thirdly, social care was apparent when care recipients were admitted to outside-of-home services. Lucy said that her mother

> hated being alone, so when she was in the hospice, I would get there at night and be there until she went to sleep … [I’d] just like potter around the hospice, you know, knitting or reading. I’d read books to her and that was quite nice ‘cause we’re both readers. And do homework, whatever (Former, 25, Pākehā, mother with cancer).

Fourth, the collective model of care often enacted by Māori carers meant that Taha Whānau support was particularly integral. Māori participants explained the importance of having “that united whānau … our cultural way of being” (Kahurangi). Finally, the propensity for Pacific young carers to enact social care was evident as several participants described regularly hosting large groups of aiga and community members. Tongan Mele explained that “all the family functions were at our house” because her family wanted to visit her grandmother:

> So that’s not just the nuclear family, it’s the extended … which is nice, honestly, it’s a wonderful time. But it was a stressful time for us (laughs) … That was the most challenging thing of caring ‘cause me and my sisters were basically … washing plates and serving food for the whole day (Former, 24, grandmother with dementia/arthritis).

Overall, all young carers provided social support extending to other family/whānau/aiga members, which could be heightened when care recipients had a limited social network, were housebound or admitted to residential services, or were Māori or Pacific.

Taha Wairua: Spiritual Care

Finally, a unique spiritual dimension of care was evident among the narratives of young carers of all ethnicities and faiths. Taha Wairua reflects “the significance of long-standing connections between people [and] ancestors” (Durie, 2011, p. 30). Specifically, some participants spoke to the integral nature of their caregiving roles as part of the bigger picture of experiencing ill health and of caring within their cultural and religious context. For example, Kahurangi used the pronoun “we” to refer to caring alongside her spiritual ancestors, explaining that “caring is not individual … Even if you might be the only person there, you’ve got all your whānau with you, [and] tūpuna, your ancestors. So when you’re doing something it’s never ‘I’. It’s always about ‘we are’” (Adult, 51, Māori, father and mother with cancer, brother and sister with schizophrenia). In Kahurangi’s quote, she uses the notion of whānau as extending to her deceased family members and tūpuna (ancestors) (Walker, 2017), which reflects her understanding of care as being embedded within the whole family past and present. Similar to Kahurangi, Melanie described her caregiving role for her friend with schizophrenia as existing within a wider framework of religion, explaining

> I had always had religion in my life but never had a belief. [Caring is] the only time in my life that I’ve had this kind of sense that maybe there is something bigger that has aligned the situation because somebody knows that I have the ability to do this … for that period of time I had this sense that it was out of my hands in a way (Former, 31, Pākehā).

Participants of Pākehā, Māori, Asian, and Pacific decent identified the use of karakia (song) (Kahurangi), prayer (Wyn), and hymns (Mele) as key means of maintaining their loved ones’ spiritual connectedness. For instance, Pākehā Wyn recalled a key element of her role;

> I would lecture [mum] at length about a particular psalm, 91 sounds familiar (scratches her head thinking). I would take her through it verse by verse, and I would lecture her about all she had to do was believe in this and she was going to be miraculously better, and this is what she had to do (Former, 67, mother with diabetes/stroke/dementia/undiagnosed mental illness).

Tongan Mele explained that for “Pacific cultures there’s a lot of spiritual connections, especially about religion. [So] we always said prayers with [grandma] and sing hymns for her … and you’d see [in] her face – she’d be at peace” (Former, 24, grandmother with dementia/arthritis). Spiritual care also brought peace for young carers themselves, in some cases helping them to cope with their loved one’s diagnosis and their role as carer. Mele went on to state, “my religion does help me a lot in dealing with circumstances … you have to pray about it [to] deal with it”. Similarly, Lucy described the importance of her “own religion” as an “outlet … connecting me to this higher thing” when she was struggling with her caregiving role (Former, 25, Pākehā, mother with cancer).

Spiritual care is seldom addressed in existing research. However, some studies exploring young caring in Sub Saharan Africa (Robson, 2004) and regarding minority ethnic or immigrant young carers (Jones et al., 2002), touch upon spiritual or religious care. For instance, Robson (2004) concluded that Zimbabwean young carers “may need and welcome support to assist the emotional, physical, social, financial, *religious and spiritual* needs of themselves, their care recipients and households” (p. 242, emphasis added). Similarly, Jones et al.’s (2002) UK study of black young carers concluded that “the diversity of *religion*, of ethnicity and also of family life-styles raises important questions about dominant concepts of family life in Britain” (p. 14, emphasis added), with one young carer explaining that, as part of her young caring role, “I pray and give them their medicine and their breakfast” (p. 15).

Overall, this section has revealed the multiple dimensions of the caregiving experience, and the centrality and importance of elements including emotional, social, and spiritual wellbeing – the latter being seldom discussed or identified in existing research.

Difficulty Ascertaining the Nature and Extent of Care

While the nature of care as encompassing all four elements of wellbeing was clear, the extent of care was difficult to ascertain. In this second section, five key reasons underlying the difficulty of identifying the extent of young caring will be outlined, being the: (1) variance in what ‘counts’ as care, (2) episodicity of disability and illness and the tendency to recognise only crisis-related care, (3) wider factors contributing to the overwhelming nature of care, (4) unclear numbers of care recipients being supported, and (5) nonfinite loss underlying caregiving tasks.

First, variance existed between young carers’ conceptualisations of **what counts as care**, with some key elements being initially unrecognised as ‘care’. In particular, the emotional, social, and spiritual tasks described above were often unaddressed in young carers’ initial descriptions of providing care. All young carers chose to speak about the physical and often domestic components of caregiving at the outset of their interviews, conceptualising their roles through a quantification of the amount of tangible care undertaken. For example, Chloe said caring for her mother with multiple sclerosis between the ages of 12 and 15 “meant doing the laundry, writing cheques, [and] lifting mum into her wheelchair” (Adult, 25, Pākehā). Louise, who cared for her father from age five to 21, responded in a similar manner, stating that caring meant “doing all of the cooking and cleaning [and] helping dad shower and toilet” (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). It was apparent that young carers’ physical task-dominated conceptualisations of their roles resulted in only a snapshot of the holistic four-pronged Te Whare Tapa Whā model initially being revealed. For instance, despite providing significant emotional and supervision support for her father who was experiencing substance misuse, Mary said that "I didn't really care for him … it was more kind of trying to stop him from hurting himself and drink driving" (Former, 27, Pākehā). The hidden layers of intangible care commonly emerged later in the interviews, when participants attributed deeper meanings to their roles. When I identified the emotional, social, or spiritual support being described as *care*, participants often said that they "didn't realise" (Anna) such tasks counted as care.

This finding reflects the international research, with one UK survey of parents and young carers identifying that "young people were less likely than their parents … to recognise their emotional caring role and tended to focus more on practical tasks that they undertook around the home" (Aldridge et al., 2016, p. 57). The discounting of intangible caregiving could be a deeper macrosystem-level issue regarding NZ society's dominant conception of caregiving. This is evident in the latest NZ Carers' Strategy (MSD, 2019), which defines carers as individuals caring for someone "who needs help with everyday living" (p. 5). Without any further delineation of the type of care enacted beyond "everyday living", this definition could infer largely physical, practical care. The oversight of intangible care is even reflected in the NZ Māori Disability Survey (Office for Disability, 2010), which identifies informal care provided in the categories of heavy housework, shopping, everyday housework, meal preparation, personal finances, and personal care, thus appearing to miss emotional, social, or spiritual care. Thus, intangible care was often missed despite its significance – reflecting participants' Taha Tinana (physical) dominated conceptualisations of their roles – which may indicate a largely hidden group of young carers in predominantly intangible care roles who may not recognise themselves or be recognised by services as young carers.

Despite the ease of acknowledging Taha Tinana care, however, some participants questioned the fit of certain physical activities within the parameters of care. In particular, variance was apparent as some young carers discounted domestic, mobility, supervision, and financial activities, seeing them as normal or everyday familial activities. Other young carers counted them, and asserted the significance of such tasks as part of providing care. I propose that the variance occurred due to participants' conceptualizations of the life-stage or age-appropriateness of certain tasks, which they used as filtering systems to ascertain the elements of their roles that counted as caregiving. This filtering reflects Olsen's (1996) assertion that "similar tasks may mean very different things when carried out by an 8-year-old, as opposed to a 15-year-old" (p. 46). The life-stage appropriateness parameter was evident as Amelia smiled as she said that, around age 21, "I [learnt] how to drive and now I can take [grandma and aunty] places. And I have a big fat map book because every day they want to go somewhere (laughs)" (Adult, 36, Tongan, elderly grandmother, aunty with paraplegia). Conversely, Rachel explained that being her brother's "transport system" during their time at university

> was hard … There was no resentment or anything, but I really didn't have any idea of what I was signing up to, and I don't think you can at 18 really … I do remember times of just almost desperation really, of desperately not wanting to go and pick him up. But every day, five days a week, I had to drive to the other side of [the city] and get him, [then] having to take him back

> at night, and … just not having this spontaneity you might expect as an 18-year-old. That spontaneity of life: it just wasn't an option (Former, 59, Pākehā, mother with depression, brother with muscular dystrophy).

On the other hand, the application of age-appropriateness as a parameter for care was particularly apparent when domestic care was considered commonplace and thus initially overlooked by adolescent and young adult participants, whereas children's involvement in housework was often highlighted as a key caregiving task. So, while Terrence initially dismissed the housework tasks that he performed in his early twenties as not being "care", stating "I know how to like wash clothes and make the bed, but I mean [at] my age … it's like real normal" (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability), Louise said that at a young age, having the "responsibility [for] doing all of the cooking and the cleaning and all that kind of stuff around the house [was] a big commitment" (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). These life-stage and age-appropriateness parameters operated as a baseline of normality, heavily informed by participants' own conceptualizations of childhood and caregiving, that existed as a product of, and was deeply embedded within their and their family/whānau/aiga's values. Interestingly, these parameters also reflect the age-appropriate narrative employed in existing research to define young carers' roles (Aeyelts et al., 2016; Becker & Sempik, 2019; Hanna & Chisnell, 2019), with young carers being understood to enact care tasks that "would usually be associated with an adult" (Leu, et al., 2018, p. 1). Overall, most participants implemented a life-stage and age-appropriateness parameter echoing that used in existing studies, which could conceal the true extent of their care tasks.

A trend was apparent throughout the interviews whereby the age-appropriateness that led some young carers to initially discount some activities as caring could later be reinterpreted due to complexities underlying these tasks. Such complexities were identified when, as interviews progressed, additional memories and new meanings were added to caregiving experiences, at which times the participants recognised considerable challenges within traditionally "simple" activities. For example, housework was initially dismissed as care by Dan, who said that in his time young caring he did "the basics … I just did the laundry", alongside general cooking and cleaning. However, he later identified the difficulty of enacting housework tasks, stating that his mother with paranoid schizophrenia

> was in a deluded state continuously [and] she wasn't well enough to … cook or clean or do any washing … So I would do all [that] … and she was a hoarder as well, [so] the house was in a hell of a state; there was two feet of newspaper and hoarded stuff and rotting food in the kitchen … [but] I was still a kid, I could only do what I could (Former, 53, Pākehā).

In other cases, a Bioecological Systems Theory (BST) lens highlighted key connections between systems, which revealed the complexities of apparently simple tasks. For instance, a pattern existed whereby families' low socio-economic status, existing due to decisions made at the exosystem level where participants themselves were not present, significantly affected the ease with which they could carry out domestic care. This was shown when Lucy later expanded on her initially casual reference to "cooking dinner":

> we didn’t have much money [because] my mum kept having her benefit like taken away because she was too sick to go to appointments and stuff, and so we’d have weeks where it was like, “we don’t have any money” … So I would go to my job after school, make enough money to buy dinner, go home, cook dinner (laughs) … I was just like *argh*, exhausted (big sigh) (Former, 25, Pākehā, mother with cancer).

Lucy’s time- and physically-intensive experience of ‘simply’ cooking dinner is demonstrative of the intensified domestic care that emerged when exosystem-level policies and procedures negatively impacted upon families’ financial standing.

Second, the extent of young carers’ roles was hard to ascertain due to the **episodicity of many disabilities and illnesses** and thus of care. Given that unwell family members’ disabilities or illnesses influence the care required (Hamilton & Adamson, 2013; Pakenham et al., 2006), then changes in care recipients’ health resulted in “varied” (Sally), “unpredictable” (Dan) care that was largely determined on “a day-by-day” basis (Anna) for over half (57%, n=16) of participants. Here, the episodicity of disability or illness, reflecting the outermost chronosystem level element of Time, resulted in fluctuating levels of care being required. Chloe described how caring for her mother with multiple sclerosis

> was dependent on how mum was doing health wise … So if she had a really bad week, she got prescribed some antidepressants, but they made her want to go to the toilet all the time … and we had to kind of hold her up … so we [did] quite a bit more for mum at that stage (Adult, 25, Pākehā).

Greg also spoke to the fluctuating nature of his caregiving role, due to the episidocity of his father’s cancer:

> he was going up and down in terms of the stages of his illness, so sometimes he was getting radiation treatment, sometimes he was on some other treatment, sometimes he was off treatment and completely fine, sometimes he was on a very heavy dose of tramadol. Sometimes he couldn’t do a lot of things and sometimes he was more capable. So I mean, [care was] all sorts of different things, but just depending when in the year or when in the week (Former, 28, Pākehā).

This was especially evident for care recipients with a mental illness or substance misuse, whose “episodes” (Phoebe) or relapses could necessitate times of intensive care, followed by periods of relative calm. For example, Dan said that, due to her paranoid schizophrenia, his mother

> had periods when she was very well, but then she had these quite severe episodes … with a lot of very severe drug treatments [with] very severe side effects … it’s traumatic to see her like that really … I was very worried and I was trying to get her to snap out of it (Former, 53, Pākehā).

Kahurangi also spoke to her caring role being more intense at peak times in her sister’s schizophrenia, as she recalled

> she’d go from being catatonic to really animated and a little bit psychotic (hands waving around her face), [and] there would be an episode and then often the police were called because there’d be a violent outburst or she would go missing … So [at those times] we were

> on edge [and] very conscious of her wellness, her wellbeing. That’s quite draining (Adult, 51, Māori).

This unpredictability is highlighted by Moore et al. (2011), who identified the difficulty of “captur[ing] the expanse of the caring role”, due to the tendency for care to “fluctuate … over time” and be “unpredictable” (p. 167).

The extent of care was hard to ascertain when it constantly shifted in intensity over time. The present study identified that, due to such episodicity, most participants initially underestimated the breadth of care that they provided. A trend emerged whereby participants initially identified only intensive care provided in response to episodes or peaks in a loved one’s disability or illness, which was not necessarily representative of their ongoing caregiving realities. Therefore, despite young carers’ roles continuing in “down times” (Lucy) or “periods when she was very well” (Dan), care in this period could be overlooked as tasks did not represent the intensity of episodes or relapses. For instance, current young carer Atalanta initially described her caring role during peak times in her mother’s chronic illness, explaining

> Oh it was kind of shocking … she’d get all hot all of a sudden and I’d have to get her like a bunch of ice packs and then I’d have to get her food and water and sometimes, if it was really bad, I’d have to call the ambulance, and get her all her clothes and that to go to the hospital (12, Pākehā).

However, throughout her interview, Atalanta also revealed that, in periods when her mother was relatively well, she would still provide care, “but not as majorly … I just get her food and water [and] I have to watch her and that … ‘cause if she eats too much [or] eats stuff that she’s not used to she gets sick”. Determining the extent of care from the initial half hour of interviews would thus have painted a very different picture to the overall reality of caregiving ascertained throughout the entire interview transcript. Here, the benefit of the whole-of-transcript approach of phenomenographic analysis was reaped (Van Rossum & Hamer, 2010), as I was able to consider participants’ entire narratives in context, rather than extracting specific segments that may not have accurately reflected the extent of young carers’ roles. Overall, participants’ initial descriptions of young caring often embodied a small selection of intensive and crisis-related care, which could misrepresent the true extent of care by overlooking the additional day-to-day support they enacted. Thus, the results suggest that placing boundaries on the definition of young caregiving requiring the quantification of the extent of care provided – seen in stipulations of significance in existing definitions (e.g., Gaffney, 2007) – could encourage the recognition only of intensive caregiving undertaken in times of crisis, and inadvertently disregard young carers’ everyday and holistic care realities.

Third, the nature and extent of care could be unclear due to additional stressors occurring alongside participants’ roles, which contributed to **the overwhelming nature of care**. Building on the discussion above concerning young carers’ initial descriptions of their care given in peak times in a loved one’s disability or illness: interviews also revealed that young carers’ perceptions of such peak times in care were impacted by wider goings-on, other than their caring roles. Certainly, many young carers initially described their roles at times when they were “so stressful” (Mary), “relentless” (Leah), or “a burden” (Greg); when participants felt that they were no longer “coping” (Chloe, Chun) or were "burnt" (Terrence). However, in many instances, young carers later expanded on these descriptions of their roles, stating that it was not simply the caregiving role itself that created such overwhelming or burdensome feelings, but "the fact that, like, there's one thing on top of the other" (Chloe, Adult, 25, Pākehā, mother with multiple sclerosis). In some cases, participants later expanded on their descriptions of overwhelming care, explaining the difficulty of maintaining their roles alongside school or university and other commitments [discussed in full in Chapter Seven], without the chance for respite. For example, current young carer Leah expanded on her initial assertion that she "wasn't coping with it that well … I mean it got to the point where I was cooking like four or five times a week", adding:

> I was falling behind on my grades (shoulders raised high) … I didn't have any time that I could actually go out. And then I was working … all day Saturday, and so my Sundays are full of homework, and it was just kind of relentless: I was just at the end of my tether (17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness).

As such, it was not simply the intensity of her caring role, but in addition the pressures of school and work, without respite, that resulted in Leah's not coping. In other cases, young carers expanded on their initial descriptions of overwhelming care, to add the impact of a dearth of family/whānau/aiga and/or formal service support [explored in full in Chapter Six]. For instance, Lucy expanded on her description of feeling "so overwhelmed" in her role, as she explained:

> I think the thing that hurt my feelings or made it hard was that like, I have a family, I have a brother, I have a dad, I have eight uncles, and I was the youngest and I was the one who had to do it. I'm still a little bitter about that, that no one stepped up and said "we can see that you're struggling, you need help" (Former, 25, Pākehā, mother with cancer).

Once again, young carers' initial descriptions of their roles could have misrepresented the true extent of care, by not factoring in the additional pressures occurring in their wider mesosystem, exosystem, and macrosystem environments. Young carers' experiences of feeling overwhelmed as a result of not only their caring roles, but additional wider impacting factors, are reflected in existing research (Becker & Sempik, 2019; Newman, 2002). For example, in a large-scale mixed methods Australian study, many young carers "described how their caring responsibilities sometimes left them feeling overwhelmed" (Cass et al., 2009, p. 81). However, akin to the present study, the researchers identified additional factors creating such overwhelm, including the pressures of high school and university, and a lack of carer respite and formal care recipient support. Overall, the nature and extent of care could be difficult to ascertain when it was not simply the caring role itself that resulted in participants' feelings of being overwhelmed, but additionally, the wider influence of inadequate support – for young carers, their care recipients, and family/whānau/aiga – and the pressures of school, university, and adolescence/young adulthood, occurring alongside their caring roles.

Fourth, a surprising finding regarding the difficulty of ascertaining the extent of care was the **unknown numbers of care recipients** that participants were providing support to. 46 percent (n=13) of participants provided care for more than one recipient, with 32 percent (n=9) caring for two individuals, 11 percent (n=3) supporting three individuals, and one young carer (4%) supporting four care recipients. Nevertheless, the extent of their roles was often only discovered towards the middle of their interviews, by which time participants had explored diverse avenues of their care provision. At the start of their interview, many young carers thought that they supported just one care recipient. For instance, in Kelly's narrative, following her initial discussion of supporting her elderly grandfather, she revealed a significant caring role for her mother with bipolar, and subsequently for her baby brother. However, it was not until I pointed out the subsequent caring roles for her mother and brother that Kelly realised,

> Oh! (sounds surprised). Yeah, I guess I never really thought about that. Yeah, I did sort of look after my mum, but … I didn't find out about her mental health issues until I was 11, and I left home about a year and a half after finding out. But I did look after her prior to knowing; it's just that I didn't know what it was essentially that was going on for her … And actually, I bottle fed my brother, I changed his nappies … bath him, shower him, you know, those sorts of things (Former, 23, Māori).

Simply extracting Kelly's initial assertion of care would have resulted in a misrepresentation of the extent of her roles, as the support of her mother and brother would not have been identified. This finding was not unique to Kelly. A further five young carers elaborated on their roles to the point that additional care recipients were identified. For instance, while current young carer Phoebe (16, Māori/Pākehā) initially discussed only her caring role for her nana who had cancer and arthritis, as her interview progressed and she described moving back home to her mother's house, two additional caring roles emerged: One for her mother with bipolar, and one for her brother due to her mother's bipolar. Phoebe said that

> living with mum was different. I didn't like it. On one side, she was a good mum. But then the other side of her wasn't. That was when she was having her bipolar episodes … At that time, I played sort of a mum role to my baby brother. He would always come to me when he wanted hugs or when there was something wrong. My mum was still the practical mum, cooking and stuff for us, but she didn't really know how to do the whole "caring mum" thing, so he looked to me for that comfort.

Four key reasons were apparent for participants' confusion regarding the number of care recipients, being their residence in large two-plus adult households, support of healthy siblings in addition to unwell loved one(s), incidences of perceived undiagnosed mental illness, and care continuing after a care recipient was admitted to formal services. Certainly, young carers' roles could be hidden among the 54 percent (n=15) of cases when they lived in large households, or in homes consisting of two or more adults. This was because care was often shared among several family/whānau/aiga members, or because several family members were transient – reflecting relationship changes and the need to find work – so that young carers picked up additional caregiving roles as needed. For example, while Mele played a key role supporting her grandmother, at one point she described her role as "just helping out" because "my aunty was living with us [and] she did most of the cares" (Former, 24, Tongan, grandmother with dementia/arthritis). This is a pertinent finding as young carers were almost equally as likely to be caring within a three person or less sole-parent/caregiver household (46%, n=13) as they were to live in a home with two or more adults, and four members plus (54%, n=15). In addition, the number of care recipients could be underestimated among the 14 percent (n=4) of participants supporting healthy siblings in addition to their unwell loved one(s). This was because sibling care could be discounted from young carers' roles as their sibling(s) was not unwell. This was evident in both Kelly and Phoebe's examples outlined above, with both girls initially not identifying their additional caregiving roles for their mothers and brothers.

Participants could also underestimate the number of individuals in their care due to the incidence (32%, n=9) of perceived undiagnosed mental illness among their family/whānau/aiga. Claire thought that her mother "must have had a mental illness", but explained, "All I know is that [mum] went to a psych[iatric] hospital when I was six [because] she had a breakdown … and from then on, she would be in bed a lot not feeling well" (Former, 43, Pākehā, mother with mental illness, sister with intellectual disability). Likewise, Leah said "there's been slight mentions of [mum's poor mental health] and I have wondered whether mum has depression or mental illness because she has a very short fuse, and she has very, very good patches and very, very bad patches" (Current, 17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness). In turn, young carers could support these individuals but commonly without the young carer being cognizant of this additional role. Instances of undiagnosed mental illness amongst participants' family/whānau/aiga is not surprising when the NZ Government Inquiry into Mental Health and Addiction (GIMHA, 2018) identified "that 50-80% of New Zealanders will experience mental distress or addiction challenges or both in their lifetime" (p. 28), including the many individuals whose mental distress remains undiagnosed.

Finally, participants could underestimate the number of individuals in their care when young caring continued even after their care recipient was admitted to formal services. As such, some participants underestimated their roles when they acted as a secondary carer to the service staff. For instance, Leah downplayed her role when her brother was hospitalised, stating, "He had really good nurses and so [my role] was just doing little things". She later admitted, however, "Over that period of time, it was just a whole other level of caring for me, with his bodily fluids … [and] always going over in my breaks [between] classes [at school] to make sure he was okay" (Current, 17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness). This is a key finding, as in all instances that care recipients were in residential services, including a hospital, hospice, or mental health facility, the young carers' roles continued. Overall, the number of care recipients being supported by young carers could be hidden due to care being carried out alongside other family/whānau/aiga members or service staff, or when care was being provided to well siblings or individuals with undiagnosed mental illnesses.

Nonfinite loss underlying care.

Nonfinite loss is the final factor making the nature and extent of care hard to ascertain. This section begins by locating participants' nonfinite loss experiences within the existing body of literature. Thereafter, an exploration of the notion of losses being defined in the 'gaps' between 'then' and 'now', and between 'should' and 'reality' will be undertaken (Bruce & Schultz, 2002). Finally, a discussion of two key areas of loss identified by young carers will be presented. I will argue that the discovery of nonfinite loss underlying all young carers' roles is a significant original contribution to our understanding of young caring.

Bruce and Schultz (2002) define nonfinite loss as "enduring loss precipitated by a negative life event or episode that usually retains a physical presence, a psychological presence, or both" (p. 9), such as the diagnosis of a degenerative disease. Nonfinite losses are "not always obvious in onset", for instance when related to "an experience that creates a lack of synchrony with one's peers" (Bruce & Schultz, 2002, p. 9). Some studies highlight the grief or bereavement experienced by young carers following a care recipient's death (Aldridge & Becker, 1993; Clabburn et al., 2019), but existing research does not explicitly refer to young carers' feelings of *nonfinite* loss. Interestingly, key changes that appeared to produce deep feelings of nonfinite loss for participants in this study were also evident in existing literature but were not discussed within a nonfinite loss framework. Consequently, adopting a lens of grief while reading existing literature highlighted consistent references to loss and grief, which were simply not interpreted or highlighted as such by the researchers. For instance, young carers of parents with Huntington's Disease in Kavanaugh, Noh, and Zhang's (2016) study highlighted the "need to protect the parent from emotional distress of thinking about their own illness or the possibility of impending death" (p. 360), with one 18-year-old participant stating, "I don't wanna make her any sadder than she already is" (p. 357). Consequently, this thesis identifies a gap in the existing literature regarding the acknowledgment of nonfinite loss experiences for young carers. By extending the review of literature beyond young caring-specific studies, the concept of nonfinite loss emerged strongly. For example, in my study young carers experienced nonfinite loss due to their awareness of their loved one's sense of loss as a result of their illness or disability, which participants in turn sought to alleviate (discussed later in this section). Thus, this section draws on additional bodies of research, including studies addressing the loss experiences of *adult* caregivers, and of children, youth, and young adults within familial units experiencing disability or illness.

Prior to outlining participants' nonfinite loss experiences, it is important to add context to their conceptualisations of loss. Young carers' losses were rooted in participants' microsystem and mesosystem level past experiences, and were defined in the gap between their and their loved ones' lives as they had been, and their current realities. This gap between then and now reflects the nature of nonfinite losses as embedded in an individual's past experience, which "becomes the baseline from which the individual interprets a sense of loss" (Bruce & Schultz, 2001, p. 45). Nonfinite loss also existed in the gap between what participants conceived that their and their loved ones' lives should have been, and their lives as they were. This gap between should and reality is echoed in Bruce and Schultz's (2001) assertion that "when we grieve, we grieve an ideal – the world that should or could have been" (p. 11). The gap between should and reality is strongly influenced by macrosystem-level societal blueprints (Bronfenbrenner, 1979) of how an individual or life should be, which underly the formulation of an individual's expectations. Certainly, young carers' loss emerging from their own lives or the lives of loved ones diverging from the 'norm', relied on participants' often subconscious conceptions of a normal relationship, childhood, and family, which were influenced by macrosystem ideals. Overall, young carers' nonfinite loss was defined in the gaps between then and now, and should and reality. As the following section reveals, participants' feelings of nonfinite loss emerged through their voices and through their bodies (most often shown when their words were accompanied by tears or other physical manifestations of sadness or loss).

Two key areas of nonfinite loss were outlined by young carers, being the loss of their unwell loved ones, and the loss of their childhoods and sense of family/whānau/aiga. Firstly, many young carers grieved the loss of their loved ones even when they had not passed away. For some, the nature of nonfinite loss was such that their loved one's physical presence endured, while their abilities and personality gradually degenerated (Bruce & Schultz, 2001). Louise commented that after her mother's stroke,

> it was really hard to have a mum but yet not have a mum. So she was my mum, but she wasn't anything like how I remembered, and she couldn't do things that other mums did. I think [caring for mum] was a reminder that things were different then and not how you wanted them (Former, 25, Māori).

Analogously, Terrence explained that, with his mother's encephalitis, and intellectual and physical disability,

> the hardest part [of caregiving] was definitely seeing how much my mum changed … It's weird because my mum is there but it's not my *real* mum at home; I so miss my mum (said in a sincere, hushed voice). I miss her 'cause I know the person she was, her spirit (Adult, 27, Niuean).

Melanie also described the nonfinite loss that she experienced as her friend's schizophrenia worsened, stating that

> Initially I just wanted [him] to get better, [but] as the months went on it dawned on me that [he] was never going to be the person that he was before he became unwell. So [care is] kind of mixed up with a sense of loss … I remember one moment when I looked at him and he didn't even look like [him]. His *eyes* were just like it wasn't somebody I knew anymore. Even our friendship had completely changed because I think when you take on that caring role, everything becomes quite different (Former, 31, Pākehā).

As shown in Melanie's quote, young carers also grieved the loss of the relationships that they previously or should have had with their care recipient(s). Fleur addressed the loss of the relationship that she once had with her mother, who had multiple sclerosis;

> there's another aspect to multiple sclerosis that isn't just the physical. It affects people psychologically, and it affected [mum's] memory, it affected her recall of events, it affected her mood. And being young I didn't really have the maturity to view what was happening for her with that level of detachment or clarity, and so I would get quite caught up emotionally with the fact that she seemed to twist things around to get what she needed, and I think that really hurt our relationship … I mean, it took a huge toll on our relationship (small, sad smile) (Adult, 39, Pākehā).

As such, participants were "grieving the daily losses" that transpired alongside their loved ones' advancing disabilities or illnesses (Doka, 2000, p. 103). As a consequence, Mary conceived of her care as "slowly saying goodbye" to her terminally ill mother;

> When you see your mum progressively become very ill (begins crying), and not be able to do certain things like drive or get into the car properly, and she needs a walking stick, it's like, "where's my mum?" Like, "come on, let's go out like we used to". And when she can't do those things anymore it's really hard … I cried a lot for her (Former, 27, Pākehā).

Young carers' own loss appeared to be intensified by their cognisance of their care recipient's losses, including their loved one's loss of identity, dignity, autonomy, and quality of life. For example, Anna addressed her boyfriend's father's loss of identity, dignity, and autonomy due to his substance misuse and cancer, as she said, through tears,

> no matter how hard I was finding it, he was finding it hard himself … I had a sense that I was dealing with someone who was incredibly fearful, and everything he was doing was just out of fear. He was completely out of control for the first time in his life, so I think that would be the script that I would tell myself to justify why he was being the way he was (Former, 27, Pākehā).

Similarly, Greg shared a very difficult memory of his father's loss of identity, dignity, autonomy, and quality of life, recalling a time when

> he lost his bowels in the foyer of the hospital, and just seeing how embarrassing that was for him to have gone from being a strong man – marathon runner, army guy – to being so vulnerable that he can't even control his bowels in the hospital … I was so happy to be able to be there at his time of need and help (nostrils flare, eyes teary) … him sitting there and being happy to see me (Former, 28, Pākehā, father with cancer/heart attack).

Experiences of nonfinite loss of loved ones are not unique to this study, with Svanberg, Stott, and Spector (2010) highlighting children's "continuous experience of loss" (p. 743) when a family member has early onset dementia. Consequently, the nature and extent of young carers' roles were hard to define when care tasks became a constant reminder of both the changes to their care recipients, and their loved ones' experiences of loss.

Secondly, most participants also described "missing out" on their childhoods, adolescence, and/or young adulthood, due to their caregiving roles. Wyn said

> I felt the responsibility that I had for my mum and that I needed to get home after school and not go to friends' houses or anything like that. I didn't have a normal playtime and it wasn't until I was an adult before I realised that I actually had no childhood from the age of nine onwards (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness).

Likewise, Rachel highlighted the loss of her adolescence, as she explained that caring for her brother with muscular dystrophy while at university

> was really hard … having that constant commitment and that knowledge that really my brother was completely dependent on me for all sorts of things … When you're 18 you're still finding your own way to some extent and learning how the world works … and I had that not only for myself, but I had it for him … [I was] deferring my own needs because I just couldn't drop everything and do what I wanted on a whim as a student (Former, 59, Pākehā).

While participants' sentiments echo the 'missed childhoods' theme highlighted in existing young caring research (Aldridge & Becker, 1993; Thomas et al., 2003), the difference in my study is the explicit connection with nonfinite loss. This was described well by Anna who cried as she explained, "you grieve yourself … as a young person" (Former, 27, Pākehā, boyfriend's father with substance misuse/cancer). As such, participants' roles also came to represent the gaps between their lives as they were or should be for an individual of their age. Lucy described how care came to represent "missing out on so many experiences that I was like, really yearning for [as] a child" (Former, 25, Pākehā, mother with cancer). The gap between a normal childhood, adolescence, or young adulthood and young carers' realities was often exacerbated when participants were confronted with their similarly-aged peers' opportunities to be "carefree" (Atalanta). For instance, Greg explained that while university is

> a time where you kind of escape from your parents and you're spreading your wings and going out into the big wide world, for me it wasn't … I suppose I didn't live as much of a hedonistic life as maybe my fellow peers did, you know? Drinking huge amounts and stuff. [And] I definitely didn't have the same socialising and friend relationships as others did (Former, 28, Pākehā, father with cancer/heart attack).

Greg and his peers' sentiments demonstrate how young carers' nonfinite loss could be exacerbated when their caregiving roles undermined their right, under Article 32 of The United Nations Convention on the Rights of the Child (UNCROC) (discussed in Chapter Two), to "rest and leisure, [and] to engage in play and recreational activities" (Article 32: United Nations Human Rights Office of the High Commissioner, 2020, p. 9).

Many young carers additionally described the loss of a sense of family/whānau/aiga. When participants were caring alongside a parent, friend, or partner, they highlighted the loss of their relationship as it once was. For instance, Anna said that co-caring with her boyfriend for his father "was very, very hard, because your priority is not necessarily each other anymore" (Former, 27, Pākehā, substance misuse/cancer). Young carers also experienced loss in the gaps caused by a lack of willing, able, and available family members, due to familial changes following a member's diagnosis. Tilly explained,

> I was quite jealous that [my siblings] could go off and do their own thing and they expected me – because I was her twin – to help out … And I think I got quite resentful of my mum, because I think she thought I should help out a lot too. But she was probably doing a lot too (Adult, 44, Pākehā, twin sister with tetraplegia).

Likewise, Chloe said that while she understood her older brother's decision, there was "a lot of resentment" when

> in high school, my brother moved out to live with my dad 'cause he wasn't coping. 'Cause at that stage he was doing the bulk of the transferring, and as a teenage boy he had had a bit of enough of being urinated on, and he was beginning to really really resent mum. I think that he punched the wall and that was the end I think of that … But the thing was [that then] myself or my sister [were] trying to transfer her, and it was a two-person job for us – 'cause at that stage we were 12 and 13 (Adult, 25, Pākehā, mother with multiple sclerosis).

In other cases, the absence or loss of a tight-knit and supportive family added deeper feelings of loss, sadness, and anger to young carers' roles, especially when individuals perceived as able to provide care declined the role. Amelia explained that caring for her elderly grandmother

> was sad [because] my mother was there, [but] she said she can't change her nappy … And I ask her, "why can't you? I'm the granddaughter, but that's your mother". She said she can't, she'll vomit (eyes roll). But I don't know how can people feel like that? But I didn't have that luxury (Adult, 36, Tongan).

Although the absence of family support for young carers is highlighted by numerous researchers (e.g., Moore et al., 2009), this absence of help is not linked to nonfinite loss for young people providing care. Overall, participants' nonfinite losses of their loved ones, childhoods and adolescence, and sense of family/whānau/aiga meant that young caring was defined not simply by the type or amount of care given, but by the losses underlying such care.

Participants' nonfinite loss resulted in their role conceptions extending beyond simply caring for their loved ones, to actions aimed at alleviating their own, their care recipients', and their family/whānau/aiga's sense of loss. In some cases, care was aimed at keeping the family as close as possible to what it was or should be. For example, Anna said that she "tried to keep some semblance of normalcy" while caring for her boyfriend's father;

> I'd always take him to [my boyfriend's] cricket games. I would have a picnic lunch all organised, and borrowed my parents' station wagon to be able to put his wheelchair into the car … And I couldn't stand cricket, I didn't understand it. I'd rather watch paint dry! [But] I'm really thankful the times that I guess I was able to facilitate the relationship between them (begins crying) … At least we had those moments, those experiences, and I know that it bought him so much joy to be watching cricket and to be seeing [his son]. And I just know how much it meant to [my partner] (Former, 27, Pākehā, substance misuse/cancer).

In other cases, care was aimed at supporting their care recipients to sustain their autonomy as much as possible, and facilitating the continuation of their prior roles within the family/whānau/aiga. Lucy said, "It was almost as if I gave [mum] the support to be able to support my brother", thus "keeping her role" as his mother (Former, 25, Pākehā, mother with cancer). In turn, it was apparent that participants considered that effective care would maintain the family/whānau/aiga and their loved ones as they were or should be. Care was thus commonly deemed to only be successfully provided by those who intimately knew the family and unwell individual before the onset or progression of disability or illness. This discovery not only offers new insights into the nature and extent of participants' roles, but also of the circumstances creating and maintaining young caregiving (discussed in Chapter Six). Furthermore, this finding highlights a key means for young carers' insights to inform care and disability policies and services, through a reconsideration of service provision to empower people with disabilities and illnesses to maintain their identity and roles within the family/whānau/aiga unit.

In this first findings and discussions chapter, I argued that young carers undertook holistic care, that is well represented by a Māori model of health and wellbeing, and which addressed four key elements of their loved one's wellbeing. In addition, I highlighted the difficulty of ascertaining the true nature and extent of participants’ care, due to the hidden holisticity of young carers’ tasks, and the novel finding of invisible nonfinite loss underscoring their enactment of support. In the following chapter, an exploration of participants’ conceptualisations of their young carer *identities* will be presented.

CHAPTER FIVE

Identity: Seeing Ourselves as Young Carers

This chapter explores how young carers interpret and make sense of their young caring identities. It begins with the argument that what it currently means to be a young carer in Aotearoa/NZ is to lack a shared young caring identity. The absence of a collective identity results in a widespread lack of awareness and understanding of young carers, and leaves them unable to self-identify even when they have the desire to do so. Based on the results of the interviews, I contend that the existing definition of young caring employed internationally and in NZ – and in my research – is in tension with participants' own understandings of their roles. Specifically, each of the seven main elements underlying the prevailing definition will be contrasted with the findings of the present study to highlight key discrepancies. The chapter concludes with the argument that until NZ's definition of young caring encompasses young carers' experiences, then their need for self-identification and support will continue to be unmet, and young carers will remain an invisible population. The chapter begins with Melanie's story, which touches on many of the tensions between participants' experiences and the definition of young caring, embedded within her whole caring experience.

Melanie's Story

Melanie is a former young carer who was supporting her friend with psychosis and paranoid schizophrenia. She lived in Auckland with her mother and step-father, and two younger sisters. Melanie is Pākehā, cared from 19-21, and was 31 when she took part in her interview.

Becoming a full-time carer. I was 19 and I had just started university [when] my friend became unwell. We had known each other for several years and we had actually been in a relationship [and] remained really good friends. But [his] behaviour deteriorated, and he became a little bit chaotic. I was aware that something was going on, but I wasn't quite sure what. It was like some kind of switch went off in his head.

I recall when it really hit me what was happening. It was after his 20th birthday. I was at uni and he rang me, and he sounded quite panicked. He thought people were saying really bad things about him, so he had gone to the police to say that he hadn't done anything. I knew that things were really, really wrong.

From that point, I became a full [time] live-in carer in my parents' house. The reason we ended up at my parents' house was because he was living with his mum, [but] she wasn't quite sure how to deal with it. Suddenly things were getting quite out of [control] and I think there was a level of denial there (hands pushing away from herself). No one else had time because they were working and they have mortgages to pay, and [he] needed 24-hour full-time [care]. So as a young person that didn't really have many responsibilities, I was the one that was able to pick that role up. At that point in time, I could put uni on hold.

Keeping him calm. In normal circumstances, he would have had to go to hospital because of the medication that they were trying. But because I put forward that I was going to be with him 24 hours a day, seven days a week, and that we were going to live in my parents' house, and that my parents were both registered psychiatric nurses, we were allowed to stay at home. I knew the struggles of facilities and the staffing and the resources so I knew that the hospital wouldn't be a therapeutic place where he would get better.

I thought if we could just keep it as calm as possible for him and surround [him with] people that he trusted, he'd be okay. I knew at any point if he showed signs of wanting to hurt himself or other people, then he would have had to go to hospital – that was made very clear. [But] even though he was very scared and hearing all these horrible voices[36], he would never lash out violently (shakes head).

My main thing with care was to keep him safe [and] as calm as possible. It was basically just being with him constantly. He was so paranoid [that] he was very fearful when he was on his own. Like, he couldn't actually go to the toilet unless someone was there because he was so anxious. His personal hygiene wasn't something that he was really that aware of, and in those really intense times I checked to see [his bottom] was all clean. I think personally that's a low point when you are showering and doing those toileting things, but then you kind of get over that and you're like, "Actually, it's just a really practical thing".

He thought he could hear the neighbours talking about him, and helicopters flying over searching for [him]. Those moments in his illness were so bizarre (head shaking and face screwed up tightly). I became really aware of anything that would trigger him getting upset. Like there might have been the smell of the toast burning, but then it would be, "The house is on fire" [and] he'd become quite agitated. It got to the point where I couldn't show any emotion because that would upset him. I [was] crying once, and he asked me why I was crying because he didn't understand the situation anymore.

I remember the sense of *relief* (sighs) I had at night, because as soon as he took his night medication, it would knock him out for that period of time. I slept when he slept because I was so tired. I think it was just emotional exhaustion because it was this constant talking to him and keeping the situation calm. But I knew even in his real deep sleep he was still having quite disturbed dreams, which he would talk about in the morning.

The weeks [were] structured around appointments. There was a lot of preparing [him] for appointments, and paper work [to] get him onto a sickness benefit and a lot of those things. In the really acute phase we had the mental health community team visiting twice a day. They just talked to him and monitored the situation. I think they were aware that I was young to be doing this, but those things were always accompanied with one of my parents. I lost all shame with the situation, in terms of everything just being open: nothing was private anymore.

Dealing with change. Initially I just wanted [him] to get better, [but] as the months went on it dawned on me that [he] was never going to be the person that he was before he became unwell. So

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[36] Referring to auditory hallucinations.

[care is] kind of mixed up with a sense of loss. It was quite a major thing to see somebody that I had known who was well, to then be getting to the point where he couldn't even really communicate. There were some days where he talked in these little riddles and rhymes. I remember one moment when I looked at him and he didn't even look like [him]. His *eyes* were just like it wasn't somebody I knew anymore. Even our friendship had completely changed because I think when you take on that caring role, everything becomes quite different.

It was a big thing for my parents to take on as well, and then it was a big thing for my mum to see her daughter go through. But for my parents, as nurses, his behaviour was nothing [new], like they had seen it all before. I was grateful for their knowledge. And my mum always approached these things with a sense of humour. So even in those really bleak moments, my mum made it light hearted.

It was kind of a mass exit of his friends at the time that he was unwell. I think that related to the nature of [his] illness: another illness that was more socially acceptable would have been completely different. [He] had one friend that braved a visit. He brought his chess set to play, and it was so lovely of him to try and play chess.

And I did have this sense with my friends [that] our lives were so different at that point in time. The things that they were grappling with were not trivial, but I found I [didn't have] sympathy with the issues in their life (looks sad). It's funny because in a way, I feel I'm more empathetic going through that experience, but in a way I'm not.

I lost a lot of weight. Almost 20kg. I [was] struggling to eat breakfast, and I remember at times feeling really shaky. I was very much on edge, [thinking] "What will today bring?" "Will this be the day that [he] has to go to hospital?"

It took a chunk out of my degree. I dropped most of my [uni] papers, but my mum wanted me to keep one paper as time out for me. I remember going to the lectures and it all being a bit of a haze. I wasn't actually being a student anymore, and my life was kind of on its head, really.

Life after care. I remember my mum and stepdad telling me to pull back a bit, because I'd become quite consumed in that caring role. I could see that [he] was getting better and I wanted him to go home, but there was also letting go of that role after it had been such an intense thing. It was a gradual transition [though], spending weekends at his mum's. I think that time away gave his mum time to come to terms with everything. I know that he's well and he's safe (face looks peaceful).

After I finished caring for [him], I just wanted to get on with my own life. [Caring] was something that was quite profound and had shaped me, but [I didn't] really want to acknowledge it. It took a lot of recovery time because I was completely emptied (hands wash from the top of her head all the way down to her legs), and for a while I was a little bit bewildered by the world, really. It made me have a sense that anything could happen – you just don't know. [But] I finished my degree, and I went over to the UK and had a working holiday.

Reflecting back. I had a choice [to care]. I felt it was the right thing to do, and I don't regret what I did at all. And it was an experience that set me up for so many things, not just in terms of what I do as a job, [but] who I am as a person as well. I went from being quite a self-conscious teenager, to then dealing with psychosis and schizophrenia, and that was a big learning curve for me. I still have this quiet sense of achievement. It is kind of the benchmark, like hell, if I can get through that, then things don't seem that bad. [And] it defined for me at that really young age what love was. It wasn't a sexual thing. It was friendship and caring and it was this ultimate kind of giving (hand on heart).

I know that [he] can't really remember that period, and I wouldn't really want him to. For me, it's more his mum acknowledging what I've done (big smile). She is very grateful for our care, and she has a lot of respect for me and my parents.

I'm glad I'm doing this [interview] now [that] I've got 10 years space from it. Because at the time, even a few years ago, I probably would have been very emotional because it was such a big thing to go through. It's an experience I don't really share or talk about much. I felt quite isolated [and] like people my age didn't really do that. Before I saw your research, I hadn't ever really considered myself to be a young carer. That was a little bit of a revelation to me. For the first time, I had a label to give that experience [and] it was a good feeling.

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No Shared NZ Young Carer Identity

In NZ there appears to be no awareness or shared understanding of the term *young carer*. While in the UK and Australia the label *young carer* is commonplace and widely understood (Becker & Sempik, 2019; Moore & McArthur, 2007). Conversely, reflecting the consensus among the small body of NZ studies (e.g., Hanna & Chisnell, 2019), young caregiving was a largely unknown term among participants. All but three young carers were unfamiliar with the term during their time caregiving, with most only becoming aware that they were a young carer after watching my recruitment video. Claire said, "It wasn't until I saw your promo [video] that I thought, 'Oh, I might be one of them!'" (looks surprised) (Former, 43, Pākehā, mother with mental illness, sister with intellectual disability). The invisibility of young caring in NZ was so great that even former young carers whose roles concluded many years prior to their interviews remained in the dark about young caring. Melanie said, "Before I saw your research, I hadn't ever really considered myself to be a young carer. That was a little bit of a revelation to me … [and] it was a good feeling". For the four participants who had heard the term young carer before their involvement in the study, three described "discovering" the term during their time caring, and one after the conclusion of his role. Louise said

> I only found out about young carers when I was doing a nursing assignment [at university] … 'cause I think I'd Googled something about children looking after sick family members and it came up with [young caring]. I was like, "*what?*" … It was quite cool (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke).

Amelia and Grace said that they were identified as young carers when their care recipient or the primary adult carer discovered the term via NZ carer organisations. Amelia explained that when she was 19:

> auntie was listening [to] a TOA Pacific[37] programme on the Tongan radio station and heard about [young caring] … and then from there I kind of feel like I'm almost an important person now, because I've been recognised by doing what I do … Whereas before I don't even know or realise, I just go with the flow … I [was] really like happy that I come to know that there is other young carers out there, not just myself, because at that time I was just concentrating on grandma and auntie, thinking that I'm the only one doing like that (Adult, 36, Tongan, elderly grandmother, aunty with paraplegia).

Dan's prior awareness, on the other hand, came from living in the UK as an adult. He said,

> I didn't know that I was a young carer, like yourself, until I was an adult … In fact, [it was] only 15 years ago when I found out about young carers [when] I heard something on the [UK] radio. I never saw myself as being in that role, but then I thought about it, and I thought, "well that's what I did", so [I got] that context (Former, 53, Pākehā, mother with paranoid schizophrenia).

As reflected in their statements, these participants felt empowered when they became aware of and identified with the term. The same positive experience of identification was also expressed by many young carers who self-identified through my recruitment and their participation in my study. For instance, Terrence said "I didn't even know [young caring] existed … I'm so pleased to do this [interview] 'cause it feels good" (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability), and Phoebe stated, "It's nice to know there are other people out there going through the same thing as me" (Current, 16, Māori/Pākehā, mother with bipolar, brother due to mother's bipolar, grandmother with cancer/arthritis). Participants conceived that the benefit of having a commonly understood young carer label, even after their role had ended, was the ability to add meaning to their experiences, which Kahurangi described as being "really quite therapeutic" (Adult, 51, Māori, father and mother with cancer, brother and sister with schizophrenia). Participants also spoke about the benefits that identifying would have had at the time of providing care, in terms of their capacity to inform people of their roles. Melanie explained, "For the first time, I had a label to … articulate that experience in a few words, without having to go through the details of it". Furthermore, participants felt that identifying during care could have helped them to meet others in similar situations to their own, and receive support to manage caregiving alongside their childhood/adolescence/young adulthood. Lucy said

> I felt *so* alone; I felt like no one had been through what I'd been through. I wish that there was some kind of support groups … I would have like *died* for that (eyes very wide), you know, to just have someone in my situation, to be able to say, "oh my God, it's so lame that I have to like give my mum this injection". But I had no one (Former, 25, Pākehā, mother with cancer).

Likewise, Mary stated,

> I really felt like I was on my own … Basically [it] would have been helpful to know other people in my situation. Even just talking to you right now about social anxiety, like you go, "oh wow, you too?" (hand reaches out towards me). It doesn't make you feel better that that other

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[37] A not-for-profit organisation that aims to address the wellbeing of 'Treasured Older Adults' (TOA), Aiga Carers, and Pacific families (www.toapacific.org.nz).

> person's gone through that, but at least they understand what you're going through, and that it's not you being a weirdo (Former, 27, Pākehā, mother with cancer, father with substance misuse/acquired brain injury).

International research also reflects positive outcomes of caregiver awareness at the time of providing care. Moore and McArthur (2007) identified that young carers "saw the great value of receiving specific interventions for themselves, such as camps, support groups and mentoring" (p. 567). Likewise, many of the 12 Australian young carers who attended a resilience-building camp said that in addition to respite, "they gained new skills and perspectives to cope with difficult situations" (Cunningham et al., 2017, p. 17). As such, while participants appreciated their newfound awareness of young caring, often gained via their participation in my research, they highlighted the importance of being identified at the time of providing care for support, understanding, and connection.

Interestingly, identification was not understood as an entirely positive experience among the three participants who were made aware of their young caregiving identity at the time of providing care. Louise, Amelia, and Grace expressed their frustrations at the lack of services for and awareness of young caregiving, which meant that their identification "didn't actually mean anything in the end" (Grace). Grace stated that it

> would have been really cool if I'd met other young carers that were going through the same thing as me, and we could just be like on a mutual understanding of each other's lives – that would be awesome … [But] like all the people I met were mum and dad, brother and sister; that "perfect" ("" with fingers) little family setting (Current, 21, Pākehā, sister with physical and intellectual disability).

Likewise, Louise said that even though she was aware of her young caring identity, she felt

> that no one else has to do this … [so] I never really talked about it with anyone … I think it would have been really nice to [talk], and normalise the abnormal: Like I'm not the only one doing that.

So, whilst in the UK and Australia identification was understood as a largely positive experience resulting in support and connection, in NZ, even when participants identified as young carers during their time caregiving, a dearth of awareness and assistance maintained their feelings of isolation.

Additionally, being made aware of the term did not result in participants' adoption of a caregiving identity. A pattern was evident whereby participants were hesitant to identify themselves as young carers, even though in all cases their experiences placed them firmly within the parameters of the young caring definition. Participants' hesitation to identify can be explained by their lack of understanding of young caregiving, which is required to self-identify, with many participants' only interaction with the term coming from my recruitment video. A lack of time to develop their understanding of young caring was shown when participants contrasted their own experiences with their largely newfound understandings of the term, teasing out the similarities and variances in order to establish their fit as a young carer. For example, early in her interview, Anna said that she had not "actually really thought about [young caring] that much … It doesn't actually seem real if that makes sense? … It's so complex". Later, Anna grappled with her young carer identity, stating, "like I don't really have a concise answer for [what I did] because there are so many things going on … I don't know (pauses) sorry … Is it [young caring]?" (Former, 27, Pākehā, boyfriend's father with substance misuse/cancer). Several authors highlighted the importance of not assuming that simply identifying someone as a young carer will result in their adoption of a caregiver identity and understanding of their role (Aldridge & Becker, 2003; Robison et al., 2017). Kennan et al. (2012) asserted that a lack of identification is commonplace when a child conceives that their role "does not merit the significance associated with the label 'young carer'" (p. 276). As such, participants' awareness of young caring in isolation of a deeper understanding of the term did not necessarily lead to their identification.

Over and above a lack of understanding of the term itself, participants' hesitation to identify appeared to be influenced by their perceptions that their lived experiences were divergent to the definition of 'young caring'. So, whilst it might be understood that participation in the study inferred participants' identifying as young carers, in fact it appeared to be their connection to my story, rather than their identification as a young carer, that led to their participation. Specifically, participants described relating to the emotions underlying my experiences in adolescence shared via the video, which closely aligned with their own. Mary explained her reaction to my posts on Facebook:

> A month ago … I saw your post about young carers … and I kind of looked at it and I was like, "Oh, that's not me". And then when you [posted the video] I was like, "*oh!*". I actually never considered myself like what you said in your video: Like you didn't even realise [you're a carer] at the time and you think you're the only person in the world that's going through this.

Also speaking about her response to my research video posted on Facebook, Ngākau said,

> I really got triggered from when you were talking about caring … I was thinking, "actually, that was my experience", but I hadn't really made that connection because it just seemed like an ordinary part of my life … It makes me realise just how unaware I was of the world (hand waving around face). Like there was no broader context for me (Former, 49, Māori, brother and sister due to parental employment and mother's undiagnosed mental illness).

Participants relating to the described emotions and experiences of caregiving, rather than to the term and accompanying definition, is evident wherein no young carers responded to my traditional poster recruitment method. Instead, the four current and 24 former young carers were recruited via written and oral (n=3) and video (n=25) storytelling, in which I shared my young caring experience and call for participants. The lack of identification among NZ young carers is highlighted throughout existing NZ research as, akin to the present study, researchers struggled to recruit participants via traditional or internationally-used methods (Gaffney, 2007; Loose, 2004; McDonald, 2008). Overall, the findings suggest that NZ young carers were not able to self-identify when their experiences and understandings did not align with the definition of young caring, but did self-identify with the emotions associated with being a young carer.

Definitional Discrepancies: Participants' Lack of Identification With the Term Young Carer

In this section I examine the tensions between NZ young carers' experiences of providing care, and the key parameters included in the definition of young caring guiding NZ research, policy, and practice. In this section, focus is placed on the experiences of Māori and Pacific young carers, whose caregiving conceptualisations – espousing empowerment, enfranchisement, and collectivism –

were the most at odds with current understandings of young caregiving. This examination will suggest areas requiring amelioration in order to enfranchise NZ young carers' self-identification capacities, and thus meet their desires for connection and understanding.

Throughout the section, assumptions underlying the definition of young caregiving will be teased out and juxtaposed against participants' own conceptualizations of their identities, roles, and familial structures. Goffman's (2014) concept of "virtual" versus "actual" social identities will be employed, with "virtual social identities" denoting "the character we impute to the individual" via assumptions, and "actual social identities" being "the category and attributes" an individual "could in fact be proved to possess" (p 256). These key concepts will facilitate an examination of participants' understandings of their own, their care recipients', and their family/whānau/aiga's identities, contrasted against both the definition and underlying assumptions inherent in the term young caregiving. Finally, the 'costs' associated with children, youth, and young adults identifying as young carers will be integrated throughout the section, in terms of the personal, relational, familial, and cultural implications of adopting a young carer identity (Bolas et al., 2007; Hanna & Chisnell, 2019).

The cultural specificity of the prevailing definition of young caregiving in UK and Australian young carers' experiences could underlie participants' lack of relation to the term. Looking to the roots of young caring, then we see that the term was borne out of the experiences of UK children, youth, and young adults, gathered via the work of Professors Saul Becker and Jo Aldridge, and colleagues, in the 1990s (Aldridge & Becker, 1993; Dearden & Becker, 1995). Early on, young carers were defined as "children who take on significant, substantial or regular caring tasks and responsibilities" for unwell family members (Becker et al., 2000, p. 13). Alterations have been made over time, in light of subsequent research findings largely emerging from the UK and Australia – and more recently Canada, the USA, Europe, and Sub-Saharan Africa – resulting in differing forms of the original definition being used across international studies. Nevertheless, the prevailing definition espoused in the bulk of recent research has its roots firmly in Becker, Aldridge, and colleagues' original contributions, with the parameters of young caring being the significant and ongoing nature of children's caring roles for a family member who is experiencing a disability or illness (e.g., Leu et al., 2018). Applying this definition in existing international studies has resulted in high-quality research with rich findings, and furthermore, has enabled a shared general understanding of young caring that has facilitated connections between researchers and organisations from diverse countries. The uniqueness of the NZ cultural landscape, however, and specifically of the Māori and Pacific NZ populations, means that unquestioningly adopting any young caring definition in Aotearoa/NZ may unintentionally serve to exclude some children, youth, and young adults. As such, the internationally established parameters of young caring may underlie NZ young carers, and particularly Māori and Pacific participants' lack of identification with the term.

Despite not appearing to encompass the realities of NZ young carers, however, the internationally established parameters of young caring are echoed throughout all existing NZ studies, including the present research. Therefore, a key reason underlying participants' difficulties adopting a young caring identity, even when made aware of the term – and a possible factor contributing to the difficulty of accessing NZ young carers for studies – could be the mismatch between their own understandings of their roles, and the definition of young caring used. A deep examination of the data revealed that even when participants recognised that their roles placed them firmly within the parameters of young caring, they could choose not to identify as such as the definition was not reflective of their and their family/whānau/aiga's conceptualisations of the role. In particular, interviews identified that participants' understandings of family/whānau/aiga, childhood, parenting, disability, and care, which shaped their roles, could be at odds with dominant societal assumptions of such concepts inherent in the term young carer. Overall, findings suggest that simply adopting the prevailing definition of young caring in NZ could further entrench the hiddenness of young caring roles – especially for Māori and Pacific young carers – who might not identify as such according to the current parameters.

In order to create an Aotearoa/NZ conceptualisation of young caregiving reflective of children, youth, and young adults' lived experiences, it is important to explore the variance between participants' own conceptualisations of their roles and the definition of young caregiving espoused throughout existing literature, policy, services, and grassroots organisations. The following argument is organised according to the key elements of the existing definition, being: Young carers are (1) *children and youth* aged up to 25 years (2) *who provide* (3) *significant* (4) *ongoing* (5) *care* for a (6) *family member* (7) experiencing a *disability, illness, mental illness, substance misuse*, or who is elderly. Each element acts as a layer that, when several are taken together, could become significant deterrents to participants identifying as young carers.

***Children and youth*: reconceptualising childhoods.**

First, some participants felt that taking on a young caring identity could shift the focus away from their continued integral identity as a child, youth, or young adult, and focus their identity instead as the carer *of*. As a consequence, participants understood that their continued capacity as a child or adolescent to be cared *for* might also be forgotten. For example, Dan said that taking on a young carer identity presents "a strange dichotomy", because "I was protecting … that mother-child bond … You don't want that bond to be broken [because] … I wanted to be a normal kid". As evidenced in Dan's quote, participants perceived an either-or scenario, whereby taking on a young caring identity was understood to come at the expense of participants' foundational or core identities, as children, sons or daughters, siblings, grandchildren, nieces or nephews, or partners. Young carers understood this as a loss, in terms of the personal cost of losing how they saw themselves "as a kid … I didn't see myself in a caring role even when I was a carer" (Dan). A theme throughout caregiving literature is the loss of identity experienced by individuals who take on an informal caregiving role, for instance, when a husband or wife undertakes care for their partner (e.g., Appleton, Robertson, Mitchell, & Lesley, 2018). However, Dwyer and Buckle (2009) challenged the loss of one identity for another, stating that such "binary alternatives" of "insider" and "outsider" "unduly narrow the range of understanding and experience" (p. 60). The researchers instead advocated for greater recognition of the "space between" (Dwyer & Buckle, 2009, p. 60). In the case of young caring, the space between denotes the fluidity of their identities as both children/youth/young adults, and as caregivers, removing any notion of reneging one identity for membership within another, and avoiding the narrowing of their experiences solely to a caring identity. As such, recognition of the space between, allowing participants' co-habitation of both child/youth/young adult and young carer identities, could alleviate their concern for the loss of their foundational identity.

The notion of nonfinite loss outlined in the previous chapter also appeared to play a key role in participants' hesitancy to adopt a young caregiving identity. Many participants' descriptions of loss surrounding their childhood, adolescence, and young adulthood appeared to underlie their resistance to being called a young carer. Adopting a young carer identity could reinforce participants' feelings that they "had no childhood" (Wyn) or were "missing out on" (Lucy) a normal childhood, adolescence, and/or young adulthood. Lucy said that she was "in a world of adults but I was essentially still a child", and was "really yearning" to maintain her childhood experiences. Likewise, Wyn explained, "somehow the child in me had vanished and an adult had come into my body and I didn't want [that] (shakes head)" (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness). The loss of childhood/adolescent/young adult opportunities was particularly pertinent at peak times of care, when participants often experienced familial chaos that heightened their need to maintain a sense of "normality" (Anna, Dan). Such normality extended to protecting their foundational identity and role as the child/youth/young adult in the household, in order to "keep things just like … they were" (Terrence). In essence, participants feared that adopting a young caring identity meant letting go of their traditional childhood, adolescent, or young adult identities, thus losing the sense of normalcy that mediated their feelings of loss.

Maintaining separation between their carer and child, adolescent, or young adult identity was seen as imperative by participants, in order to uphold their status in both worlds. Participants explained "stepping into" and "out of" their carer and child identities, with the home being described as the "threshold [between] those two worlds" (Dan). Dan explained,

> you'd be out shopping and doing your things, [but] you know as soon as you walk to the front door, then that was like a threshold: you'd enter into her world then, having to have that relationship with my mother, which I knew was wrong, but which I was protecting.

In one sense, participants separated their identities in order to protect their normal childhood, adolescent, or young adult experiences. They described setting aside their caring personas at times so that they could invest in feeling "like a normal family to some point" (Louise), or so that they could do what a university student "normally would have done" (Lola). Existing studies also identify young carers' separation of childhood/adolescence/young adulthood and young caring, in order to gain a sense of normalcy (Leu et al., 2018; Watt et al., 2017). For example, McDougall, O'Connor, and Howell's (2018) qualitative study identified that some of the 13 Australian young carers "do not identify" as such because "the label inferred that the role of a carer was atypical and they made an active effort to maintain a 'normal' family dynamic" (p. 576). Thus, young carers' conscious separation between their caring and childhood/adolescent/young adult worlds could have fed into their hesitancy to explicitly adopt a young carer identity.

On the other hand, young carers were acutely aware that what was considered normal changed across different microsystem settings and groups. So, whilst at home providing care may have been a normal occurrence, that same role could be deemed as different at school. Lucy explained that at school she hid her role, “like I didn’t tell anyone … I wouldn’t expect them to have known what to do”. She explained that her peers already “thought I was a bit weird … so I started just telling little lies that turned into big lies. And I could tell when people knew I was lying but I just kept lying (laughs)”. As shown in Lucy’s quote, accompanying each identity were corresponding norms that outlined how to act within a given setting. Participants spoke to parking their young caring identity and “playing a role” (Anna) or “acting” (Dan) amongst their peers in order to fit in. Dan explained “I was very good at covering up at school … I was acting … telling secrets and lies at school to hide what was going on … I would have no close school friends and nobody would come into the house”. Children/youth/young adults hiding their young caring roles in order to blend in is found throughout the research, with Bolas et al. (2007) asserting that young carers’ roles often remain hidden due to fear of judgement from their peers. As such, young carers’ concealment of their caring identities when their roles may have been considered different could once again have underscored participants’ resistance to identifying as a young carer.

All young carers identified a time when their two worlds collided, which caused the young carers worry or distress. Despite working hard to compartmentalise their identities and enact the required norms, all young carers experienced crossover between their public and private lives. At such times, participants struggled to maintain an air of normalcy as their caregiving or home-life reality was exposed. Wyn said that her mother

> came to one school sports day with a neighbour, but she was very ill and she shouldn’t have been there. And it was embarrassing for me to have her there, which is an awful thing to say, but it is the truth … She had facial hair, and because I didn’t know what to do about facial hair (head resting in hands), and she was beyond doing anything about facial hair, and dad didn’t do anything about facial hair: It was just very difficult.

Dan also addressed his caregiving role and home-life being exposed, as he explained that because schizophrenia is “heavily stigmatised … you don’t want to talk about it, so I was continually protecting my mother [so] she’s not out in society”. However, like Wyn, Dan recalled the moment when his two worlds collided:

> My mother went into this catatonic state and she threw a clock [and] smashed the front window … Suddenly [we were] letting the world in, when for five years I kept the world out; for a third of my life or more! [So] I nailed a sheet to the outside of the house where the window was smashed [but] I was distraught that now the world could see … what was going on. I couldn’t escape that.

As seen in Wyn and Dan’s quotes, times of exposure left young carers feeling vulnerable, and exacerbated their sense of difference. In turn, such feelings could have fuelled participants’ resistance to adopting a young caregiving identity that might further entrench their sense of difference. A pattern in the data existed whereby young carers of loved ones with stigmatised illnesses or disabilities, or with particularly chaotic home lives, were most fastidious about maintaining separation between their caregiving and outside worlds. These participants described having a lot to lose if their peers discovered their home-life reality, making the personal cost of identifying as a young carer too great. For example, Grace explained that due to her sisters disability, and her subsequent caring role,

> I'd have people as mutual relationships within school, but out of school it just got totally awkward and I wouldn't let it happen. I just blocked people out because I didn't want them to come to my house … I'd always make sure we'd meet up not at home. That was really shitty.

Similarly, Claire said that she had "no idea if [her peers] knew what was going on inside our four walls", but due to her mother's mental illness and her sister's disability, "I wouldn't like to think they did [because] it was just embarrassing; well not embarrassing, but private, you know? Their houses weren't like that, somehow the dynamics were different". Aldridge and Becker (2003) also highlight the capacity for young carers of loved ones with a mental illness to conceal their roles outside of the home. Overall, participants' experiences of crossover between their caring and non-caring worlds left them feeling exposed and unlikely to willingly share their young carer role with others.

Widely-held understandings of children and youth as dependent are embedded in the invisibility surrounding the existence of young carers. Macrosystem level conceptualisations of childhood and adolescence as a time of being "inherently vulnerable" and cared *for* were in direct contrast to young carers' 'actual' (Goffman, 2014) identities as autonomous, capable, decision-makers and to their roles as caregivers. Current young carer Leah (17, Pākehā) explained that she was "perfectly capable" of looking after her brother with autism and an intellectual disability, and analogously Louise said that she felt like "I'm a little bit of the head of the house … [and] get a bit more say in things as well. You know, like 'I'm doing something good here!'" However, due to strongly embedded notions of childhood and adolescence as a time to be cared *for*, participants were acutely aware that their adoption of a young caregiving identity, where they were conceived as a child or youth undertaking care, would be deemed inappropriate by others. Anna said, "I had a lot of people saying, 'oh, why are you doing that?' 'You're too young'. 'You guys shouldn't have that responsibility on your shoulders as a young couple'". Even as a former young carer, Ngākau said that she felt cautious sharing her role with others:

> I remember telling a friend who's a social worker … about me doing this work with my siblings, [and] she was saying, "that's so abusive, you were too young". But I really argued that, like I didn't see that as abusive. That was just a natural part of who I was as a child.

Participants' perceptions are reflected in the literature, as Olsen (2000) argued that the term young carer assumes a "normal" conception of childhood that is in turn challenged (p. 386). Olsen's sentiment is echoed by Gaffney (2007), who identified the "notion that some children should not be providing the level or type of caring that they are based on some ideal concept about what childhood and family life should be like" (p. 18). Heidbrink (2018) contended that such a view of children and youth as dependent or vulnerable "stands in marked contrast to the integral roles children often assume in familial decision-making processes, as well as to the decisions they make as social actors" (p. 34). Bronfenbrenner (1985) challenged such concepts of childhood and caregiving in his curriculum of care, as he proposed that a foundational aspect of childhood and adolescence should be providing care. Bronfenbrenner's position is strongly reflected in the experiences of participants in the present study, but in contention with wider societal understandings of childhood and adolescence as a time to be cared *for*. Bronfenbrenner's assertion is also echoed by Becker et al. (2000), who stated that "most children will care about and sometimes care for family members and significant others. This caring needs to be encouraged and nurtured if children are to value caregiving both during childhood and later in adult life" (p. 13). As such, participants felt their young carer identity could challenge commonly-held or traditional conceptions of childhood and adolescence.

***Who provide*: recognising collectivism in caregiving.**

Second, in addition to the tension between participants' understanding of their roles and prevailing notions of vulnerability in childhood and adolescence, young carers disagreed with the implied individuality of caregiving roles that could be in tension with their experiences of a collective model of care. Such implied individuality in the term children and youth "who provide" could overlook the extensive family/whānau/aiga networks that the young carers sit within. Whilst some participants undertook care without other family members' support, most participants identified their role as being embedded within a wider caregiving unit. For instance, Melanie lived "in my parents' house" during her time caring for her friend with schizophrenia, "[because] my parents were both registered psychiatric nurses … It was a big thing for my parents to take on as well … [and] I was grateful for their knowledge". As such, Melanie did not consider her role as an individual undertaking. Likewise, Alice said,

> It's a natural part of our family that we all help each other in some way (hands making a circle on the table), and so if I wasn't having a role in helping [my brother], then I would feel I suppose more disconnected from him and the family (Adult, 25, Pākehā, brother with cerebral palsy).

In particular, Māori, Pacific, and Asian young carers identified the cultural importance of enacting a collective model of care, and dichotomised their family/whānau/aiga model with that espoused in the individualist society in which they were embedded. Tongan Mele said that while it was commonplace for Pākehā to use the services of a rest home, her family

> Didn't want to put [grandma] in a home. And that was just for cultural and personal preferences as well, [because] in our culture, we believe in taking care of our elderlies … We look at it as our role to take care of each of our elderly. So mum … taught us that it's important to respect and complete your role (Former, 24, grandmother with dementia/arthritis).

Likewise, Kahurangi explained,

> I think Māori have become so disempowered that they think authorities and services know more than them and we have compromised our cultural way [of caring] and that's a sad thing, because we think we have got to go to that service, where if we had that really whanaungatanga[38] concept (hands come together in a circle) – which a lot of us are still doing – we wouldn't have to be reliant on services … That's why I nursed my dad, because he said "I never want to go to a home" and we said "we'd never put you in a home" … We all just had a role to play and we knew that.

Hong Kong Chinese-born Chun described a "Chinese model" of care, stating;

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[38] A sense of family connection through shared experiences and working together (Kia Eke Panuku, 2019).

> I think it is quite usual for Chinese family [to have] a really large extended family in their own home … So it's expected I think for people to just do [caring], and I felt that family pressure [to care], even though we were separated from them from afar (Adult, 27, mother with stroke/dementia/cancer, father with undiagnosed mental illness).

These comments reflect the wider collectivism inherent in Māori, Pacific, and Asian cultures, where the family/whānau/aiga are integral to a culturally embedded shared model of caregiving (Collins & Willson, 2008; Suaalii-Sauni et al., 2009). Overall, participants appeared to be discouraged from adopting a young caring identity when the term did not acknowledge the collective care of the wider family/whānau/aiga unit.

Collective care was enacted in the continual renegotiation of familial roles to meet "the individual yet interconnected needs of each family member" (Aeyelts et al., 2016, p. 76). Many participants' narratives revealed a caregiving 'dance' whereby the family/whānau/aiga unit moved in unison, with all members giving and receiving care. Such a dance of care was particularly common among Māori and Pacific young carers' narratives, but also extended to many Pākehā families. Māori Kahurangi said that when her father became unwell "we automatically as a whānau took on the certain roles … We all just had a role to play and we knew that". Likewise, Tongan Mele said "us [four] siblings; we all have the same mindset", that care was undertaken by aiga to reflect "the unconditional love that you have for your family members. I wouldn't change it … I was just blessed to have my family there". Such a dance of care was reflective of the way that "care circulates through families and households" (Heidbrink, 2018, p. 31), varying in response to familial disability or illness, and movements in members' availability and willingness to provide care. Cyclical care and role fluidity were pertinent, as declines in care recipients' health were often not linear but episodic, and their ability to carry out aspects of their familial role also fluctuated. Pākehā Lucy explained that her mother with cancer "had many rounds of treatments and responded quite well, so … the roles kind of switched a little bit" (hands move in a turning motion). Similarly, Pākehā Claire said that for her family, supporting her mother by caring for her sister with a disability "chopped and changed";

> Dad was a fisherman and he was often away for six months at a time … [and] mum wasn't so well herself … Depending if dad was home, I'd sort of make sure everyone was up and out the door for school or whatever, [and] my sister would wet the bed and so I'd strip it down, [because] mum would often still be in bed not well.

As evidenced in Claire's quote, a fluidity of roles among family members was central to enabling the unwell individual to continue their integral roles – a key goal of young caring described in the previous chapter. Participants' conceptualizations of the fluidity and continual reshuffling of familial roles contrasts to a bulk of the literature referring to children "filling in gaps" due to their unwell family member no longer being able to fully enact their roles (Boumans & Dorant, 2018; Leu, et al., 2018, p. 929). Such care gaps were evident in the present study but were more often created by exosystem level service inequalities for individuals with disabilities or illnesses and their family/whānau/aiga (see Chapter Six for full discussion), rather than participants conceiving of gaps being created solely by their care recipient's role loss. Overall, many participants identified a collectivism of care wherein the continued renegotiation of familial roles among members supported unwell individuals to maintain their status in the home.

As a consequence of the collectivism of care, participants often perceived of their caregiving as moving through various traditional familial roles, oftentimes alongside other family members. Rather than the existence of a young caring role, participants often instead conceived that they held multiple fluid and interwoven roles enacted as part of being within a family/whānau/aiga unit. Māori Kahurangi expanded on her description of whānau as "automatically" taking on "the certain roles", as she explained that generally,

> My sister … was the cleaner, I did the nursing, my other sister managed the money, [the] boys came in and relieved during the day [so we] have a break. So it was just automatic (hands moving in constant circles) … there was no squabbling, nothing … So it's never talked about, it's just you do it, you know?

The only real compartmentalization of child/youth/young adult and young caring identities was thus visible outside of the home, between microsystems such as home and school, as previously described. The high instance of collectivism of care identified in the present study is not reflected in the bulk of national or international research, which largely identified that young carers "often have to fulfil all caring responsibilities with little support" (Noble-Carr, 2002, p. 5), commonly in isolated, sole-parent families (e.g., Aldridge, 2018). African young caring research, however, highlights the propensity for care to be undertaken as a familial act, with Skovdal (2009) reporting that in Western Kenya, "caregiving was often a shared responsibility" between immediate and extended family members (p. 178). Furthermore, literature pertaining to Black, Asian, and Minority Ethnic carers (BAME) identifies cases of collective caregiving among culturally diverse groups of caregivers, who Tribe and Lane (2017) have asserted more commonly "look after their own" (p. 154). The authors highlight the additional influence of "gender roles and family responsibilities", however, which "will vary across communities and within families" (Tribe & Lane, 2017, p. 154). Therefore, the discrepancy between collective and individual care between the present and existing research could be explained by the higher number of NZ young carers in the current study who were Māori (21%), Pacific (14%), and Asian (4%), and the evidence of collective caring in some Pākehā families. Consequently, adopting a young caring identity was challenging for participants who instead perceived of their roles as sitting within a collective and fluid familial care structure.

***Significant*: redefining the significance of care.**

Third, the "significant" level of care outlined in the definition of young caregiving was at odds with participants' own conceptualisations of their roles as normal. Participants often discounted their eligibility as a young carer because overwhelmingly they considered it as a normal role. Many participants' caregiving roles were interwoven into the fabric of their familial or culturally-informed understandings of what it meant to be a child, adolescent, or young adult in a family/whānau/aiga unit experiencing a member's disability or illness. For example, Pākehā Alice said that caring for her brother with cerebral palsy

> was just something that I naturally fell into [as] a sister … I don't really think that I'm doing anything special or anything different. What else would I do, you know? I wouldn't think twice about what I do.

Likewise, Māori Kelly explained that supporting her grandpa as

> the eldest grandchild … wasn't really like a job or a chore, it was just sort of a family thing, like arrangement … And you know, those were happy, fun memories of looking after him … seeing him feel so happy. I *really* enjoyed it. And once he was gone, it was something that I definitely really missed (Former, 23, elderly grandfather, mother with bipolar, brother due to mother's bipolar).

In fact, several participants, explaining the normality of caregiving, highlighted the difficulty of *not* providing care when formal services took over. Pākehā Wyn recalled that it was difficult when in-home carers "would try to help" with caring for her mother following her stroke, because "it was *my* job to look after mum, and no one else needs to know … I turned them away and I was probably very rude". Similarly, Pākehā Anna explained that "there was one carer" for her boyfriend's father

> who I didn't really like too much … instead of coming in, doing the job, and getting out, she would stay there and … I just didn't understand why this person was impinging on our time and impinging on our space? … That really, really *fucked* me off, 'cause I thought, "you asshole".

Several studies highlighted young carers' perceptions of their roles as "a normal part of many young peoples' lives" (Warren & Edwards, 2017, p. 114) or representing "the natural help within the family" (Nagl-Cupal & Hauprich, 2018, p. 532). For example, questionnaires completed by 428 Australian youth whose parent had a serious illness identified "mutual care among family members" that is "naturally embedded in the reciprocity of family caregiving" (Pakenham & Cox, 2018, p. 2503). In such cases, identification as a young carer may be deemed unnecessary when care is "not defined as an additional role" (Tribe & Lane, 2017, p. 154). The NZ Carers' Strategy (MSD, 2019) also highlighted that carers "might see caring as a natural part of what [they] do for the people [they] love" (p. 5). Consequently, the participants did not consider their role as significant, but instead as a normal role for children living within a familial unit experiencing a members' ill health.

In some instances, participants identified specific positions within the family as resulting in their caregiving role. Specifically, females, and especially grandchildren or eldest daughters, could be more likely to take on caregiving roles, particularly among Māori, Pacific, and Asian families. Hong-Kong Chinese-born Chun said that while caring in her culture was carried out by both genders,

> males [are] expected to help in a very different way than a female … a female may take over the kitchen or they share some of the load. But [for] male their "presence" ("" with fingers) in itself is the help.

As such, Chun asserted that caring was essentially a female role. Likewise, Māori young carer Kelly described how working alongside her mother to care for her grandfather came about "'cause we're both the eldest in our generations – like, I'm the oldest grandchild, and she's the oldest daughter". Tongan young carer Mele also described caregiving for her grandmother with dementia and arthritis as "what you're supposed to do … as a granddaughter". Mele went on to explain,

> in our culture it's perceived as a woman's job, which is why my mum [also] took on the role of carer; she's the eldest daughter, she wants to take care … But it can vary in each family depending on who's available. And they might just have their own belief, you know? The elderly might be closer with the son, so it would be the mother-in-law [caring].

Existing research also highlights higher instances of females and eldest children providing care (Barry, 2011; Dearden & Becker, 2004), with several UK and Australian studies also pinpointing the greater likelihood of normalised role-based conceptions of care amongst cultural and ethnic minority young carers (e.g., Ethnic Disability Advocacy Centre, 2003; Hill et al., 2009). When a female was not available to care, however, or when more than one carer was required, the findings identified several instances where boys took on caregiving roles. For example, Mele went on to state,

> Mind due, my brother did help out, because there always had to be two people that changed grandma … In terms of a guy being involved, it really just depends on each family … Because in our [Tongan] culture, there's a taboo respect thing between girl and boys, so we wouldn't change her together with our boy cousins, we would change her with my aunty ... But, because us and our brother have a close relationship, that taboo thing is not as strong, so we'd change her together with my brother (hands interlocked).

Likewise, Māori Kahurangi said that care was carried out by "men and women" as part of a whānau effort, stating that when she needed a break, "the boys showered [dad] when he had times in hospital". Furthermore, in many cases, females and males cared alongside one another, particularly in the case of siblings enacting care, as described earlier in the thesis. For example, Miharo explained that care for her meant that "me and my brother were the mum and dad, and the other three our children". When males and females undertook caregiving together, tasks were often divided according to the gender of the individual receiving support. In particular, intimate care tasks were matched by gender when the option was available. As Niuean Terrence explained, "when my sister was home she'd do the showering" for their mother who had encephalitis and a disability, "'cause she's a girl", but because "my sister is working … I did it too". Overall, young carers were unlikely to identify their role as significant when it was expected as part of their position in the family.

Children, youth, and young adults undertaking care of elderly loved ones appeared to be particularly unlikely to identify as young carers, wherein their role was unlikely to be seen as significant due to the normality and expectation inherent in such care. Māori, Pacific, and Asian participants in particular said that caring for elderly was commonly undertaken by children, youth, and young adults. Hong Kong Chinese-born Chun described a "generation kind of model" of care, in which "it is quite usual for Chinese family [to care] for parents in their own home ... when they get more frail: It [is] a norm for us, an expected thing". Participants conceived that their care was a means of "repaying" (Mele, Tongan) or "giving back" (Kahurangi, Māori) for the sacrifices that their kaumatua [elderly] had made for the benefit of the next generation, particularly by enabling participants' better quality of life, and educational opportunities beyond what past generations had experienced. For example, Tongan Amelia said "I can look after her, because grandma looked after me … because in Tonga grandma adopted me (smiles), [and] because grandma is getting old now … they leave the care to me". Similarly, Tongan Mele explained, "in our culture we believe in giving back to our elderly", so caring for her grandmother with dementia and arthritis was,

> what you can give her for the sacrifices that she made for our parents back in the day (throws hand back). 'Cause they lived on a really isolated island in Tonga, and my mum wanted to go to school, so they moved to the main island in order for my mum to get education. And then mum was able to have the opportunity to go study overseas and get educated. And now we're here in New Zealand and we're able to have the opportunity to have education, because of that decision that she made for my mum. So in a way, it's us repaying the sacrifices that they made in the past, [which] is why we're here now.

Existing NZ studies also highlight the integral role of family in caring for the elderly. Bellamy and Gott (2013) identified "the pivotal role played by family members in the provision of care", especially for "Māori, Pacific Island and Chinese elders" (p. 26), and Dellmann-Jenkins, Blankemeyer, and Pinkard (2000) noted the high incidence of "a new population" of NZ young adult carers aged 18-40 enacting their "filial duty" due to the "expansion of the family to four generations" (p. 180). As such, where care of the elderly was seen as a particularly integral and normalised childhood, adolescent, or young adult role, participants appeared unlikely to identify as young carers undertaking significant roles.

Māori participants explicitly identified care carried out by children and youth as a natural and expected whānau role. So, while for many participants their young caregiving *became* an integral and normal component of their identity after a family member experienced a disability or illness, for Māori participants, care was conceived as an innate aspect of their very identity as a Māori child, regardless of the existence of disability or illness in the whānau. Kahurangi explained that "care is just a natural part of being Māori". Analogously, Māori Ngākau described care as being "just a natural part of who I was as a child. I'd never questioned whether or not I should do it … [because] it's very ingrained". The naturalness of care was especially pertinent when Māori young carers described supporting elderly family members. Kelly explained that as the oldest grandchild, "when my nana was around, before she passed, apparently she was going to take me on … 'cause my nana is the one in my family that brings the Māori culture". Kelly said that in turn, she would have supported her nana growing up. Similarly, Ngākau asserted that it is "a very solid Māori tradition for the oldest child of the oldest son to be given to the grandparents", and as they grow up, "the grandchild cares for the grandparents". Ngākau went on to explain,

> I was just saying to my son … who is 22 … "Why are you not at home? You should really be thinking about giving up your job and going home to live with your koro [grandfather], because your koro is old … and you know he misses you and he wants you there".

The extension of care into the next generation was shown again when Māori Kahurangi spoke about her own tamariki (children) undertaking care, stating that her sons "looked after my dad when he got older … Recently, my son said that he was shocked by [a Pākehā] family … fighting about who's taking [care of] nana … because for us it's normal".

As shown by these participants' quotes, caregiving was not only undertaken for participants' own nuclear families, but extended to supporting the wider whānau. This was especially evident at the marae[39], where Ngākau said there was

> that whole sense of looking after older people … So always about "are our elders ok?" Like today I was at the marae, and it's like "does everyone have a cup of tea? Are the older ones talking? Have they got a chair to sit on? Is it too hot?" [And] the younger ones go and do it.

Similarly, Kahurangi explained,

> when we go to our marae … if we've got any of our kuia or kaumatua, our elderly, in a wheelchair, I see the young ones … oh gosh, they would be about seven/eight … and they just automatically come in [and] would be helping feed, or they will do the hair (imitates stroking her hair), and put [on] the blanket. They just know.

As shown in Ngākau and Kahurangi's explanations, the commonality of children and youth undertaking care in culturally-meaningful settings such as on the marae resulted in the visible status of young caregiving roles. This extended to school, as Kahurangi went on to say,

> we had quite a few Māori at my school [and] … I was well known for it. I was quite good at sports but I had to get home because I had jobs to do, and caring to do. So it was sort of a joke, you know; it was an excuse that I couldn't stay for things.

It was apparent that the deeply embedded notion of naturalness surrounding whānau care – and the commonplace occurrence of children and youth in caregiving roles – could discount the view of care as significant. As such, participants who were brought up in an environment of children and youth caregiving may have been unaware that they were *in* a caring role. Consequently, when caregiving was interwoven into the meaning of being a Māori child or youth, participants were unlikely to perceive of their role as significant or identify as young carers.

Another explanation for the lack of identification of Māori young carers, despite the participants' explanation of the visibility and naturalness of their roles, could be the tendency for participants to hide the existence of young caregiving outside Māori-oriented and thus 'safe' settings such as the marae. So, while participants said that observing children and youth providing care on the marae was commonplace, such an openness of care did not extend outside of the marae to environments where a Māori model of care, disability, and whānau did not prevail. In such environments, Western notions of what childhood, adolescence, family, and parenting should look like, and the amount of care that children and youth should undertake in a normal version of childhood and adolescence, could result in Māori participants' roles being seen as inappropriate or unusual. For example, Ngākau and Kahurangi both described a whānau model of care as uniquely Māori, with Ngākau asserting, "that responsibility and duty of care … [and] that whole sense of looking after … is the Māori thing", and Kahurangi stating "that united whānau and that really whanaunatanga concept (hands come together in a circle)" of care represents "our cultural way of being". Overall, the term

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[39] According to Metge (1967), the term marae is used by Māori in two related ways. Firstly, as an "open space reserved and used for Māori assembly", and secondly, "for the combination of this open space with a set of communal buildings which normally includes a meeting house" (p. 73).

young caring appears to be strongly linked to Western ideals and is expressed in English, which could explain the invisibility and lack of identification of Māori young carers.

The impact of cultural context on the practice of young caregiving has been internationally under-researched, especially in NZ where the experiences of indigenous Māori young caregivers are largely invisible (cf. McDonald, 2008; McDonald et al., 2009; Nikora et al., 2004). The latest Carers' Strategy (MSD, 2019) is making steps towards meeting the needs of Māori carers, highlighting that "more research is needed", "particularly" regarding Māori carers, and which adopts "a Kaupapa Māori [Māori-centred] approach" (p. 12). Whilst not attributing care to children and youth specifically, several Māori researchers highlight the integral aspect of care in Māori life, and the fluidity of care among whānau (Moeke-Maxwell et al., 2013; Nikora et al., 2004). The naturalness of care expressed by Māori participants can be seen in the "cohesive whānau collective support system" that wraps around Māori with a disability or illness (Moeke-Maxwell et al., 2018a, p. 31), echoing the capacity for whānau as "the driving force" for "individuals to act in this world for and with others" (Kohere, 2003, p. 23). As such, whilst a dearth of Māori young carers' experiences exist in the literature, studies pertaining to Māori culture offer key insights into the naturalness and visibility of Māori children and youths' caregiving roles.

The naturalness of Māori, as well as Pacific, Asian, and some Pākehā participants' caregiving, suggests a change is required in the current significance parameter underlying young caring. International notions of significant or substantial amounts of care were clearly in tension with many participants' understandings of their roles as natural or normal. In particular, the significance of care was often only observed at peak rather than everyday times in caregiving, for instance, during mental illness-induced episodes, or palliative care. As such, it was evident that participants were interpreting significant care as times of intensive and overwhelming caregiving, which often no longer reflected a normal or natural familial or culturally-informed care model. In turn, young carers' attempts to define their caregiving in terms of its significance could result in them underplaying or ignoring their day-to-day natural care undertakings. If this pattern identified in my research holds true nationally, then large numbers of children, youth, and young adults may be carrying out caregiving roles, but be largely unrecognised by themselves or formal services because they conceive the provision of care as normal. A caution does need to be made against assuming that all children, youth, and young adults whose family/whānau/aiga are experiencing a members' ill health or disability are young carers, or that all Māori, Pacific, or Asian children, adolescents, and young adults conceive of caregiving as natural and are thus providing care. Another interesting point to consider is that where participants perceived their roles as a normal or natural aspect of their identity as a child, youth, or young adult, then notions of being socialised into young caring outlined in existing literature (e.g., McGibbon et al., 2019) take on a different meaning in NZ. Overall, using the stipulation of significance in NZ could result in participants identifying as young carers only in times that their roles felt overwhelming, and discount activities they consider as normal or natural caregiving roles.

***Ongoing*: acknowledging the episodicity of care.**

Fourth, young caring being predicated on its ongoing nature also appeared to erect a significant barrier to NZ young carers' ability to identify. Linking back to Chapter Four and the notion of episidocity in many disabilities and illnesses, and thus in young caregiving, reveals participants' difficulty in perceiving their care as ongoing. Instead, many participants described the fluctuating nature of their roles, often experiencing periods of intensive caregiving during peaks or "episodes" (Dan, Kahurangi, Phoebe) when they could identify as a young carer. They contrasted these experiences with "down times" (Lucy) in their roles, when they no longer felt that they qualified as a young carer. Claire described how her role "chopped and changed" due to her father's job as a fisherman, so that the level and intensity of caring for her mother and sister was dependent on "if dad was home". Likewise, Lucy explained that her role as a young carer was "kind of confusing because [mum] was like in and out of illness … so there'd be like down times and up times, when the roles kind of switched a little bit". As evidenced in Claire and Lucy's quotes, the participants found it difficult to define interrupted care as "ongoing", despite the findings establishing that whilst the intensity of care eased, young carers very much remained caregivers with considerable care workloads. It appeared that rather than addressing the stopping and starting of caregiving per se, young carers were once again classifying periods when their roles were overwhelming as young caring, and stages of perceived normal or natural care as "not really" (Leah) young caring. As such, many participants experienced uncertainty regarding their status as a young carer, due to the episodicity of their caregiving roles.

Participants caring for loved ones with a mental illness or substance misuse appeared to be the least likely to identify their roles as ongoing. As previously discussed, episodicity was greatest when care recipients had a mental illness or substance misuse. In turn, these participants often understood their roles as "sometimes" (Kelly, Phoebe) providing care, or as "protecting" (Dan, Sally) rather than caring for their loved one(s): "I didn't see myself in a caring role [but] I've been protecting [mum] I suppose" (Dan). This is a worrying finding as participants caring for family members experiencing mental illness or substance misuse were identified in my study as having the greatest instances of feeling overwhelmed in their roles, due to the heavy emotional-support focus of their caring, the stigmatised nature of their loved ones' illnesses, and the commonality of isolation in care. For example, Dan went on to say, "I look back at it in hindsight [and] there's that caring role, but it's mixing with how extreme my mother's condition was, and all the stigma that's attached to [schizophrenia]". Participants' hesitancy to identify as young carers due to the requirement of ongoing care is supported in the literature (e.g., Aldridge et al., 2016), with Moore et al. (2011) asserting that meeting the ongoing level of care can be difficult when young carers' roles "fluctuated over time", especially in instances of parental substance use (p. 167). In line with this, Wong (2016) questioned, "how do we define 'regular and ongoing'? This vague description is open to much interpretation and can make identification difficult" (p. 380). Overall, the stipulation of ongoing care for identification as a young carer could particularly deter participants supporting loved ones with a mental illness or substance misuse, whose roles could be particularly episodic.

Thus far, the chapter has identified the lack of a shared NZ young carer identity, embedded in the disunion between many participants' conceptualisations of their roles as dynamic, collective, natural, and episodic; and the current definition of young caring as static, individual, significant, and ongoing.

***Providing care*: young carers offering support.**

Fifth, young caregiving being defined as *providing care* was in contrast to NZ young carers' own conceptualizations of their roles as offering *support* or *help* to their loved one(s). Specifically, linking back into participants' Taha Whānau (social care) as maintaining the embeddedness of care recipients within their family/whānau/aiga and wider communities, young carers said that they supported their loved ones to maintain their previously-held positions and relationships. For instance, Terrence explained that due to his mother's intellectual disability, "My niece talks to my mum as if she's a friend now. Like she's kind of lost the respect for her grandma, you know, as someone older". As such, Terrence said that he was "really strict" on his niece to remain respectful of her grandmother as she should an elder. Many participants thus resisted the concept of *caring for* espoused in the term young caring, which could undermine such continued roles and relationships. For example, Mary explained her hesitancy to identify as a young carer because her mother

> was always staunch, and she never wanted help; and I think that was the hardest thing for her, to be debilitated in that way … she absolutely hated [being] seen as sick. [So] I could more just *help* her; [be] her partner in crime … But she [was still] my mum being my mum.

Therefore, while participants identified periods when their care recipients were unable to carry out certain aspects of their roles, young carers did not necessarily perceive of themselves as *caring for* their loved ones, but as *helping* or *supporting* them to maintain their previously-held and continued roles.

A trend was apparent whereby participants were conscious of the fact that their loved one's roles were at the very core threatened by simply *having* a disability or illness or employment away from the home, rather than any real inability or failure to carry out that role. This was especially the case when they were traditionally the care*giver* not receiver, and in instances when they were the parent. In turn, participants feared that their role as *providing care* for their loved one(s) could embed such assumptions. This was shown when Ngākau recalled a friend identifying her young caring role as "abusive" because she was "too young", which she disagreed with:

> Mum was coming home at whatever hour and then getting up to get our breakfast; I mean that's extraordinary amounts of work from her! She must have just been operating on bare minimum to do what she was doing [for us kids], and then going back off to work [night shift].

Participants' understandings here not only add rationale for their hesitancy to adopt a young carer identity, but also offer insight into young carers' aim to close the gap discussed earlier in the thesis: here, between the role that their loved one did in fact play, and how society portrayed them, due to their need for support. Participants' assertions of the need for greater acknowledgement and support of their loved ones' continued roles within the young caregiving relationship is echoed in the sentiments of Disability Rights authors (Newman, 2002; Olsen, 2000; Parker & Clarke, 2002).

Certainly, a key tension highlighted by Disability Rights researchers is the assumption that parents who have a disability or illness cannot provide quality parenting (Newman, 2002; Olsen, 2000; Parker & Clarke, 2002). For example, Tarleton and Ward (2007) highlighted the dominance of literature sharing “concerns about whether adults with ID [intellectual disability] *could* be adequate parents without detrimental effect to their children’s development and welfare” (p. 194, emphasis in original). The present data suggests that this questioning of parenting capacities also extends to parents with a chronic or mental illness, or substance misuse, a claim that is supported by Aldridge and Wates (2005) who argued that current mental health interventions do not consider parenting capacities of individuals with mental illness, and instead “undermine their parenting roles” (p. 85). As a consequence of individuals with disabilities or illnesses being framed as incapable of quality parenting (Newman, 2002; Olsen, 2000; Parker & Clarke, 2002), parents with a disability or illness who receive support from a young carer experience a triple discrimination: firstly as a person with a disability, secondly as a person with a disability who is a parent, and thirdly as a person with a disability who is recieving care from a child. Overall, participants overwhelmingly conceptualized their positions as supporting their loved ones to maintain their roles in the home and community, including as a parent, grandparent, or employee. As such, their understandings of caregiving were in contention with the concept of *providing care* espoused in the young carer definition.

Participants were particularly hesitant to adopt an identity as *providing care* when they considered themselves a secondary support to the primary adult carer. Ten NZ young carers understood their roles as supporting the primary adult carer, as opposed to undertaking a young caring role per se. In some cases, participants appeared uncomfortable adopting a young carer label when they would “kind of help” (Atalanta) or “just jump in and do what you can” (Grace) when the adult carer “was stressed” (Leah) or “struggling” (Grace). Here, the underlying goal of care as maintaining their loved ones’ previously held or traditional roles extended to the primary adult carer, as participants described supporting their parent/caregiver to maintain their position, for instance, as a mother or father, despite an additional caring role for the unwell family member. For example, Alice explained that she cared for her brother with cerebral palsy to alleviate some of her mother’s workload and stress, because “my mum has always been at home [caring and] … working part time … [and] whenever I talk to mum she’s saying, ‘I’m worried about this or I’m worried about this’”. In other cases, participants felt that adopting a young carer identity could take away credit from or undermine the capacity of the primary adult carer. Atalanta emphasized that her role caring for her mother with chronic illness was carried out together with her father, as she explained; “usually dad would be there … [and] I feel safer when like dad’s there ‘cause I know he’ll take care of [mum], so I didn’t feel that worried” (Current, 12, Pākehā).

Similarly, participants who did not care directly for the unwell family member, or who provided largely non-physical care, also often conceived of their roles as supporting rather than caring for. The 11 young carers who were providing care for their siblings in order to relieve the primary adult carer or their unwell family member were unlikely to conceive of themselves as carers with regard to this aspect of their roles. Instead, these participants identified their roles as “helping”. For example, Phoebe said

> I played sort of a mum role, helping my baby brother. He would always come to me when he wanted hugs or when there was something wrong. My mum was still the practical mum, cooking and stuff for us, but she didn't really know how to do the whole "caring mum" thing, so he looked to me for that comfort.

Analogously, the many young carers undertaking largely emotional, social, and spiritual care roles could discount their caregiving as "supporting" their loved ones, "trying to stop him from hurting himself and drink driving" (Mary), or "watching for if he showed any indication of like self-harm" (Melanie). Melanie expanded on her role supporting her friend with schizophrenia, stating that

> My main thing with care was to keep him safe [and] as calm as possible. It was basically just being with him constantly [because] … He was so paranoid [that] he was very fearful when he was on his own.

Here the discounting of non-physical care outlined in Chapter Four is pertinent, as many young carers of loved ones who required largely emotional care – most often those individuals with a mental illness or substance misuse – could conceive of their caregiving roles instead as support. Overall, participants were unlikely to identify as young carers when they conceived their role as secondary support to the primary adult carer, did not care directly for their unwell family member, or when their roles were largely seen as providing emotional, social, and/or spiritual support.

Young carers' conceptualisations of supporting rather than caring when they were "part of a 'care team'" supporting the primary adult carer are reflected in existing caregiving literature (Meltzer, 2017; Moore & McArthur, 2007, p. 564; Tribe & Lane, 2017). Smyth, Cass, and Blaxland's (2011) qualitative Australian study identified that many of the 68 young carers "found it hard to relate to the term 'carer', because they considered what they did as simply 'helping out' rather than 'caring'" (p. 30). Likewise, the 50 Indian young carers in Sahoo and Suar's (2010) study were hesitant to identify as carers "because their parents may be perceived as inadequate" (p. 323). In line with these authors' discoveries, the NZ Carers' Strategy (MSD, 2019) pointed out that "the term 'carer' might not work for everyone, with the term "supporter" being suggested to "better describe" individuals' roles (p. 5).

Finally, nonfinite loss also appeared to play a key role in participants' hesitancy to adopt a young carer identity defined as *providing care*. This was seen in the high instance of young carers of loved ones with a mental or terminal illness among participants who were hesitant to adopt a young caring identity. My findings suggest that the more exaggerated their loved one's loss of abilities, personality, and behavior, and the further the relationship moved from the original activities that defined the bond, then the greater the participants' experience of nonfinite loss of their previously-held relationship. Mary explained that prior to her terminal illness, she and her mother

> used to go out for dinner all the time, and go out to movies … so we were really close … And when she can't do those things anymore it's really hard (crying) … it's like, "where's my mum?" Like, "come on, let's go out like we used to".

As evidenced in Mary's quote, such nonfinite loss of the relationship as it was could also jeopardize the participants' relational role, for instance, as a daughter, son, or grandchild, resulting in participants' hesitancy to adopt an identity as *providing care* for their loved one. Linking back into young carers' awareness of their loved one's sense of nonfinite loss, then participants' nonidentification as young carers could also be explained by their efforts to protect their loved ones from experiencing further loss. Anna explained that when caring for her boyfriend's father with cancer and substance misuse, she remained mindful that "He was completely out of control for the first time in his life". As such, she made sure that despite requiring support, he felt "in control of the situation". Similarly, Greg said that his father

> didn't want to be a burden at all on me, and he was very clear about that … But it was a pleasure to spend the time I did with him … I told him every day that … it meant a lot to me to be there (Former, 28, Pākehā, father with cancer/heart attack).

Anna and Greg's sentiments are reflected in several international studies that highlight the awareness of parents who are unwell or have an illness regarding their own parenting limitations (Aldridge & Becker, 2003; Aldridge & Wates, 2005), and "their children having to grow up faster and take on 'adult roles'" as a consequence (Backer, Murphy, Fox, Ulph, & Calam, 2016, p. 223). As such, nonfinite loss played a key role in some young carers' hesitancy to adopt an identity as *providing care*, especially due to their mindfulness to reduce their loved one's sentiments of loss.

Participants often saw their caregiving roles as part of an interdependent relationship that sought to acknowledge and maintain their loved one's positions and relationships within a wider familial model of collective care. Alice explained her relationship with her brother with cerebral palsy as being "almost just like we are two independent people, and I'm the one who does the driving and I'm the one who does more of the cooking or more of those roles". Reciprocity was evident in participants' descriptions of the care that they received in return from their loved ones, which aligned with their understandings of a normal version of the relationship. Greg explained that "even though I was caring for [dad] in some ways, he was also being a parent to me, very much caring for me". Similarly, Dan said that despite his mother's paranoid schizophrenia, "When she was well … there was still some kind of normality between the mother-child bond … I know that she did love me and was a good mother". In many instances, young carers perceived that the reciprocity of care continued even when their loved one's illness or disability had reached its most severe point. With a big smile on her face, Mary recalled visiting her terminally ill mother after a sporting accident had left Mary with a sprained arm:

> The night before she died in the hospice she couldn't really talk; she was very much unconscious … I had my sling on. And then I went over to her and I lent over and I gave her a kiss and I said, "hay mum" … And then she opened her eyes, and she kind of squinted at me, and she said, "is that sling on right?" (said in a very frail voice). She was worried about if my sling was on correctly. That's classic her (smiles), I mean, she was dying!

Young carers' noted the reciprocal nature of their caregiving relationships, particularly when the care provided to their loved one aligned with their understanding of a typical version of the relationship.

Participants were aware that notions of reciprocity in relationships relied on a person's status as able and living. Participants said that the existence of reciprocal relationships when a member experienced a disability or illness could challenge society's deep-seated assumptions of care, especially of a parent-child relationship when the child or youth was posited as the carer. Terrence said that when he went out clothes shopping with his mother, people would stare, thinking "it's weird seeing a grown man walking around the women's section … holding her hand". Several authors asserted that children and youth being carers conflicted with "embedded assumptions about what is normal and natural" in childhood, parenting, and care (Meltzer, 2017; Thomas et al., 2003, p. 44). In NZ, Hanna and Chisnell (2019) stated that "ordinarily, within families, parents or adult caregivers provide care to dependent children. In the case of young carers, however, the reverse is true" (p. 9). Heidbrink (2018) argued that such a conceptualisation of care can inadvertently "reduce the multi-faceted and historical conditions" underlying children and youths' caregiving roles "to one of parental ignorance and culpability" (p. 34). Whilst in some instances participants described feeling like "the mum" (Miharo, Phoebe) at times, no young carers in my study saw their role as taking over that of their loved one. This is analogous to Bjorgvinsdottir and Halldorsdottir's (2014) qualitative study, wherein none of the young carers of parents with multiple sclerosis "believed they ever 'parented their parents', although they claimed they sometimes 'felt like parents' as they had younger siblings to care for" (p. 42). Overall, participants were hesitant to be identified as *providing care* for their loved ones due to the consequent oversight of the reciprocity inherent in relationships.

Literature often highlighted an absence or loss of a parent's capacity to parent due to illness or disability (e.g., Pakenham & Cox, 2011). For example, Bjorgvinsdottir and Halldorsdottir's (2014) study of 11 young carers of parents with multiple sclerosis reported that due to "their growing weaknesses and disabilities, many parents also had to abandon their parenting roles" (p. 42). However, the results of my study raise the question as to whether these authors in fact meant that parents had to abandon their *typical* parenting role, rather than giving up a parenting role altogether. Certainly, Aldridge (2006) argued that even when "parents are incapacitated by their illness ... parents continue to retain the *status* of parenting, if not always the physical ability to parent in practical terms" (p. 82, emphasis in original). Aldridge's argument is supported by Aeyelts et al. (2016), who contended that despite a child and their mother both giving and receiving care, "this does not, however, impinge on the mother's ability to maintain her parenting status" (p. 75). Nevertheless, my study strongly suggests that the extent of reciprocity extends beyond loved ones retaining the *status* of parenting, to continuing to provide integral parental support for the child/youth/young adult. Once again, the lesser focus on intangible emotional, social, and especially spiritual care in the existing research – highlighted by participants as key reciprocal elements of young caring – appears to underlie such claims that parents retain the *status* of parenting, when physical care is restricted or no longer enacted. Instead, in my study, reciprocity was understood by participants as lying in care beyond immediate physical acts. For instance, some participants identified reciprocity in the past-actions of their care recipients, carried out prior to the young carer's role commencing. For example, as Tongan Mele discussed historically-located acts that she was reciprocating, being "the sacrifices that [grandma] made … back in the day". In other instances, young carers conceived of their bond as reciprocal wherein they were repaying their loved ones, often a parent or grandparent, for the many years of care received during childhood. Tongan Amelia said that she cared for her elderly grandmother "Because grandma looked after me … because in Tonga grandma adopted me (smiles)". The findings suggest that the reciprocity inherent in caregiving relationships could be missed when researchers adopt notions of interdependency as immediate, physical, reciprocal acts of care, rather than including historical and emotional, social, and spiritual care reciprocated years later. The chronosystem concept of time is thus key to understanding the reciprocity of young carers' roles, with reciprocal acts occurring not only in microtime, but also in mesotime and macrotime (Bronfenbrenner & Morris, 1998). Overall, in the present study children, youth, and young adults saw their relationships as being very much reciprocal even when the reciprocated act occurred many years prior or were intangible. As such, young carers could be resistant to notions of their role as simply *providing care*.

***Family member*: beyond nuclear family to wider whānau/aiga.**

Sixth, in my study, caregiving extended beyond the nuclear family to supporting non-blood-related loved ones. The present study highlights the limitations of current definitions of young carers as supporting their "family members", when one NZ youth was providing care for her boyfriend's father (Anna), and another for her friend (Melanie). Melanie explained that she supported her "friend [when he] became unwell. We had known each other for several years and we had actually been in a relationship [and] remained really good friends". In addition, the prevailing understanding of family members as being individuals related by blood or residing in the same physical location could discount young carers instead supporting wider whānau members. Collins and Willson (2008) highlighted that whānau extends beyond the nuclear family, to include "kin, as in whakapapa whānau, or people with a family-like commitment to a common interest, as in kaupapa whānau" (p. 5). The extended notion of whānau is evident in Kahurangi's description of her "big family", as she explained "I'm the youngest of nine … because in the Māori world there's a whangai[40] (hands come together) … so you have other children that becomes part of your whānau". She explained that these other children were not related to her "in their blood … but they were because of their upbringing, because [we] were raised together". As such, Kahurangi's caregiving extending to her sister and brother included her whangai siblings. Looking to the Pacific notion of aiga, and the same extension beyond the nuclear family unit is apparent, with aiga including "even those who although not related are yet subject to the family control" (Tuvale, 2016, p. 1). This wider notion of family is also evident outside of NZ, with one UK study of 11 black young carers concluding that "the diversity of … family life-styles raises important questions about dominant concepts of family life in Britain", which can discount care provided for loved ones "with whom they may not live" (Jones et al., 2002, p. 14). In my study, several young carers supported loved ones who they did not live with full-time. For example, while Phoebe lived with and cared for her nana, she also supported her mother with bipolar, and her younger brother, who lived in another location. She said,

> I worry about him. I wanted him with me [at nana's], and I didn't find it fair that he had to stay [with mum], especially 'cause he's younger [than me] and still needs looking after. I was scared 'cause anything could happen while I wasn't there, [so] I'd go and stay [at mum's house] whenever I could.

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[40] A "Māori customary practice" that, while "often equated with adoption or foster care", is largely focused on "establishing, nurturing and cementing relationships between individuals, families and broader relational networks" (McRae & Nikora, 2006, p. 1).

Likewise, Miharo explained that even though “me and my [eight-year-old] brother went to live with our dad” while her siblings remained with their mother who had a physical disability and schizophrenia,

> we would go back to mum’s in the weekends and holidays … [and] it was almost like we would release our youngest siblings from their duties caring for mum: me and my brother were the mum and dad, and the other three our children.

Miharo went on to state that her caring role also continued when she was at her father’s, as “I was always worried. I would ask mum, ‘What is the home help looking like this week?’ ‘What’s happening in terms of the kids?’” Participants’ caring for non-blood-related or geographically distant whānau/aiga, or loved ones beyond the nuclear family, could be deterred from identifying as young carers due the tension between their experiences, and the concept of family members as related by blood and/or physical proximity.

***Disability and illness:* diverse conceptualisations of disability.**

Finally, researchers highlight the existence of multiple identities held by individuals with disabilities (Dajani, 2001; Johnstone, 2004). Participants were cognizant of such multiple identities, shown not only in their assertions of their loved ones’ continued roles and relationships, but also as young carers did not identify their care recipients solely or even primarily by their disability or illness. Certainly, participants often constructed alternative identities for their loved ones, to help them to understand and support their care recipients’ unique abilities. For instance, Grace described her older sister with an intellectual and physical disability as being “just like a big little sister”, and Claire explained, “We just treated [my sister with a disability] the same although she was different”. As reflected in Claire’s quote, participants often said that their family/whānau/aiga worked hard to include their loved ones in family life in the same way that they did for other family members. In turn, participants could be deterred from identifying as young carers when their loved one’s disability or illness was reconceptualised and embedded within the normality of family life, and when the young carer label could highlight the existence or severity of their loved ones’ ill health or disability.

Hesitancy to identify as a young carer could be even greater when the care recipient’s illness or disability was stigmatised. Several disabilities and illnesses were understood as a “punishment” (Mele, Tongan) or a “curse” (Kahurangi, Māori) among Māori, Pacific, and Asian family/whānau/aiga and communities. Participants explained that the reason certain disabilities or illnesses were seen as “taboo” (Mele, Tongan) or carried “a lot of stigma” (Chun, Hong Kong Chinese) was the strong culturally-bound beliefs regarding the meaning underlying such conditions. About dementia, Mele said “maybe it is stigmatised in general? But I would say more so in our [Tongan] culture. ‘Cause they come up with myths of why you got the disease, like ‘God is punishing you’, or ‘you must have done something bad’”. Likewise, Kahurangi explained that for Māori people, schizophrenia was considered

> a tohu, a sign … like a curse. So it’s something that has happened prior and there is a reason it’s been passed down. So my mum’s way of looking at it was … we’d done something for this to happen, and [my sister] has carried that dark spirit.

Mele and Kahurangi’s narratives highlight not only the cultural- but also the historical-embeddedness of disability and illness, located in previous generations’ actions and, in this case, wrongdoings. As such, the chronosystem element of macrotime is essential for understanding the nature of young caregiving that is impacted "by processes and outcomes of human development over the life course" (Bronfenbrenner & Morris, 1998, p. 995). Historically- and culturally-located conceptualisations of disability/illness highlighted by young carers are reflected in the 2006 Disability and Māori in New Zealand report (Office for Disability, 2009), which stated that "more research needs to be done on how contemporary Māori see disability" (p. 9), because narratives of disability and illness that are not reflective of the Māori experience could "lead some Māori to be reluctant to identify themselves or whānau members as being disabled" (p. 9). Overall, the use of the phrase *disability, illness, mental illness, or substance misuse* in the definition of young caring could match only a portion of young carers' perceptions, and might exclude families who do not identify their loved ones' conditions with these labels.

A significant cultural cost would thus underlie some participants' adoption of a young carer identity, when identifying meant accepting a concept of disability and illness as medically diagnosed and embedded within the individual. Furthermore, a cultural cost was apparent when identification could bring to light their loved ones' ill health and result in stigma, "shame" (Mele, Tongan), and even "shunning" (Chun, Hong Kong Chinese) experienced by the whole family/whānau/aiga. Chun said,

> in traditional Chinese cultures, just the worse thing possible [is] to be mentally unwell. You'd rather die, rather have committed a crime, than be a person with mental health problems. You're just kind of immediately shunned by your community and there's a lot of stigma around it.

As such, young carers seeking to conceal not only their caring roles, but the very existence of their loved one's illness or disability, would be unlikely to identify as young carers.

Overall, this chapter has argued that the definition of *young carer* does not appear to reflect the realities of participants, who commonly do not identify with the term. The chapter has raised key questions, such as: How can we redefine young caregiving to minimise the personal, relational, familial, and cultural costs of identifying? And: How can we encourage children, youth, and young adults' identification from the outset of their caregiving roles, and not at a time when care reaches crisis point? This chapter has extended our understanding of the diverse meanings underlying young caregiving tasks. As in the previous chapters, it was not simply the task itself that participants spoke about, but the reciprocity of care, fulfilment of family/whānau/aiga roles, and enactments of traditional cultural and familial ways of being, which were pertinent to and interwoven into young carers' acts of care. As a result we cannot simply rely on international literature to understand the experiences of NZ young carers, nor adopt notions of caregiving in childhood, adolescence, and young adulthood as something that should not happen. To do so would be to overlook the place of caregiving in the very meaning of what it is to grow up within a family unit in NZ. Finally, the chapter highlighted once again that it is not the *existence* of young caregiving that is the issue, but instead young carers' and their family/whānau/aiga's *choices* related to the uptake and level of care undertaken by children, youth, and young adults, and their capacity to self-identify and access support when desired, which is important. The conclusions of this chapter sit alongside the wider findings of the thesis, which taken together, paint a picture of action needed to truly enfranchise and give voice to young caregiving family/whānau/aiga.

In the next chapter, I examine the *motivations* underlying the creation and maintenance of young carers' roles.

CHAPTER SIX

More of a Push Than a Pull: Factors Contributing to the Onset of Young Caring

This chapter explores what it means to be a young carer in Aotearoa/NZ by examining the circumstances that create and maintain young caring roles. The immediate and wider forces underlying care are explored via a push-pull metaphor, used in several existing studies (e.g., Becker 2007; Cass et al., 2009). The chapter begins with a brief overview of young caring onset, followed by an examination of three main factors pulling participants into their positive caregiving roles. Thereafter, such positive care is juxtaposed against young carers' and their family/whānau/aiga's forced care choices and the resulting feelings of being overwhelmed in their roles, that exist due to numerous key push factors. Overall, the chapter argues that while care is often a choice for NZ family/whānau/aiga and young carers, several significant push factors restrict familial decision-making autonomy, and result in young carers' roles becoming overwhelming. As in previous chapters, I first share one participant story in order to demonstrate the pulls and pushes into care, within the context of that young carer's whole caring experience.

Miharo's Story

Miharo is a former young carer who, together with her four siblings, supported their mother due to her physical disability after an accident and undiagnosed mental illness. Miharo identifies as primarily Māori, but also as Samoan and Pākehā, and grew up in a sole-parent household in the South Island of NZ. Miharo cared from the age of nine to 16, and was 41 years old at the time of her interview.

Childhood. When I was nine, my mum had a motorbike accident and got a C4 spinal injury[41]. I'm the oldest of five kids. At the time my brothers were eight, six, and three, and my sister was five. We had a really complex family situation: me and my next brother have the same father. [Mum's] partner at the time of her accident is the father of my next two siblings, and my youngest brother's father was in prison. My [stepdad] soon left us. My nana and granddad lived in [another town], so they couldn't help.

Because mum had an accident, she was assessed through ACC[42] and got home help, but she was high maintenance and the carers would burn out really quickly. I knew she was burning people out because I could hear the caregivers quietly saying, "Oh my God, I don't know if I can keep doing this". That's 'cause she also had mental health issues and used drugs and alcohol as part of her coping mechanisms. Even worse, she had met up with a gang member in [rehabilitation] and he

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[41] A severe form of spinal injury often resulting in limited mobility, restricted breathing, and difficulty controlling bladder and bowel function (https://www.hopkinsmedicine.org/health/conditions-and-diseases/acute-spinal-cord-injury).

[42] The Accident Compensation Corporation [ACC] is responsible for administering NZ's no-fault funding scheme for injuries caused by an accident (https://www.acc.co.nz).

linked her up with the local Mongrel Mob[43] who came and supported her. This all compounded on her role as a parent.

So, me and my [eight-year-old] brother went to live with our dad. We would go back to mum's in the weekends and holidays; staying as a family was really important. We would lie to our dad though. If he knew *half* the stuff [that went on] he would not have been happy. When we went home, it was almost like we would release our youngest siblings from their duties caring for mum: me and my brother were the mum and dad, and the other three our children. The kids knew that we were coming, and they would wait for the bus, come running out to the gate and give us hugs and kisses, because they knew that it was their turn to be kids (smiling wide). They would go and play with their friends and know that they wouldn't have to be responsible for mum.

The responsibility was huge. At first, we just did cooking, cleaning, grocery shopping. But soon mum had burnt the last of her friends [and] the physio and district nurses stopped coming. I think they didn't want to come into our house with the gangs there. So, we also had to bathe her, and that was hard [because] the house wasn't really modified. At that time, she didn't have a wheelchair so the kids somehow had to transport her from her bed, and she was a big woman. They did it by putting her on a sheet, lifting her off her bed, putting her on the skateboard, and carting her around like that. In the end, mum would just wait [to bathe] until me and my brother got there in the weekend because we were bigger than the other kids [and could] lift her.

Sometimes we would do catheterising. I just didn't think it was right that we had to hold mirrors while she catheterised herself, especially my brothers because it's like "if I don't like looking at it, how are you poor boys doing?" And like, poor [mum], you could tell she didn't like it as much as we didn't like it but it had to be done. Then when she started to become incontinent with number two, she would poo and not know that was what she had done, and there would be a mess during the night. So whoever was sleeping with her would have to then wake up, help her clean the mess, and then go back to bed, and I think that happened at least you know twice a night. So the kids [living with mum full time] were too tired to even go to school the next day. But the kids often [had to] sort out between themselves who would stay home from school to look after mum.

They were really hard times in terms of poverty too. Mum having her power disconnected was a constant thing, and paying the bills was always an issue. I remember we would come and there'd be no food in the cupboards, so we learnt to make do with flour, water, and baking powder by making Māori fried bread. Me and my brother would steal food from our dad's cupboard because we wanted our brothers and sisters to eat.

Reaching out to services. My most memorable time [caring] was when I was 12. I remember getting to mum's house one weekend and my siblings just looked exhausted. When mum's ACC case manager came in I said to him "We are having to catheterise our mum and bathe her. Is that what we are meant to do? Is this normal?" And he just looked straight through me, turned his back, and walked out the front door. I was like, "Oh my God, it must be normal then" (eyes wide and

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[43] According to Wikipedia, the Mongrel Mob is an organised street gang with over 30 chapters throughout NZ (https://en.wikipedia.org/wiki/Mongrel_Mob).

looking shocked). So yeah, in the end it was just the norm. Well, I think the younger three were more inclined to think that was the norm ‘cause they didn’t know as much as me and my older brother. But we knew that was really not normal. Even when I was at dad’s I was always worried. I would ask mum, “What is the home help looking like this week?” “What’s happening in terms of the kids?”

Adolescence. Over time mum got worse and [so did] the services. I remember going to mum’s when I was 16 and my youngest brother who was about 10 didn’t come to greet me like he usually does. I went inside and he was sitting on the edge of his bed, the TV right in front of him, and he was just rocking backwards and forwards. I said to him, “Are you all right?” And he just looked at me, looked straight at the TV, and kept rocking. So, I walked to mum’s room and she let out this really crazy cackle. And when I looked inside, there was all these utensils like an axe, knives, scissors, and sharp blades lined up beside the bed. As soon as I’d taken a couple of steps into her room the carpet was soaking wet. What had happened was she had slit her waterbed to give herself a bath because the district health nurses hadn’t been to see her all week (shakes head). She had been lying there for three days in her own urine and faeces. No wonder my brother is in that room looking the way he’s looking. Mum didn’t have a wheelchair again, and I was six months pregnant, so I got my youngest brother to help me get her from the waterbed into the lounge. And next thing the district nurses turned up. It was such a relief for me. I was thinking, “Oh, here goes some adults who can take control and take over now”. In the end they actually phoned the doctor and she went to the psychiatric unit.

But for all that time, what I couldn’t understand [was that] people could see what was happening but weren’t doing anything (shakes head). How could the professionals think that it’s okay for that to be happening? [Mum] actually became fixated on suing ACC for lack of attendant care and childcare, but nothing ever happened.

Adulthood. Looking at where we are now, as adults, for me, I left school at 16, being pregnant, and I think I only had three school cert[44] subjects. I eventually got back on the right track though. I went to Work and Income when I was about 28; I just wanted to get off the DPB[45]. I thought, “I don’t know if I’m clever enough to go to polytech”.[46] But I went anyway and did a social work certificate and I did really well in that. I met a good friend at that course, so we went to uni together to see what our chances were with the diploma, and I got that too. I think I have resilience because I was a bit older than my siblings.

[My oldest brother] did pretty well; he’s a high achiever, works well under stress. But he’s shut off, he won’t talk about anything because for him the experience was terrible. The next oldest brother

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[44] NZ School Certificate was a Year 11 (students aged 15-16) qualification achieved by taking public examinations. School Certificate was phased out in 2002 and was replaced by the current National Certificate of Educational Achievement (NCEA) (https://www.nzqa.govt.nz/qualifications-standards/results-2/secondary-school-qualifications-prior-to-2002/).

[45] The Domestic Purposes Benefit (DPB) was a social welfare payment, paid under the NZ social security system, primarily for single women with dependent children (https://nzhistory.govt.nz/page/legislation-introduce-dpb).

[46] Polytech is a slang term for polytechnic, an organisation that focuses on applied skills training in a range of trades, occupations, and professions (http://schoolleaver.nz/study/tertiary-study-and-training-providers/polytechnics).

has been in and out of jail for stealing stuff [because] he tells people that he's had a good upbringing and he needs the gears to show that. He's got the biggest heart though. My sister is drugged up on P.[47] She lives with mum, but mum is actually in hospital now because [my sister] hasn't looked after her properly. And the youngest [brother] lives each day as it arrives. He's laid back but I think he has buried some stuff in the past. We are all very open-minded though. It's almost like when you've had to be responsible at a younger age, you are wiser before your time.

Finding out you were a young carer. For me it was a relief. It's like, "Wow, I'm not the only one" (looks wide-eyed). I wanted to share my story 'cause I would hate to think that kids today would be experiencing what we did. Being a young carer is almost like surviving your childhood. There needs to be a voice to gain awareness and recognition at a national level, and I think professionals are the target in terms of preventing such a huge responsibility happening to other kids. 'Cause that's the thing; it was just too much on us kids. There were so many adults who were around [but] we pretty much did it *all*.

* * * * *

Role Onset

In this first section, the onset of young carers' roles will be explored. The commencement of care echoed existing conceptualisations of role onset as either "sudden", "gradual" or "natural" (e.g., Leu, et al., 2018, p. 929). Almost 30 percent (n=8) of participants identified the sudden onset of care, as a result of an accident or change in family dynamics. For instance, current young carer Atalanta explained that her role began

> When I was seven, me and dad were driving home one day from school and dad got a phone call … that mum's at the hospital … From then on she kept on having these times where she got really sick [and] her heart would go really fast and her blood pressure would go really low and I had to help her … So I adjusted to it quite quickly (nods head) (12, Pākehā, mother with chronic illness).

Ngākau also described a sudden onset of care, necessitated due to her family's changed financial circumstances: "Mum had to find work [but] I don't think there was any transition [to] me caring; all I can remember is that I came home one day, and I was doing it" (Former, 49, Māori, brother and sister due to parental employment and mother's undiagnosed mental illness). The gradual onset of care was more commonplace, however, with over 70 percent (n=20) of participants stating that they "drifted" (Dan) or "crept into" (Wyn) their roles. Gradual care onset often reflected the gradual progression of a care recipient's disability or illness, alongside young carers' increasing age and understanding of their care recipient's needs. Dan said that the onset of his role supporting his mother with paranoid schizophrenia "didn't just happen overnight … there was a transition period … For her, things got worse and worse, but I [got] very adept at dealing with it" (Former, 53, Pākehā). McDonald,

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[47] P is a NZ slang term for methamphetamine, an illegal Class A stimulant (https://www.drugfoundation.org.nz/info/drug-index/methamphetamine/).

Dew, and Cumming's (2010) interviews with 14 NZ young carers also identified their tendency to take on "more responsibility as they got older", when "understanding of a family member and their needs also increased" (p. 463). Often, participants in the present study described both a gradual and sudden care onset within the one role. For instance, care could gradually onset as a care recipient's illness slowly progressed, then suddenly increase due to an abrupt health decline. Chun explained that her mother "had cancer [and] we were already doing [care]", but when her mother later had a stroke followed by dementia, "that's the turning point … when the carer role really begins" (Adult, 27, Hong Kong Chinese). As such, pinpointing the time of role onset was difficult for many participants.

Pulls Into Care

A key pull factor underlying the uptake and continuation of young carers' roles was the third category of onset, being the normalcy of children, youth, or young adults providing care, as discussed in the previous chapter. Many participants wanted to carry out their natural familially and culturally significant caregiving roles. For instance, Mary said that care "was my choice [and] I made it my priority … I would have done it no matter what [because] she's my mum" (Former, 27, Pākehā, mother with cancer, father with substance misuse/acquired brain injury). Likewise, Mele explained that she "wants to take care" of her grandmother, as care represented "the unconditional love that you have for your family members … it's my role" (Former, 24, Tongan, grandmother with dementia/arthritis). Young carers often identified the "honour" (Mele), "privilege" (Kelly), or "pleasure" (Greg) of enacting such care, which in turn sustained their roles. Kelly explained "those were happy, fun memories looking after [her grandfather]" (Former, 23, Māori, elderly grandfather, mother with bipolar, brother due to mother's bipolar), and likewise, Rachel said, about her brother, that she felt "great joy every time I saw him … with his lovely smile on his face and knowing [I was] part of that" (Former, 59, Pākehā, mother with depression, brother with muscular dystrophy). Several researchers have highlighted young carers' decisions to provide care motivated by deep familial love (Aldridge, 2006; Nagl-Cupal & Hauprich, 2018). Overall, participants perceived that care was a choice made to fulfil what they saw as normal or natural roles.

The positive outcomes of care sustained young carers' roles. Confirming the findings of existing studies (Hamilton & Cass, 2017; Noble-Carr, 2002), participants valued being trusted to carry out care tasks, and understood that they gained maturity in doing so. For example, Atalanta said, "I think I'm more mature and I've got better logic than most kids my age" (Current, 12, Pākehā, mother with chronic illness). Likewise, Fleur "felt like there was a lot of trust in me and there was no question that I could do stuff, which was really cool" (Adult, 39, Pākehā, mother with multiple sclerosis, brother due to mother's illness). Such positive outcomes experienced during caring could in turn encourage young carers to maintain their roles. Fleur went on to explain, "I really did draw quite a lot of personal validation from the role … it always made me feel like the 'onto it' member of the family and [like] I could do anything". Participants also identified the positive impacts of their care for their loved ones. Mele said that she made her grandmother "happy", and Mary asserted, "I definitely improved [mum's] quality of life". In turn, participants were acknowledged and thanked by their care recipients, which again appeared to encourage their role continuation. Ngākau said that her mother "was really grateful" that she supported her siblings, which “motivated me to carry on”, and Mele explained that her grandmother “used to say thank you for changing her, and feeding her … so that was rewarding”. Such acknowledgement generated young carers’ understandings that care recipients were, as Kelly put it, “grateful of the things that I did”. As such, the positive aspects of caregiving for participants and their care recipients acted as a sustaining pull factor for participants’ choice to care.

Young carers commonly reported deeper relationships with their care recipients that generated a continual “pull” towards caregiving. This finding echoes existing literature, which highlights the close relationships formed between young carers and their unwell family members (Aldridge, 2009; McDougall et al., 2018). In some cases, participants described the rich relationships that grew as a consequence of time spent together. Greg said that he and his father shared “these real pockets of time that mean a huge amount ... If I hadn’t been caring for him, we wouldn’t have ever had that” (Former, 28, Pākehā, father with cancer/heart attack). In other cases, participants identified changes in their loved one’s dispositions as a result of their ill health, which could deepen their relationships and lead to greater understandings of one another. Chun explained, “The pre-stroke mother that I had was a different person, we had a terrible relationship, [but now] she’s actually quite nice ... we got a second chance to have this different … relationship”. Also feeding into participants’ choices to care was their awareness that relationships could be short-lived, due to the nature of the disability or illness. Fleur recalled, “my relationship with mum for the most part was difficult [but] because you know it’s a finite relationship, you learn to really appreciate the good times”. Participants perceived that their strong relationships placed them in the best position to support their care recipients, as Greg explained: “I think it’s absolutely true that knowledge is invaluable … I definitely used it all day every day, when I was interacting with [dad]”. Overall, many young carers made a continued choice to care, based on the strong bonds that had developed, normal conceptions of their roles, and positive benefits for themselves and their care recipients.

Pushes Into Care

While several studies have acknowledged children’s, youths’, and young adults’ decisions to care (e.g., Aldridge, 2006), many researchers also have identified variance in the “degree of choice or obligation” held by young carers (McDonald et al., 2010, p. 469), who “exercise agency within a number of constraints” (Hamilton & Adamson, 2013, p. 102). Such constraints are posited to exist in the immediate microsystem and mesosystem, where familial expectations, family compositions, and the materialization of the disability or illness are housed (Becker & Becker, 2008; Smyth et al., 2011). Additionally, constraints exist in the exosystem and macrosystems, due to a lack of quality and accessible formal services, alongside societies’ high esteem of familial care (Olsen, 2000). Studies identify that constrained choices often result in young carers’ “excessive” (Hanna & Chisnell, 2019, p. 14) or “inappropriate caring roles” (Nagl-Cupal & Hauprich, 2018, p. 532). The present study echoes the notion of agency within constraint, as numerous push factors, existing at all bioecological levels, decreased young carers’ and their family/whānau/aiga’s care-related decision-making autonomy. This section unpacks four key factors pushing young carers’ roles beyond their normal conceptualizations, often resulting in participants’ experiences of overwhelming care loads: (1) the expectation for families to care, (2) primary carer distress, (3) fear of familial disjunction, and of greatest impact, (4) inadequate services.

Expectations for families to care.

Firstly, a key narrative thread throughout participants' interviews was the underlying "pressure" (Chun) for family/whānau/aiga to care for their own. Lucy explained, "There's this expectation on families to care for their own, but families are human, and humans are fallible" (Former, 25, Pākehā, mother with cancer). In some cases, the expectation for families to care was evident as young carers conceived that accessing services translated to their family/whānau/aiga opting out of their role. Kahurangi said that when her sister was "committed into a psychiatric hospital … [that] triggered a form of depression in both my mum and dad having to make that choice … that whole feeling of failure" (Adult, 51, Māori, father and mother with cancer, brother and sister with schizophrenia). In other cases, the expectation to care was conveyed via extended family's, friends', or other party's comments. For instance, Hong Kong Chinese-born Chun said that she "felt that [extended] family pressure" to care for her mother in a certain way, "and I just felt so angry … I'm trying to handle the situation as best as I can". Similarly, Chloe explained that her mother with multiple sclerosis had a full-time carer, but their family friends "were [still] saying, 'Oh, the girls are here. Why aren't they helping you?'" (Adult, 25, Pākehā). As demonstrated by Chun and Chloe, the expectation to care could translate into participants feeling obligated to care, even when they felt overwhelmed, or had opportunities for respite. Services could also communicate the expectation for family care, when staff assumed that family members were providing support, or when they appeared to accept participants' caring roles. For example, Louise said that hospital staff "knew it was me and they just went, 'Okay'… [There was] kind of that expectation" (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke). Likewise, Miharo said that she felt the expectation to care when she reached out to her

> mum's ACC case manager … I said to him "We are having to catheterise our mum and bathe her. Is that what we are meant to do? Is this normal?" And he just looked straight through me, turned his back, and walked out the front door. I was like, "Oh my God, it must be normal then" (eyes wide and looking shocked). So yeah, in the end it was just the norm.

Echoing Louise's and Miharo's sentiment, Lilly, Robinson, Holtzman, and Bottorff (2012) highlighted a Canadian healthcare "system premised on expectations for family care-giving" (p. 110).

The expectation felt by families to care for their own could be amplified by a care recipient's refusal of services. Many young carers described their unwell family member's resistance to formal support, due to their desire to remain autonomous and in the home, or denial of the extent of their illness or disability. Chloe said, "Mum was fiercely holding onto her independence and staying at home". Analogously, Kelly explained that her poppa "said he will … *never ever* want to go into a rest home". Participants understood that such resistance reflected their care recipients' nonfinite loss of who they once were, embodied in a lack of autonomy that was exacerbated by formal support. The threat of accepting services on her boyfriend's father's perceived identity was evident, as Anna explained:

> he would be on the verge of tears at some points when talking about having to go into a hospice or respite care or anything like that. I don't think he viewed himself as an old man, so by going and doing that he was an old man (Former, 27, Pākehā, substance misuse/cancer).

Other young carers highlighted family/whānau/aiga members' resistance to services for their care recipient, which stemmed from denial or lack of awareness of the severity of the disability or illness. Claire explained that "no one came to the house or assessed [my sister] or anything like that because mum … [was] sort of in denial [thinking that] there wasn't anything wrong with her". Historical negative service experiences could also underlie service resistance. When individuals had received past support that did not maintain their dignity and wellbeing, families were unlikely to trust the service moving forward. Service representative Tim said that it was not uncommon for "failure previously" to have the result that families did not "want to be involved with services". Several concerning examples of service maltreatment were provided by young carers in my study. For instance, Miharo remembered

> going to mum's when I was 16 … I walked to mum's room and she let out this really crazy cackle. And when I looked inside, there was all these utensils like an axe, knives, scissors, and sharp blades lined up beside the bed. As soon as I'd taken a couple of steps into her room the carpet was soaking wet. What had happened was she had slit her waterbed to give herself a bath because the district health nurses hadn't been to see her all week (shakes head). She had been lying there for three days in her own urine and faeces.

Grace also had a negative service experience, as she shared the following incident:

> like, five or six years ago. Mum put [my sister] in a facility … and she escaped out the window. There is night staff but they just sleep. And she was found in her sleep suit, in the rain, drenched, her full nappy, only half a meter from the road … So now [mum's] trust is just gone, completely (Current, 21, Pākehā, sister with physical and intellectual disability).

A lack of trust often extended beyond the specific service with whom the negative experience occurred, to all formal services. Grace went on to state that, even now, "Mum doesn't want [my sister] to go to community houses and stuff … mum's not ready for it". Furthermore, even when such care was not experienced first-hand by the family, hearsay surrounding quality of care could result in families refusing their support. Previous negative service experiences could thus have far-reaching effects on family/whānau/aiga uptake of future support. Echoing my results, Aldridge (2018) also identified that an individual's refusal of support could be a key catalyst for familial care, alongside previous negative service experiences. Consequently, resistance to services by care recipients and family members could contribute to the uptake and maintenance of young caring roles.

The expectation for families to care could be difficult to achieve, despite family/whānau/aiga desire to do so. Family members were not always aware of the need for, or were not willing, able, or available to provide care. Several participants said that their extended family were unaware of the extent of care required, and thus were not in a position to offer support. Chloe explained that her extended family "were a bit clueless. I'm not sure why on earth [they] didn't try and take over the situation or do anything like that; I don't know? They were always in a bit of denial". In other cases, young carers spoke to their family members being unwilling to provide care, despite their availability to do so. Lucy said, “The thing that hurt my feelings or made it hard was that … I was the youngest and I was the one who had to do it [because] no one stepped up”. Nevertheless, later in their interviews, participants often revealed deeper reasons underlying their family members’ unwillingness to provide support, that instead positioned them as unable to care. For instance, Lucy went on to state that her father and brother “had mental health issues, and my mum’s partner committed suicide so … I am lucky in that I haven’t faced those difficulties so I was able to carry the family”.

Overwhelmingly, however, participants identified alternate carers as being unavailable due to geographical distance, or having significant work, family, or other commitments. Miharo explained that she and her siblings cared for their mother who had a physical disability and schizophrenia, because “we had a really complex family situation … my youngest brother’s father was in prison. My [stepdad] soon left us. [And] my nana and granddad lived in [another town], so they couldn’t help”. Melanie also described a lack of alternate carers, stating:

> No one else had time because they were working and they have mortgages to pay, and [he] needed 24-hour full-time [care]. So as a young person that didn’t really have many responsibilities, I was the one that was able to pick that role up. At that point in time, I could put uni on hold (Former, 31, Pākehā, friend with schizophrenia).

Likewise, Mele highlighted her and her siblings’ suitability to care, stating, “We knew [that mum was] our main breadwinner … [and] what are we going to do? Just study?” This dearth of family support underlying the uptake and maintenance of young caring is also a common theme in existing studies (Aldridge, 2018; Cooklin, 2010). Noble-Carr et al. (2009) asserted that it was “not uncommon for extended family to have become estranged from young people and their families … because of conflicts that had occurred”, so that young carers were often left with significant care roles (p. 59). These researchers’ finding is supported by McDonald et al. (2010), who identified that in NZ, extended family became “less able to help as they aged, or less available because of their own family circumstances and needs” (p. 463). Subsequently, a dearth of informed, willing, able, and available family members could prompt the need for young carers’ roles.

Primary-carer distress.

Secondly, primary *adult* carer distress was another fundamental catalyst for young caring. Almost 40 percent (n=10) of participants, including all current young carers (n=4), were in a co- or secondary-caring role, assisting the overwhelmed primary carer. Young carers perceived that primary carers were “stressed out” (Grace) with managing their responsibilities, the continued running of the household, and financially supporting the family/whānau/aiga when the unwell family member could no longer sustain employment. Echoing the sentiments of her fellow young carers, Kahurangi stated that due to her mother’s cancer and consequent long hospital stays, “my dad found it extremely stressful trying to manage a house, three children at home”. Likewise, Grace said that her sister with an intellectual disability “can be awake for three days … and I’ve seen mum, especially when I was young, break down so many times, just ‘cause she’s so sleep deprived”. Participants conceived that undertaking such substantial care and household responsibilities without support or respite opportunities culminated in poor mental health for the *adult* carer – an observation that could, in turn, lead to the uptake of participants' roles. Grace went on to state that her mother was

> closed off 'cause she was really, really struggling … no one wants to see their mum or dad suffer, so you just jump in and do what you can … Just knowing I gave mum that relief [and to] see her happy: that's why I did it.

Caregiver burnout, stress, and burden are key themes throughout existing literature (e.g., Early, Cushway, & Cassidy, 2006). Studies identify a lack of training, few opportunities for respite and counselling, and inadequate support to enact complex care, which results in caregivers feeling overwhelmed (Lilly, Robinson, Holtzman, & Bottorff, 2012; McDonald, McKinlay, Keeling, & Levack, 2017). Several young caregiving studies highlighted the impact of such burnout on children, youth, and young adults, with a key consensus among researchers being the propensity for young carers to take over from their burnt-out parents or caregivers (Kroll, 2004; Moore & McArthur, 2007). Overall, the present study suggests that the expectation for families to care for their own could lead to familial carers maintaining overwhelming roles, despite experiencing poor mental health as a consequence, resulting in some young carers supporting the primary *adult* carer.

Fear of familial disjunction.

Thirdly, concern regarding familial disjunction appeared to be another push factor for the emergence and maintenance of young carers' roles. Some participants who supported their parent(s) experiencing mental illness or substance misuse when aged 16 years or under, stated that fear of familial disjunction discouraged them from accessing support services. NZ service representative Tim said that in such cases, families "didn't allow outsiders in because they were too scared". Certainly, several young carers feared for the wellbeing of their loved ones if they were no longer able to provide care. Chloe explained, "There's a lot of uncertainty: If I don't do it, who will?" In addition, participants identified the loss of relationships that could occur if they were separated from their family. For instance, Dan said that he was "protecting … that mother-child bond: you don't want that to be broken even though you know it's [become] incredibly wrong". Unwell family members could inadvertently feed into participants' fears by sharing their own concerns with the young carer and encouraging secrecy surrounding their role. Dan went on to recall how his mother "would threaten" him and his sister "not to say anything to anybody, and not let us in the house unless we promised not to say anything to anybody … That was just her mental state" due to paranoid schizophrenia. Existing research also suggests a fear of familial disjunction underlying the hiddenness of young caring roles, with studies identifying the removal of young carers by social services as the root cause of such fear (e.g., Kroll, 2004). For instance, Hanna and Chisnell (2019) reported that young carers "usually want to continue with their caring responsibilities because they do not want to disrupt the family or risk being placed in state care" (p. 13). As such, some participants' fears of child removal could have been a contributing factor to their uptake and continuation of care in the present study.

Inadequate services.

Finally, all young carers' families used a number of formal services [see table 5], which participants understood as overwhelmingly aimed to meet their loved one's physical and medical needs. Services were carried out in formal and in-home settings, by a range of staff, and in short- and longer-term arrangements. However, a key narrative throughout young carers' interviews was a lack of adequate services for individuals with disabilities and illnesses and their family/whānau/aiga, which acted as a fundamental push factor for young carers' roles. Five barriers to the commencement and longevity of services underscored young carers' descriptions of inadequate support, being the propensity for services to be: (1) difficult to access, (2) piecemeal and ad-hoc, (3) narrowly-focused, (4) inflexible in their delivery, and (5) culturally unsuitable. The following discussion continues to address the creation and maintenance of young caring roles, but also addresses how current public policies, services and practices affect young carers' access to and use of support.

First, **difficult to access** services was the first significant barrier identified by participants. Young carers said that families were expected to approach services, despite their lack of understanding of the breadth of support available, and without guidance to navigate the process. Amelia explained that her family struggled to access services because "at the time we didn't really exactly know how it works" (Adult, 36, Tongan, elderly grandmother, aunty with paraplegia). In fact, many young carers outlined a model of service access whereby families were required to fight for services to secure the support that they were entitled to. Leah explained that even though her brother "is what you'd call completely dependent", accessing services was "a battle … Recently, they decided that he was going to be mentally ill and not autistic, which is just like anyone else! … [So] mum's on the phone for hours at a time negotiating funding" (Current, 17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness). This echoes Collins and Willson's (2008) assertion that "whānau caregivers find that accessing necessary entitlements for the person they care for can be stressful and time consuming" (p. 28). McDonald et al. (2009) quote a participant who needed to "'stamp my feet and throw tantrums' to get what was needed" (p. 124). Such continual pushing for services was difficult for families who were already overloaded with responsibility, and could result in a lack of formal care even when families wanted such support. For instance, Louise said that despite beginning her caring role age five, "I was 17 before dad got assessed for home help hours [after] my uncle threw his toys out the cot and went to his MP" [Member of Parliament].

Young carers understood that the fight for services required 'disabling' their care recipient, by highlighting their weaknesses rather than strengths, which could create a further barrier to services. In some instances, participants described the inappropriateness of disabling the very person whose dignity, autonomy, and continued roles and relationships the family and care recipient worked hard to uphold. Mary said that her mother hated "to be debilitated in that way … she didn't like to be perceived as a cancer patient … she never cried, she was always staunch, and she never wanted help". As such, the need to disable an individual to access support placed doubt in families' minds regarding the capacity of services to care for their loved ones in a manner that aligned with an empowering model of care. In turn, service representative Tim asserted that families often ask

Table 5

Services Used by NZ Young Carers' Families

Type of service	Comprising	Understood to	Accessed by
Medical	Doctors, specialists, surgeons, nurses, ambulance	Address physical symptoms, be carried out in a formal setting (e.g., hospital, clinic), be an intensive, short-term service, and abruptly stop upon patients' medical stability, or recovery.	100%
Support staff	Nurses, physiotherapists, disability support workers, formal caregivers	Maintain care recipients' physical health and day-to-day living, provide family/whānau/aiga carer respite, be primarily carried out in-home, and rarely address mental illness.	Over 50%
Financial	Childcare, Health, Disability, and Care Benefits, Disability Allowances, Childcare Grants, health insurance	Cover medical, housing, food, education, and formal care-staff costs.	Over 50%
Family/whānau/aiga	Sibling and carer support, social workers, crisis teams, counselling, emergency services	Be accessed via referral from one of the previous three service groups.	Over 30%
Young carer services	Workshops, groups, respite opportunities	Specifically address young carers' respite, social, mental health, and educational needs.	None, but requested by most

whether services are "going to get the results that I want? Or, is it better to say, 'no I'll do it myself because I know what … is best for my child, my sibling, my brother?'"

The task of accessing services was made especially difficult for Māori young carers who did not share prevailing medicalised notions of disability and illness. The requirement to disable an individual in order to access services relied on whānau speaking the language of disability. However, Māori young carers' interviews suggested that whānau were unlikely to do so. For instance, Māori Kahurangi said that her mother "never, ever thought [her daughter] had schizophrenia. She sees it as a tohu, a sign". A NZ report into Mental Health and Addiction (GIMHA, 2018) identified "that the Western model of mental health, enshrined in the health system and legislation, is based on beliefs that are not shared by all Māori and are not always helpful" (p. 39). The inappropriateness of disabling a loved one could extend beyond Māori participants, however, to family/aiga who described the taboo nature of mental illness and some disabilities and illnesses. In such cases, families were unlikely to discuss certain aspects of their loved ones' conditions with needs assessors, even if they were fluent in the language of disability. Hong Kong Chinese-born Chun said that her father could not acknowledge his mental illness “because he genuinely did not see that it was a mental health issue … He interpreted it in a different way [so he] didn’t have the language [to] associate it with mental health [and] reach out for help”. Service representative Kyle also addressed tensions surrounding the term “mental health”, which carries:

> a lot of negative connotations … the sector [is] making it harder for ourselves than it needs to be ‘cause we’re using the wrong phrase and terminology. But .. you’ve got to use words that everyone’s familiar with as well, otherwise we won’t convey the awareness. So it’s really challenging.

Overall, the requirement to fight for services could result in care gaps being filled by young carers.

A second element of the disabling fight for services was their family’s inability to speak the language of services, which locked them out of possible support options. Hong Kong Chinese-born Chun explained, “It’s the health literacy side of things [that is] really difficult about [accessing services]”. Several participants identified the support of key family members who were able to navigate the system due to their experience in the industry as a key reason for their access to services. Mele explained, “Mum’s younger sister [is a] trained family caregiver … she basically organised access to health resources … I actually don’t know how she organised that”. Several participants felt that the expectation for families to speak the language of service agencies was discriminatory against non-English speaking family/whānau/aiga, for whom the requirement to speak not only English, but understand complex terms, acted as an even greater barrier to support. Tongan Mele went on to consider that if service access was difficult for her family who spoke English and had a member who was a trained family carer, then what about “migrants from Tonga who don’t know how to speak in English, and they’re not educated – how are they supposed to deal with it?” Similarly, Hong Kong Chinese-born Chun stated:

> I can’t expect my father to [organise services] because … the language would have been a problem … even someone with okay English will still struggle! I keep imagining, what would happen to my parents if they didn’t have any children … or if their children migrated later?

In such cases, young carers could take over the service coordination role, due to their ability to speak and understand English. Existing NZ studies have also identified the role of hard-to-access services in the uptake of young caring (e.g., Hanna & Chisnell, 2019; McDonald et al., 2009). As such, young carers could be leading the fight for services, especially in cases when their family did not speak or understand English.

Second, even after overcoming access hurdles, many young carers described the difficulty of dealing with the many **piecemeal and ad-hoc** services that each treated one aspect of their care recipient’s disability or illness. Rather than integrated services, a compartmentalised system prevailed whereby many different services, each with its own narrow focus, provided support. For instance, Leah’s interview revealed her family’s piecemeal use of home-help carers and nurses, therapists, doctors, specialists, and respite services. Young carers struggled to co-ordinate so many compartmentalised services, which added another task to their care workloads. Chun said such a role could be difficult as, following her stroke and the onset of dementia, her mother “had so much health history, and [the different services] are not necessarily aware of that”. Participants also shared their frustration with a lack of clarity surrounding the ongoing support for which their care recipient was eligible, which left many participants “in the dark about where to next” (Chun). Terrence said that “there was no follow up” after his mother’s discharge from formal services (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability). Such a lack of ongoing support once again appeared to create care gaps that could be filled by young carers. For instance, Tilly said that her role began following her sister’s discharge from hospital, as “her life is really crap … [because] she wasn’t allocated many [formal carer] hours from ACC [Accident Compensation Corporation] so she couldn’t really do too much” (Adult, 44, Pākehā, twin sister with tetraplegia). UK service representative Jodie asserted that for services to be effective, “the main thing is that you actually have a strategic approach to what you’re doing … The worst thing that can happen is just this random, ‘We’ll get somebody in’ [but] … where’s your debrief, where’s the [ongoing] support?” Consequently, a piecemeal service model lacking long-term support appeared to play a role in the creation and maintenance of young carers’ roles.

Accompanying the piecemeal services was a continuous stream of new and unfamiliar care staff. Service representative Tim stated that “the high turnover of staff is just huge” in NZ, a notion reflected by Amelia, who recalled that her grandmother and aunty were “not really happy with the people coming in [who] keep on changing”. A significant barrier to services identified by young carers was the inappropriateness of having a “stranger” (Amelia) in the home, due to their care recipient’s desire for privacy. Mary explained, “Mum was very private [so] she didn’t want people to see her without her wig on”. In addition, participants said that new staff did not understand their loved one’s unique needs and preferred care styles, so they had to brief the many new staff. Grace described the importance of such briefing so that formal care staff can “find out what suits the person … to learn about [their] ways and how cares should be done and what [they] should be doing”. Participants could, however, face resistance to a young person demonstrating a care recipient’s needs to staff, resulting in their insights going unheard. Chloe said that she felt “so helpless … no one ever spoke to [my sister and I] … and we could have easily said … ‘Mum's falling this many times a week’ … [then] all those [supports] that should have happened [would] happen”. Hanna and Chisnell (2019) asserted that a “key aspect” of services “should be to listen to what children and young people are saying and involve them in professional discussions about their own care and that of their parent(s) and siblings” (p. 13).

In many cases, short-term staff were not conducive to young carers’ overall role perception of maintaining their loved ones’ roles and relationships. Without cognisance of the unique functioning of their family, participants perceived that formal carers could fail to see the continued roles that their loved ones played, alongside the role rearrangement of other family members who kept their family/whānau/aiga united. In fact, participants said that staff could undermine or even take over theirs’ or their care recipient’s roles. Anna explained that one of her boyfriend’s father’s formal carers “was just such an intrusion on our space, taking over like somehow there’s a deficiency in mine and [my partner's] level of care. Oh, it was just an awful, awful feeling”. Ultimately, some young carers perceived that the many new staff could not provide care in a way that aligned with the individual’s and family/whānau/aiga’s values, and formal services could thus be resisted or rejected.

In contrast, long-term care staff could have a significant, positive impact on young carers' acceptance of formal support. In the two cases where participants described longevity in a care staff member, a positive services narrative prevailed. Grace and Louise were comforted by having a familiar carer who "became a family member" (Grace). Grace recalled that her sister's carer "loved my sister and me". Likewise, Louise stated "we had a couple of district nurses come in that I got to know really really well over the next eight or nine years … they really cared". Participants described the stability and respite that longer-term carers gave to them, and furthermore, to the primary *adult* carers and care recipients who had someone to confide in. A stable carer could alleviate a significant emotional workload for young carers, in the form of social and emotional support for their loved one and other family members. Grace explained that her family's "home help lady [is] awesome. She's been through quite a bit with mum 'cause mum couldn't really talk to me … about how she's feeling and stuff [but] … mum could talk to her". Many existing studies highlighted the positive impact that regular care providers, familiar with the family's care arrangements and preferred means of care, can have on care recipient wellbeing and familial confidence in services (e.g., Moore & McArthur, 2007). Overall, a piecemeal service system with a high turnover of formal staff was often inconducive with participants' and their family/whānau/aiga's conceptualisations of care, and could as a consequence, result in a refusal of services in favour of young carers taking over or continuing a caregiver role.

Third, as a consequence of a piecemeal system, participants felt that services were **narrowly-focussed**, with no single service able to gain a holistic or full picture of their loved one's health or overarching needs. Instead, young carers said that individual staff got snippets or a snapshot of the extent of their care recipient's health conditions, rather than a holistic understanding of the context and the full extent of their disability or illness. Alice explained that even though cerebral palsy "is a very broad term and the spectrum of it is quite large", services viewed the condition via "little boxes and [my brother] doesn't quite fit [so] he misses out" (Adult, 25, Pākehā). Young carers' perceptions of a lack of service holisticity was exacerbated by a lack of clarity surrounding the parameters of care provided by individual providers, and a dearth of communication between the many compartmentalised services. Without clear guidelines and communication among service providers, young carers felt that many of their loved one's needs went unmet. In some instances, young carers perceived that staff assumed other services were addressing those needs. Chloe explained that her mother with multiple sclerosis had

> two people coming to help her shower, and two people coming to do her respite, and it's like, "well, what do you think happens the rest of the time?" I feel like there's so many gaps that could have been filled, or people could have realised what's happening.

In other cases, participants said that their loved one simply "fell through the cracks" (Lucy), something that was all too easy without an overarching plan or co-ordinator. Such a 'falling through the cracks' was evident when Miharo described her and her siblings' increased caregiving role for their mother with a physical disability and schizophrenia, when the

> district nurses stopped coming. I think they didn't want to come into our house with the gangs there. So, we also had to bathe her … [And] sometimes we would do catheterising. I just didn't think it was right that we had to hold mirrors while she catheterised herself.

As in this study, a lack of holisticity among services is a common theme in NZ literature, with researchers stressing the need for effective, multi-agency systems that "work effectively together to assess concerns and support families" (Hanna & Chisnell, 2019, p. 13).

In particular, young carers highlighted the failure of services to address poor mental health. This reflects the commonality of undiagnosed and thus unaddressed mental illness outlined in existing literature (GIMHA, 2018). Young carers expanded on the finding of undiagnosed mental illness outlined earlier, stating that services' not identifying mental illness resulted in a greater care workload for them. Specifically, participants said that the absence of medication prescribed to address their loved one's mental health needs could result in their use of drugs and alcohol as "coping mechanisms" (Miharo), and thus increase the young carers' care load. Anna explained that her boyfriend's father "coped" with his cancer diagnosis by

> drinking … He was an alcoholic by anyone's definition … and when you're caring for someone [and] they want a drink, and they shouldn't be drinking … and you have to take it away from him, but they're someone who's so much senior to you … well it was all very *tense*.

Other young carers described staff being untrained in mental health, and burning out at peak times of their care recipient's mental unwellness. In turn, when care recipients required the greatest level of support, young carers could be left on their own to provide care. Miharo explained that her mother with a physical disability and schizophrenia

> was high maintenance and the carers would burn out really quickly. I knew she was burning people out because I could hear the caregivers quietly saying, "Oh my God, I don't know if I can keep doing this". … [so] the responsibility [on us kids] was huge.

Consequently, a lack of support for care recipients' mental health needs appeared to be a key factor in young carers' overwhelming care roles.

Narrowly-focused residential support services often failed to acknowledge care recipients' continued familial roles and enduring reciprocal relationships, especially when they were a parent. As outlined earlier, unwell family members' key roles and relationships were sustained regardless of the degree of their disability or illness, or residence outside the home. Conversely, young carer participants' narratives identified the dominance of a medical model understanding that framed services, whereby the maintenance of roles and reciprocal relationships seemed to be reliant on an individual's good health, alongside their physical presence in the home. In turn, services did not often identify care recipients' continued responsibilities when their disability or illness endured, or when they were in a residential placement. Miharo explained that although her mother received some support for her disability, "she actually became fixated on suing ACC for lack of attendant care and childcare" because she did not receive parental support despite remaining at home with her children. Existing studies also highlighted a lack of support for parents with disabilities, reflecting a wider services inequality for these parents (Newman, 2002). Wates (2002) asserted that if services instead aligned with a social model of disability, they "may be found more acceptable by disabled parents, since the focus is the removal of barriers to successful parenting, rather than identifying the parents themselves as the problem" (p. 44). Newman (2002) contended that such a social-model alignment is integral, as “the child’s well-being is best secured by ensuring that their parents are able to carry out their duties” (pp. 618-619).

Individuals’ continued roles and relationships also relied on residential services being mindful to include the family/whānau/aiga unit. In some cases, young carers felt unable to visit their loved one regularly, due to distance. Chloe said that her mother’s care facility, “was quite far out of town … we couldn’t like walk or bike to see her, so it was quite hard in that respect”. In other cases, residential services restricted the number of visitors allowed. Such restricted access acted as a significant barrier to enduring roles and relationships – key elements of Taha Whānau social wellbeing – especially among Māori and Pacific participants, who said that visiting their loved ones was key for all family/whānau/aiga members. Tongan Mele explained that “all family members come and see the elderly, so … it’s my grandma’s sister’s family, that includes her kids, and then her grandkids, and then my grandma’s brothers’ whole families”. Mele is supported by Bellamy and Gott’s (2013) assertion that it is essential for “large family groups keen to be involved in care” to have their needs met (p. 29). In turn, services could be seen as inappropriate for meeting a loved one’s holistic and specifically social/whānau needs. Overall, without a holistic understanding of care recipients including their continued roles and relationships, the ability of services to implement “adequate” support appeared unlikely.

Fourth, services being **inflexible in their delivery** was a further barrier to their suitability, which appeared to contribute to the creation and maintenance of young carers’ roles. Participants often said that services were not flexible enough to cater for the episodic nature of their care recipient’s disability or illness, or their care recipient’s age-related development. In turn, services could become “not enough support” (Terrence) or “too overbearing” (Anna), and could be deemed to no longer meet their loved ones’ needs. Grace described how her sister with a disability learnt to turn on the taps, “so she has flooded the house I don’t know how many times? [But] mum’s had to wait for *years* for [services to] actually put [the tap] on the wall in a locked cupboard”. Furthermore, services were not deemed to be adaptable to the changing circumstances of the family/whānau/aiga unit in which the care recipients were embedded. Leah explained that when “mum and dad go away on the respite funding … I can’t be paid for looking after my brother … instead someone else is paid to come and sit in the house while I do the looking after”. Young carers believed that services inflexibility was a result of the absence of feedback and feed-forward not only between services, but between care recipients and their family/whānau/aiga. Additionally, participants identified the expectation for families to request changes or additional funding, which was daunting for young carers. For instance, Tilly said, “I think [services] definitely take advantage of people … because [they’re] not going to tell you if you are entitled to something … You have to really push to check if something is available [and] it’s quite hard as a young person” (Adult, 44, Pākehā, twin sister, tetraplegia). As such, despite their care recipient being in receipt of services, young carers often filled in when changes to their loved ones created care gaps, as they could provide more “dynamic” (Greg) care. Aldridge and Wates’ (2005) research echoes this finding, as she found that “the onset and continuation of care by children occurred” largely because young carers “could provide more consistent, flexible, and long-term assistance – aspects of intervention that were missing from health and social care services” (pp. 83-

84). Saxena and Adamsons (2013) have stressed that “families and siblings change over time” (p. 310), and thus services must remain in communication with, and be flexible to meet, care recipients’ and their families’ changing needs.

Fifth, services were described as **culturally unsuitable** by numerous young carers. This final section of service inadequacy will explore young carers’ diverse and culturally-embedded understandings of caregiving, disability, and illness, which led to variation in their understandings of what were appropriate services. This examination will highlight three other key circumstances creating and maintaining young carers’ overwhelming roles, as they filled in for culturally inappropriate services, being a lack of relevant language support, the tendency for services to match staff to families based on culture, and the challenge of enacting cultural models of collective care in the modern society.

A lack of relevant language support was evident when services did not cater to the seven young carers from families who did not speak English as the primary household language. A trend was noted whereby elderly family/whānau/aiga who oftentimes did not speak or understand English were excluded from conversations around their or their loved one’s health, due to the dominance of English spoken in formal services settings. As discussed earlier, young carers translated during English-language appointments to Cantonese, te reo Māori (Māori language), Tongan, and Samoan. However, young carers not only translated words, but also concepts. A deeper examination of the findings with new understandings about culturally-diverse conceptualisations of disability and illness among participants, brings to light the cultural translations being undertaken by young carers. Specifically, participants had a key role in translating taken-for-granted dominant notions of disability, illness, and care underlying service discussions into Māori, Pacific, or Asian understandings and worldviews. In doing so, young carers reconceptualised messages from service providers into culturally appropriate and meaningful language, thus bridging the gap between the prevailing medicalised terminology and culturally significant understandings of disability and illness. For instance, Chun translated using her father’s understanding of mental health, shaped by his traditional Hong Kong Chinese culture, as she explained, “I didn’t want to frame it like [mental illness] because it means [dad] might just shut off [so I] … framed everything from that sort of Buddhist religious lens”. Young carers also enfranchised their family/whānau/aiga’s use of services by alleviating doubts regarding a service’s capacity to meet their loved ones needs. Tongan Amelia said that she tried to make her elderly grandmother and aunty with paraplegia "open up [and] be comfortable … with services [that can] help them … instead of being private in their own [house] … [because] they found it really hard”. Despite participants being aged just 5-25 at the time of providing such support, they demonstrated not only their linguistic bilingualism, but also their ability to navigate meanings and understandings among cultures. Ultimately, these young carers could bridge the gap between strongly medicalised and individualist disability and care narratives underlying formal services, which could act as a barrier to indigenous and migrant family’s access to services.

For the young carers in my study, the tendency for services to match staff to families based on culture could act as a barrier to service access for Pacific aiga. Samoan and Tongan participants emphasised that care staff who aligned culturally with their aiga were inappropriate providers of care, because they could expose stigmatised illnesses or disabilities to the wider tight-knit community. Mele explained, “We wouldn’t want Tongans because grandma has dementia, which is quite a stigmatised disease … We’re a small community in NZ and they would expose our family”. Likewise, Tongan Amelia explained that “some Island [staff] … gossip when they leave … even if it’s confidential. So it’s important for my auntie and my grandmother to feel comfortable and not think, ‘She’s going to go and tell this to some other Tongans’”. Participants perceived that such gossip in the community would jeopardise their loved one’s standing or position, as well as make them feel uncomfortable accepting support. Pacific young carers said that avoiding staff from their own culture was difficult, however, as “a lot of the carers are Tongan women” (Mele). In instances when Pacific staff were providing care within Pacific families, participants described hiding the extent of their loved one’s disability or illness and, in some instances, ceasing service use altogether. Tongan Amelia recalled that her grandmother and aunty discontinued formal support after “a couple of months … They decided no, they want me to carry on”. The importance of also recognising variance between cultural communities and individual families was highlighted, for instance, as Tongan Mele explained:

> Pacific [people] tend to be all lumped in one, but all of those different Pacific ethnic groups are different; we have different languages, we have different customs. So services are not tailored to meet the needs of those certain groups, so then we won’t [use them].

Mele’s sentiment is reflected by Agnew et al. (2004), who identified that “ethnic matching of consumers and/or families with service workers or therapy groups is not necessarily appropriate for all Pacific” aiga (p. x). Individualisation of services thus appears integral, not only between divergent groups of young carers, but also within cultural groups, in order to understand the family/whānau/aiga’s unique care style, support needs, and preferences for carers.

Young carers indicated that their cultural models of collective care were often challenging to maintain in the modern society. A move was evident from family/whānau/aiga care, which would have historically been provided by many family members working together to meet the needs of their loved ones, to a reconceptualisation of familial care within an individualist society, being undertaken in some cases in isolation by young carers. Hong Kong Chinese-born Chun explained, “It is quite usual for Chinese family [to care] … so it’s expected for people to just do it … [but] I did feel really alone … [because] I felt like at that time I didn’t really have anybody to [help me]”. Tensions among family/whānau/aiga could arise as few members sought to maintain the traditional roles meant to be carried out by many, alongside employment and taking care of their own offspring. Mele explained that despite the importance of aiga care for the elderly in her Tongan culture, “there was quite a big disagreement between my mum and her sisters, because they wanted to put [grandma] in a home, but my mum didn’t want to put her in a home … for cultural and personal preferences”. Mele explained, however, that she and her siblings “did most of the cares” because her mother worked to support the family, thus highlighting the tension between Mele’s mother wanting to enact a Tongan aiga model of care, but facing competing demands. Similarly, young carers described their own conflicting emotions between wanting to fulfil their culturally relevant caregiving roles, whilst also struggling to maintain the overwhelming load being carried by few members. Tongan Amelia explained “it’s me caught in the middle” as her family “say [grandma and aunty] feel safe to stay in their own little place and they all comfortable … [but] all I [do] is just stay with them and look after them". Collins and Willson (2008) stated that although "whānau values such as aroha and manaakitanga suggest that the tensions of caring for a whānau member would be spread around the entire whānau" (p. 30), in smaller whānau units, care can be undertaken by just a few members. This was reflected when Kahurangi highlighted the importance of care being "done with a very whānau concept", but stated

> the modern thing is Māori have become … so disempowered … we have compromised our cultural way of being and that's a sad thing … If we had that united whānau and that really whanaungatanga concept … we wouldn't have to be reliant on services to step in.

As such, the participants' stories indicated that a collective model of care was difficult to enact in a modern-day individualist NZ society.

Despite describing their family/whānau/aiga's aversions to formal services, the participants were often open to such support. Several Māori, Pacific, and Asian young carers encouraged an integrated model of care, uniting traditional and formal services, but said that their older family/whānau/aiga members could staunchly refuse non-traditional services. Hong Kong Chinese Chun explained,

> My father was the person that for a long time I was the most concerned about because [I could see] signs of depression … I did suggest services to him but it not something he was willing to even consider … It's that older Chinese mindset … whereas I am able to reach out for help because I know it's all normal.

This description by Chun appears reflective of Heidbrink's (2018) explanation of how "care moves across generations and how moral and cultural values are brokered and regenerated" (p. 31). As such, young carers could hold differing views of care and service use to their older family/whānau/aiga members.

Service and agency representatives suggested several reasons for the inadequacy of services. Representatives said that the participants' fight for services reflected the dearth of available services, leaving few providers spreading themselves thinly across many care recipients. Service staff, therefore, did not have time to become familiar with care recipients and their family/whānau/aiga, nor address issues wider than the immediate medical concern. Tim recalled that when he worked in an aged-care facility,

> I only worked four hours a week with each person [because] the ratios [of staff to clients] were just ridiculous … it was just so draining and I felt so sad every time I came home, because all I was doing was getting Margaret up, putting food in Margaret's face, dressing Margaret, and sitting Margaret in the lounge … Just this routine bullshit. And I'd sit down on the bed and talk to Margaret [and] some really amazing stuff comes out … [but] I [got] told off for doing that.

Representatives also identified how low pay and long hours stood in the way of care staff's investment in care recipients' lives. Tim explained that care is "an unattractive industry because it's low paid … but it's an industry that's kind of easy to slip into because you don't [need] qualifications to get in there". The ease of entering this level of care service was also outlined by Jodie, who asserted, "A lot of … people who have been excluded from schools … go into care". Jodie did not suggest that being excluded from school resulted in an individual’s poor caregiving, but that students often ‘fell into’ care due to a lack of qualifications, rather than following their passion. The same factors underlying service inadequacies were highlighted by Aldridge and Wates (2005), who identified heavy caseloads resulting in a lack of time for staff to consider the wider familial context of care recipients. Ultimately, representatives conceived that young carers “tend to fill … the gaps in the services” (Kyle) due to a dearth of providers, low remuneration, and a lack of passion among staff.

This chapter has argued that while young carers often initially chose to undertake care due to key pull factors, the perceived inadequacies of services, alongside other push factors, resulted in participants often maintaining overwhelming roles that were no longer reflective of familial and culturally appropriate models of care. Taking into consideration the estimated 40,000 young carers aged 15-24 in NZ (MSD, 2019), then ongoing inappropriate services could negatively affect the lives of tens of thousands of NZ young carers. In the next chapter, the *impacts* of care for young carers will be examined.

CHAPTER SEVEN

Overwhelming Care Roles: A Key Factor in Negative Outcomes

This chapter continues to build on what it means to be a young carer in Aotearoa/NZ, by exploring the ongoing educational, social, vocational, and health impacts of young caring, including the transition to adulthood. The chapter is divided into three sections, the first of which presents findings that show that, despite demonstrating positive educational attitudes, most young carers experienced some form of educational marginalisation that often resulted in poor educational outcomes. The socialisation impacts of young caring will be embedded within this discussion, as a lack of opportunities to form deep friendships impacted on some young carers' school enjoyment. In the second section, young carers' non-disclosure of their roles will be discussed. Thereafter, their overrepresentation among early school exit and Y-NEET (Youth not in Education, Employment or Training) statistics will be unpacked, alongside their reduced experiences and opportunities to engage in higher education and employment. The final section will present an overview of health implications, identifying that almost all young carers experienced poor mental health, that could endure into adulthood, and which was often heightened by the disenfranchisement of their grief (Doka, 1989). Throughout this chapter, the impact of wider influences underlying participants' overwhelming care roles, rather than simply the existence of young caring itself, will be argued to result in the high prevalence of poor educational, socialisation, vocational, and health outcomes. As in the previous three chapters, to retain a sense of completeness I will begin with a story, which demonstrates the educational, social, and mental health impacts of young caring, in the context of one participant's caring experience.

Phoebe's Story

Phoebe is a current young carer who has supported her nana, mother, and younger brother since she was 10, due to her nana's advancing age and cancer, and her mother's bipolar disorder and substance misuse. Phoebe grew up between two sole-parent/caregiver households in the South Island. She identifies as predominantly Māori but also as Pākehā. Phoebe was 16 at the time of her interview and was in her penultimate year of high school.

My nana took me in when I was one. My mum was 17 when she had me and it didn't work out. I liked living with nan. I always lived with her, so she became my family, my mum. And I liked it 'cause I got to see my [younger] sister even though she was in foster care. Then when I was eight nan got bladder cancer and I had to move back to my actual mum's. Giving me back to my mum was tough for her, and I didn't really understand why I had to leave. Like, I knew that my nan was sick, but I thought "I should be staying with her when she's unwell".

Living with mum was different. I didn't like it. On one side, she was a good mum. But then the other side of her wasn't. That was when she was having her bipolar episodes. Basically, you could tell when she wasn't on her meds 'cause she was lying and talking to herself and ready for an argument to happen, and that was really scary. She'd hang out with quite dodgy people and make really bad decisions. I called [mum's friends] "aunty" and "uncle" but I didn't have respect for them because of what they were doing.

We were always staying at other [people's] houses after parties, so I had quite a lot of days off school and I hated it. I got jealous of my friends because they had their parents [who] would wake up and get ready with them and walk them to school. But I didn't get woken up by [my mum] even if we were at home; I got woken up by the alarm I set. And she didn't come and have breakfast with me or anything like that – it was just me getting myself ready and having to go to school on my own.

At that time, I played sort of a mum role, helping my baby brother. He would always come to me when he wanted hugs or when there was something wrong. My mum was still the practical mum, cooking and stuff for us, but she didn't really know how to do the whole "caring mum" thing, so he looked to me for that comfort. And I mean, it was good because we got close, but 'cause I was young I didn't really understand why my mum couldn't do it.

Then over the next two years, mum's bipolar got worse 'cause she didn't take her meds. She lied all the time. She lied about who my dad was and lied about [being] pregnant. I knew it wasn't true, but I played along because I didn't want to get her angry. I gave her space, but I'd stick around for her and for my brother. I knew she was sick, but I wasn't educated about the whole bipolar thing at that stage, so it was all really scary.

Supporting nan. In the end, I moved back in with nan in my first year of intermediate [school, aged 10]. My nan rang up and told CYFS[48] straight away, and CYFS told her that I couldn't go back [to mum's house], I had to stay in my nan's care. I'm happy 'cause living back with nan is calmer, and it's like nan is my mum again. But I worry about [my brother]. I wanted him with me, and I didn't find it fair that he had to stay [with mum], especially 'cause he's younger and still needs looking after. I was scared 'cause anything could happen while I wasn't there, [so] I'd go and stay whenever I could.

I guess it was quite strange when I moved back in [with nan] because it wasn't the same. The roles have changed. She can't do much things that she used to do 'cause she's sick and getting older [and] losing more of her independence, so I help her a bit more than she would like (laughs). She is a very hard woman, and [even though] you can tell that she wants me to help, she's like, "I can do it for myself" (said strongly) when really, she can't. But she's a very caring person too. I know she just wants [our relationship] to be the same as it was when I was younger. And it is, she's definitely still the person that I talk to about anything that I have on my mind.

She has a nurse every Monday to do her compression stockings, and [home help] comes and cleans the house each week. But because I'm the one who lives with her, most of the time it's just me and nan (looks sad). Mostly I just keep her company. We don't really go out. Hopefully soon I'll get my [driver's] license and then I can take us out more. But that's expensive and she's on the benefit, [so] we find it real hard to get by as it is. Half the time we only have one bag of groceries a week and it still

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[48] Child Youth and Family Services (CYFS) is a NZ government department that supports children whose wellbeing is at significant risk. In 2017, CYFS was renamed Oranga Tamariki: Ministry for Children (https://www.orangatamariki.govt.nz).

costs so much money. My school [supplies] and uniform are expensive too and having to pay that is quite hard. I'll ask dad, "Can you pay for school shoes?" or something like that, and he says, "It's nanny's job" or "Go to WINZ" [Work and Income NZ], but you have to pay WINZ back.

[Nan] has to go to the hospital sometimes. I go with her, but I usually just wait in the waiting room. When she gets real sick she has to get the ambulance to hospital. I can remember when she got real sick the first time, I grabbed all her medication and packed everything for her 'cause she was too ill to do it. It was so scary 'cause I never did it before. Now I do it fine 'cause I'm used to it. I stay home alone until she gets back, and it's all right. I worry though, 'cause she doesn't really talk about [her illnesses] with me, and it's kind of sad 'cause I'm usually the last one to know what's happened. I get quite emotional if I find out something bad happened because I feel like I should have been there to help; it's my responsibility. I know it's just the fact that she doesn't want me to worry, but I do worry. It's scary because I don't know how long I have with her. All I know is [that her illness is] ongoing and she keeps in a lot of pain because of it, but other than that I don't really know much.

School's pretty good, but I worry [there too]. If I wake up in the morning and [nan is] saying that she's not feeling well, I do worry about going to school because I'm scared that something will happen. But she won't let me stay home even though I want to. On those days I'm a bit down and can't focus on my work. Some of [my teachers] know that I live with my nan but not that she's sick [or] I help [her].

I do a few after-school things. Nan can't come into school to watch though [because] she has difficulty getting people to bring her, or there might be stairs and she can't walk up the stairs with her walker.

I find it hard to hang out with my friends. In the whole time I've lived with my nan [13 years in total], I've only had one person that's seen inside my house. I do ask her to have friends over but it's hard affording another mouth to feed, and the house is so small anyway. I don't really talk to my friends [about my home life] at all 'cause they don't understand. I do talk a bit about nan with my sister when I see her, 'cause her foster mum gets quite unwell, so she understands how I worry. I'd really like more people to talk to about it all (said quietly whilst crying).

Caring from a distance. I still stay over at mum's to be with my brother. I worry so much, 'cause he's not happy like a normal nine-year-old. I try to make him happy but it's real hard because he just shuts off and then he wants to be left alone. He doesn't really show his emotions and tell you how he's feeling. I worry that I didn't really get a chance to tell him why I had to go; it all happened so fast. Lately, he actually seems a lot happier. My mum and her partner aren't together anymore, so she's focusing on her and my brother and that's good. He really needs that one-on-one. And for me it's been good 'cause I've learnt more about her bipolar and I kind of get what happened now. I know a bit more and I understand why mum needs to take her meds. We don't really have a mother-daughter relationship but we're friends, or it's like she's my aunty, and that's okay.

My future. I'll go back to school next year. I want to be a fashion or interior designer [or] do something around music. I really want to go travelling too, but I don't know? I worry about my brother and my nana, ‘cause what happens to them if I leave? To be honest, it feels like I’m putting things on hold for me. I don’t really think about myself, and I worry more about what my nan and my brother and my mum need, rather than what I need. I find it hard because it’s good to care and be there, but at the same time, they always come first before my own stuff and there’s a lot to worry about.

I wanted to be part of [the research] to know more about other people that care. It’s nice to know there are other people out there going through the same thing as me, [and] hopefully we can get some support.

* * * * *

Positive Educational Attitudes and Experiences

Overwhelmingly, young carers and their family/whānau/aiga held positive attitudes towards school. Schooling was a key form of respite, facilitated participants’ maintenance of an identity outside of young caregiving, and provided stability and predictability that mediated their often chaotic home lives. For instance, current young carer Leah described how she “really liked the time out” from her caring role and home life that school afforded, as she explained, “My school days normally go from 8:30 in the morning to 4:30 in the evening, and often I have extracurricular stuff outside of school as well [because] I quite like to spend quite a bit of time outside of home” (17, Pākehā, brother with autism/intellectual disability, mother with undiagnosed mental illness). Likewise, Lucy said, “Learning has always been a bit of a salvation for me, like a comfortable place … [an] outlet” (Former, 25, Pākehā, mother with cancer). Reflecting Bronfenbrenner’s (1979) assertion that interaction between environments is reciprocal, the positive impacts of school were not unidirectional. Instead, a mesosystem-level interplay of home and school was evident, as capacities gained both in the classroom, and at home via caregiving, were interchangeable, with each context affecting the other. For instance, several participants described improved self-image gained via their achievements at school, which carried over to their confidence enacting caregiving at home. Fleur explained that she did “quite well” at school, which made her “more confident as a carer” (Adult, 39, Pākehā, mother with multiple sclerosis, brother due to mother’s illness). On the other hand, some participants asserted that the skills and maturity gained at home via caregiving, despite being unacknowledged, translated to leadership positions at school. Dan said, “I always made captains of teams and stuff … I guess I was seen as more responsible than some of the other kids” (Former, 53, Pākehā, mother with paranoid schizophrenia) – responsibility that Dan supposed resulted from enacting care. Previous research also identified such positive aspects of school for young carers, which can offer “respite from caring responsibilities” (Watt et al., 2017, p. 36), the “opportunity to leave the family home and have time out from their care” (Moore, Morrow, McArthur, Noble-Carr, & Gray, 2006, p. 24), and “help to preserve or restore predictability” (Sanders & Munford, 2016, p. 40). Overall, young carers held positive attitudes towards, and described the benefits of, attending school. Participants’ narratives suggested that fostering young carers’ optimism and motivation for education could be a powerful protective factor for their enjoyment and retention in the education system.

Negative School Experiences

Despite generally positive school attitudes and experiences, the significant challenges inherent in young caregiving could disrupt students' learning. Specifically, six challenges, outlined in Table 6, reduced young carers' capacity to fully engage with their learning. Each challenge acted as another layer of educational marginalisation, interrupting young carers' ability to fully invest in their education, and negatively impacting on their school attendance, enjoyment, and achievement. Taken together, the challenges appeared to significantly affect young carers' full access to education.

Table 6

Six Layers of Educational Marginalisation Experienced by NZ Young Carers

Layer	Experience causing marginalization
1	Irregular school attendance
2	Tiredness and distraction
3	Incomplete homework and poor grades
4	Restricted extracurricular commitments
5	Family financial strain
6	Limited social opportunities

Layer one: irregular school attendance. Caregiving significantly disrupted many young carers' ability to attend school. Most participants reported arriving late or leaving early from class, "wagging" (Grace) periods or entire school days, and experiencing significant stints of absenteeism. Phoebe said that due to her mother's bipolar disorder, "[Mum would] hang out with quite dodgy people and make really bad decisions … We were always staying at other [people's] houses after parties, so I had quite a lot of days off school and I hated it". Fleur recalled, "I spent less time at school than I did at home [due to] my care … and I didn't want to be at school if my mum was dying and [I] might never have a chance to see her". Young carers' narratives often revealed the forced choices they made between meeting their care recipients' needs, and attending class. For instance, Wyn said that after her father left for work in the morning, providing care for her unwell mother

> was me until the [nurse] came when I went to school … I remember [when] the nurse didn't come … and it was *horrific*: I didn't know what to do? I couldn't go to school. I kept hopping out to the gate to see if there was any sign of this woman (Former, 67, Pākehā, mother with diabetes/stroke/dementia/undiagnosed mental illness).

Miharo also recalled that her "mum would … need someone to stay home from school to help … [so my siblings] would sort out between themselves who would stay home from school to look after mum", while Lucy explained that her mother with cancer "was a teacher – and this sounds crazy now (laughs) – but some days I'd skip school and go and help her in the classroom, 'cause I knew she couldn't cope [when] she was really sick". Prior studies have reflected a similar dilemma, with young carers being "often unable to attend school" (Moore et al., 2009, p.10), particularly "when family obligations sometimes have to take precedence and school attendance is sacrificed for that reason"

(Cline et al., 2017, p. 528). In the present study, key factors underlying young carers' lateness and absenteeism were: parental unavailability due to their disability or illness, or their own caring role; intensive morning care routines completed prior to leaving for school; peaks or episodes in their care recipient's disability or illness, or times of palliative care; and the inadequacy of formal services, resulting in young carers' doubts that their care recipients' needs would be met while they were at school.

Layer two: tiredness and distraction. Even when young carers were present in class, tiredness as result of providing care, and concern for their care recipient, often impacted their ability to learn. Specifically, young carers' tiredness and worry impacted on their concentration and participation in class, involvement in school life, and overall academic attainment. Sally said,

> There was all sorts of things that just made it really difficult to think, to concentrate, to be present, because in the background you've got this pressure and worry: Is today the day that I'm going to be called 'cause she's been successful [in her suicide attempt]? (Adult, 32, Pākehā, mother with cancer/bipolar/depression).

Chloe explained, "[Care] takes so much out of you, like [my sister and I] were getting interrupted sleep all the time … I think in the long run it did … majorly affect our schoolwork" (Adult, 25, Pākehā, mother with multiple sclerosis). Young carers' worries were intensified when their care recipients had experienced poor health or emergencies in the past when they were at school. Chloe went on to assert that at school she:

> was always … [thinking], "Oh please, today don't let mum be on the floor" … [because] she fell so often when we were out, [and] there was a couple of times that she whacked her head on the sink in the bathroom and that was always quite scary.

Participants' concerns were also exacerbated when their loved ones were unwell or appeared distressed prior to leaving them for school. For example, Rachel said that every morning on her way to school "I used to think, 'is this going to be the week that dad rings and says mum has been admitted to the psychiatric unit, you've got to come home?'" (Former, 59, Pākehā, mother with depression, brother with muscular dystrophy). Likewise, Phoebe explained,

> If I wake up in the morning and [nan is] saying that she's not feeling well, I do worry about going to school because I'm scared that something will happen … On those days I'm a bit down and can't focus on my work (Current, 16, Māori/Pākehā, mother with bipolar, brother due to mother's bipolar, grandmother with cancer/arthritis).

Wyn remembered when she was nine-years-old,

> one morning the [insulin] needle broke in [mum's] leg and I needed to get help … So I headed for the neighbours and they rang [the doctor], and I stayed at home until … he got it out. But I'm not sure what happened after that, because the neighbour told me to go to school, and I didn't want to go to school, but I went. [But] from then on it just became more important to know that she was ok and what she was doing when I was at school.

Participants' tiredness and worry is reflected in many existing studies (Cluver, Operario, Lane, & Kganakga, 2012; Moore et al., 2009). Aldridge et al. (2016) identified the tendency for young carers "to experience tiredness when in school" (p. 57), while Leu et al. (2018) reported that young carers "often had trouble concentrating" at school, "due to worrying about their ill or disabled family member" (p. 932). Overall, young carers' tiredness, coupled with concern for their loved ones' wellbeing in the hours that they were at school, made concentrating in class difficult.

Layer three: incomplete homework and poor grades. Poor academic achievement represents the third layer of many NZ young carers' educational marginalisation. While several young carers achieved well at school, overwhelmingly participants described their caregiving roles as interrupting their capacity to complete homework, meet deadlines, and prepare for examinations. Fleur said that "school never really worked" for her due to her role caring for her mother with multiple sclerosis: "I never gave it much attention. I think I could have been really good at school, but I just wasn't very into it". Current young carer Leah also struggled to maintain school and caring, as she explained:

> I quite like school [but] last year it was a bit nuts because I missed lots of deadlines [and] often [didn't] get my homework done … because I was looking after [my brother] … [I] would be on the threat of detention [which] is really bad! (sounds stressed).

Reflecting Davey and Jamieson's (2003) notion of "potential" versus "actual" learners (p. 278), young carers understood that their school performance was not reflective of their actual ability. Louise asserted that such a mismatch in potential and achievement existed due to an "expectation" regarding students' commitment:

> Most kids would just go home and all they have to do is school work, but it wasn't really a priority for me … in my final years, [I was] picking easier subjects just because they took less effort; I didn't have to do so much at home for them (Former, 25, Māori, mother with illness/stroke, father with arthritis/stroke).

Participants' experiences of not fulfilling their potential are echoed in prior research (e.g., Stamatopoulos, 2018), with almost half (n=22) of the young carers in one Australian study reporting "that their grades at school were not as good as they could have been because of their caring responsibilities" (Moore et al., 2006, p. 40). Most participants in the present study felt unable to achieve highly due to the difficulty of balancing schoolwork and caregiving.

Layer four: restricted extracurricular commitments. Young carers were often unable to participate in extracurricular activities despite their desire to do so. Most participants joined an elective activity at some point, but almost all young carers reported the challenge of seeing their commitment to fruition. Kahurangi recalled, "I was quite good at sports but … I couldn't play … because I had jobs to do and caring to do" (Adult, 51, Māori, father and mother with cancer, brother and sister with schizophrenia), and Rachel remembered, "I didn't play any sport or anything because I knew my mother needed me at home … I [was] carrying a big load". Similarly, current young carer Atalanta said that while she is in

> a band at the moment … [but] it's annoying 'cause like, if I say "I need to be back by this time", they'll be like, "No 'cause you've got commitments", and I'm like, "Well that [being home for mum] *is* my commitment!" (said very forcefully) (12, Pākehā, mother with chronic illness).

Key barriers to participation were participants' caregiving commitments, their concerns about their loved ones' wellbeing, physical and emotional fatigue, and a lack of financial means to pay for uniforms and excursions. Young carers' lack of involvement or difficulty investing in extracurricular activities is not uncommon. Reflecting the results of the present study, Moore et al. (2009) found that while the 51 school-aged young carers in their Australian study regarded extracurricular pursuits as "important", over half were "unable to participate in activities outside of school hours because they were needed at home" (p. 11). However, in several cases in this study, young carers successfully maintained an extracurricular activity, when the activity occurred during school hours, or when another family member was able to provide them with respite to attend. These participants highlighted the benefits as receiving respite, developing friendships, receiving recognition, gaining a sense of achievement, and being given leadership opportunities, all of which reflected the positive school experiences outlined at the outset of the chapter. For instance, Dan explained that he enjoyed "all the team ethics [and] friendships … and positive reinforcement" that came from playing softball and rugby, and "worked in a dairy … so I could make money to buy rugby boots". He shared a particular instance in his interview, when he was selected aged 13 to play in

> a national softball tournament … I remember when I was batting, the ball just seemed to be coming to me in slow motion, it was like a big melon, and … everything just came together and I'm sort of flying … [Afterwards] I just remember sitting there in the changing rooms with these other players, and everybody had a fantastic smile on their face, and it just meant the word to me: it just really gave me a lot of strength that I'd done that. And then when I went back to school kids found out about it, and they started to respect me … I got bullied at school, but that changed after that point.

Layer five: family financial strain. The fifth layer of educational marginalisation was a lack of financial resources. Many young carers mentioned their families' financial constraints, which resulted in their inability to afford resources including laptops, school uniform items, extra-curricular activities, school trips, and healthy food for lunches. Lucy recalled, "there'd be field trips [but] I'd be like, 'Oh, we can't afford it so I'm not going to do that'", and Phoebe said that "school [supplies] and uniform are expensive too and having to pay that is quite hard. I'll ask dad, 'Can you pay for school shoes?' or something like that, and he says, 'It's nanny's job' or 'Go to WINZ'". In particular, participants working to support their families struggled to balance their work with school. Ngākau said that she would be tired in class because "I was working in a dairy after school and all weekend … [as] a financial contribution to our household … And that was quite a lot of work when I think about it, it's like 10 hour shifts" (Former, 49, Māori, brother and sister due to parental employment and mother's undiagnosed mental illness). Similarly, Lucy explained, "I started [working] when I was 12 [because] my family didn't have much money. So I would go to my job after school … teaching dance, and also work[ing] in an ice-cream store" (Former, 25, Pākehā, mother with cancer). Such work commitments could further exacerbate the negative school experiences outlined in this chapter. This is consistent with previous studies, which outlined the strain placed on educational attendance and achievement for the many young carers living in households affected by financial strain (Aldridge et al., 2016; Moore et al., 2009).

Layer six: limited social opportunities. Representing the final layer of educational marginalisation was young carers' experiences of social isolation. Participants identified four key barriers to the formation of deep and meaningful relationships being: a lack of shared life experiences with their peers, non-disclosure of their caregiving roles consequenting in a lack of honesty in the relationship, limited time outside of school hours to cement friendships, and emotional outbursts resulting in participants' feelings of being different to their peers. For example, Greg found that his "relationship with girlfriends and friends were effected … [because] I didn't really talk about it, and they were understanding but not particularly (shakes head)" (Former, 28, Pākehā, father with cancer/heart attack). Likewise, Lucy explained, "I just struggled to actually have really honest relationships, because I didn't want to talk about the truth, and when I did, it became too much for people". Phoebe said that she found it

> hard to hang out with my friends. In the whole time I've lived with my nan [13 years in total], I've only had one person that's seen inside my house. I do ask her to have friends over but it's hard affording another mouth to feed, and the house is so small anyway. I don't really talk to my friends [about my home life] at all 'cause they don't understand.

In some instances, young carers intentionally resisted close friendships, selecting peer groups who would not be interested in their home lives. Grace chose to hang with

> the wrong crowd … I didn't want to let anyone in to know that side of me … [And] those sort of people will only attach themselves to you for a good time out, but there's no close bond, like "oh come over to my place for a movie". It's just for meeting up and getting wasted … That's why those sort of people attracted me; 'cause it wasn't a grounded friendship … I still don't actually have a lot of friends … that's why I'm pretty lonely now. But I'd rather be lonely than hang out with a bunch of people that don't really give a shit about me (Current, 21, Pākehā, sister with physical and intellectual disability).

As evident in Grace's quote, young carers' reduced chances to establish deep friendships could result in limited social networks that endured beyond school. However, the importance of deep friendships was highlighted by the seven young carers who reported succeeding in forging strong connections. Lucy explained, "There's that different level in which I never have to explain myself because they grew up with me and they understand, especially now that we're a bit older, they get me". Greg explained how much he valued his

> one friend who had lost her father when she was 13: we bonded over that [and] we talked about it … [Because] a lot of my friends haven't even lost their grandparents let alone lost their parent, and so … the realities of terminal illness and death and painkillers and hospital: It's just concepts that are entirely foreign to other people of this age bracket. They were totally naïve and not empathetic really.

Over a third of young carers were bullied, reflecting their lack of belonging amongst their classmates. In no NZ cases were peers aware of their young carer role. Participants instead believed that their heightened maturity, their peers' awareness of their loved one's disability or illness, or their family's difference (e.g., as a single-parent household experiencing poverty), led to bullying. For instance, Leah explained,

> I didn't like intermediate. I got quite badly bullied there. Part of it was to do with [my brother] being disabled … I think it probably started with me being completely naïve and assuming

> that everyone not only found it normal, but would understand and not think it was weird. And so there was a lot of 'retarded by association', which is just disgusting.

Similarly, Dan recalled, "I got a lot of bullying at school, a hell of a lot of it … [so] I was a scared kid … I was cornered and attacked and punched … [I] must come across as being different". Many studies have found "a higher likelihood of bullying" for young carers versus their non-caring peers (Aldridge et al., 2016, p. 57; Bibby & Becker, 2000), with researchers also highlighting that bullies target students in families experiencing a members' disability or illness (Gray et al., 2008). Overall, most young carers reported a lack of deep friendships established at school, as well as instances of bullying, which could culminate in their limited social networks extending into adulthood.

In the second section of this chapter, the reasons underlying young carers' decisions not to inform their teachers of their young caring roles will be unpacked. Thereafter, instances of early school exit will be explored, followed by a discussion of the positive influence of strong teacher-student relationships. The section will conclude with an examination of young carers' higher education and vocational experiences, including their overrepresentation in NZ Y-NEET statistics.

Non-Disclosure of Caring Roles to Teachers

All young carers chose not to disclose their caregiving roles to their teachers, and instead "just left it" (Louise). They gave several reasons for their non-disclosure. Reaping the positive elements of school described at the outset of the chapter required participants to maintain a level of blending in amongst their peers. Dan said that at school, "I wanted to be normal like everybody else, 'cause that's what you want to do as a kid; you don't want to be different". Other participants were not able to inform their teachers "because I didn't even know at that time I am a young carer" (Amelia). Participants identified multiple opportunities when their teachers could have picked up on their caregiving roles, but could not due to their own lack of knowledge of young caregiving. This resonates with Moore's (2005) argument that "as the wider community has little awareness of the existence and needs of young carers, so too is there a lack of awareness of young carers within schools" (p. 54). Research consistently highlighted the positive influence that teacher awareness of young caregivers, coupled with tools to meet their needs, can have on students' educational achievement and retention (e.g., Becker & Sempik, 2019). This is reflected in my study, among the several young carers who disclosed aspects of their loved one's disability or illness – but in no cases their caring roles – to their teachers. Wyn said that her teachers "were aware" that her mother was unwell, "so I never got into trouble for being late … so I liked school and the teachers". Leah explained, "This year I talked to my deputy principle" about her brother's disability and the difficulties that she was having at school, resulting in her "dispensation from homework if I need it … which was great! I think my grades have improved because I'm not sitting there stressing about 10 million different things".

However, many participants perceived that even if they told their teachers about their roles, there was no guarantee that they would understand what this meant for the young carer. Participants identified a wider macrosystem, societal-level lack of awareness of the reality of living within a family/whānau/aiga experiencing disability or illness, so that teachers would not comprehend the impact of participants' role and home-life-realities on their schooling. For example, Grace said, "I don't think it would be much different" if she told her teachers about her caregiving or her sister's disability, "'cause I don't think they're educated, they don't really know what it's like. They'd just brush it off, like as if it was a little baby in the house or something". Likewise, Lucy explained that she would not inform her teachers as "there was no way that they could have understood what I was doing". The participants' sentiments were reflected in Sempik and Becker's (2013) finding that young carers often felt "there was no point" informing teachers of their roles (p. 17). Overall, young carers chose not to disclose their roles due to their desires to be normal students, lack of awareness of their caring identity, and/or perceptions that their teachers would lack understanding.

Early School Exit

Of the 19 young carers who provided care whilst of secondary school age (12-17/18 years), over 20 percent (n=4) exited school prior to the start of Year 12. According to the Ministry of Education (2017a), these four young carers are early school leavers, as they left school prior to or at the age of 16. This instance of early exit among young carers is higher than that reported in recent statistics, which placed NZ early school leaver rates at around 11 percent (Education Counts, 2019). The findings of the present study reflect those of international young caring studies, however, which identify reduced school completion rates for young carers compared with their non-young-caring counterparts (Carers Australia, 2002; Moore, 2005; Moore et al., 2006). For example, one Australian report found that "young carers were less likely to have completed" high school than non-young caring students, with "only 41 per cent of young primary carers" having completed secondary school, compared with 65 percent of non-young carers (Hill et al., 2009, p. 57).

Table 7

NZ Young Carers' School Leaving Ages

Year level	Age	Number	Percentage %
Year 10	14-15	2	11
Year 11	15-16	2	11
Year 12	16-17	1	5
Year 13	17-18	14	74
Total		19	100

Note. Table 7 does not include the nine young carers who were not of school age at the time of providing care (i.e., they began care when they were aged 17/18 or over).

The four early-exiting young carers stated that rather than having any actual desire to leave the education system, their premature departure was, in part, due to a lack of support to maintain both school and caregiving. For instance, Amelia said,

> I really love school, [but] I was 15 [when] I didn't go to school … I just stay home with grandma and aunty and look after them … [and] to weave stuff that we sell [because] we didn't have any income at all … So at that time I [was] feeling sorry for myself, like "oh my

> goodness, my study is not even happening" (Adult, 36, Tongan, elderly grandmother, aunty with paraplegia).

Current young carer Grace explained:

> I left school really young, 15 … I was miserable … No one knew what [I was] really going through at home … that I'm *so fucking busy* at home … They just saw me with shitty grades, where I would just wag classes, forge notes. They just saw me as a badass, but really I was wanting help. As much as it didn't look like it, I just wanted help … So I was a little bit lost there in the system, which sucks.

Other factors underlying their early school exit were also cited, including a teenage pregnancy (Miharo) and a learning difficulty (Grace). Existing studies also stress that young carers often do not want to withdraw from education, with researchers instead describing the dilemma they face when leaving school is "just their only option", and does not "reflect their ideals about the importance of education" (Carers Australia, 2002, p. 44; Cluver et al., 2012).

A significant number (42%, n=8) of young carers *considered* leaving school early, but did not. These participants commonly described having "one really great" (Lucy), "supportive" (Dan), or "really influential" (Louise) person, which I have termed 'That One Person' (TOP): a specific teacher or coach in the school context who had a significant positive impact on the young carer's educational journey. International literature highlights the positive education impacts of teacher awareness of students' young caregiving roles (e.g., Sempik & Becker, 2013). The interesting distinction in this study is teachers' and coaches' capacity to not only support young carers, but to have a significant positive effect on their school retention, despite the non-disclosure of their caregiving roles. Instead, TOP's recognition of adversity in participants' lives enhanced their capacity to remain at school. Lucy said "I think there was an awareness" by her teacher "that I was having a hard time", a sentiment echoed by Wyn who said that despite her teachers being unaware of her caring role, "they worked out something was going on [and] I never got into trouble for being late … I liked school". Because of the tendency for TOP to intervene at critical points when young carers' educational retention was at risk, participants understood that TOP turned around their school experiences. For instance, Lucy described achieving when

> I just didn't think it was a possibility, but luckily I had this teacher who … just in the background was being an advocate … She was my creative writing teacher actually – and she was like incredibly supportive … I'm still good friends with her; we still catch up. She's amazing, and good teachers are like the salt of the earth, like they're just wonderful people.

Specifically, TOP emphasised and nurtured young carers' positive experiences and attitudes towards school, discussed at the outset of the chapter, and assisted students to navigate the challenges that were barriers to their full educational investment. Lucy went on to explain, "A couple of times I had complete like breakdowns at school, and she was the one who … helped. I had a key to her office and could just go there". Dan explained, "I was selected as the vice-captain of that team to go to a national softball tournament", because his coach gave him "positive reinforcement … and that really meant a hell of a lot to me. It really did … 'cause I had nothing: I had no role model as a father figure except an alcoholic, who was violent" [referring to his mother's boyfriend at the time]. In doing so, TOP appeared to enfranchise young carers' educational attainment, minimise the incidence of early school exit, and facilitate participants' successful transitions out of school. Dan explained that because of the support and advocacy that he received from TOP "I've done well with my career, I've travelled the world with my job, [and] that's the thing that I'm most proud of". Analogous to this study, a key theme in the research is teachers' capacity to turn around the negative experiences of vulnerable students, via support, mentorship, role modelling, and guidance (e.g., Sanders & Munford, 2016). TOP was also present in higher education and vocational settings. Lucy recalled;

> I had a big panic attack at uni … as a response to what's happening [at home] … And my professor, who's lovely; I went and sat in his office for a while… But it was really out of control, like I was still shaking afterwards and like couldn't really catch my breath and it had been like a good hour or something. And he drove me over [to] the medical office.

Mary explained that having a "really brilliant" boss made a

> *huge* difference … like I needed to take mum to surgery or I needed to take her to chemo, and he was always really supportive, which I really appreciated … I probably would have left earlier if I hadn't had such a good boss (Former, 27, Pākehā, mother with cancer, father with substance misuse/acquired brain injury).

Overall, strong coach-, teacher-, lecturer-, and employer-young carer relationships had a significant positive impact on young carers' educational and vocational achievement and retention.

Not in Education, Employment, or Training (NEET)

Many participants described feeling "stuck" with regards to their employment and higher education opportunities. Terrence explained,

> It sucks because I feel like – oh I don't like saying it – but I kind of feel stuck and there's not a lot what I can do right now (looks very tense), because I'm a dancer, but I'm not a dancer, you know? I mean like, I didn't get to finish my degree because I had to drop out of uni because it was just me and mum living together … So that's pretty hard (Adult, 27, Niuean, mother with encephalitis/intellectual and physical disability).

Speaking to her plans after high school, current young carer Phoebe also described feeling stuck:

> I really want to go travelling too, but I don't know? I worry about my brother and my nana, 'cause what happens to them if I leave? To be honest, it feels like I'm putting things on hold for me. I don't really think about myself, and I worry more about what my nan and my brother and my mum need, rather than what I need … they always come first before my own stuff.

Such feelings appeared to come about as a result of participants' sacrifices made to provide care, and due to uncertainty regarding the length and intensity of caregiving, resulting in a lack of future-planning opportunities. Current young carer Leah acknowledged that "at some point I will have to look after [my brother] full-time … [because] he's going to need family around, and I am his only family". Likewise, Grace, also a current young carer, said of her future caring for her sister with a disability:

> It's a really scary thought. It scares me man. Mum doesn't want her to go to community houses and stuff. She doesn't want that … But I know mum's getting older; she's not getting younger. So I think we'll just play it by ear and see what happens.

As evidenced in Leah's and Grace's quotes, young carers were not only planning their young adulthood around their current young caring role, but were also factoring in possible future care when their loved one's illness was long-term, and/or when the primary *adult* carer stepped down. As such, young carers' feelings of being stuck could be exacerbated, when they felt time-pressured to complete their own university and vocational pursuits, prior to their *adult* carer role commencing. Chun explained:

> On the one hand, I'm really grateful because I don't do *so* much of the care right now: I kind of see this as a short-term window … to pursue my own things, like do this [study]. Because I know that with my mum with her disability [progressing], I will have to take that [full-time] role on again within the next five to 10 years probably … But on the other hand, I do feel … trapped, because my life will go on hold and I can't do anything for a while. So it makes me kind of anxious … What if my [study] didn't get finished before that happens? Or what if I want to do something else after the [study] and I run out of time? (Adult, 27, Hong Kong Chinese, mother with stroke/dementia/cancer, father with undiagnosed mental illness).

Participants' experiences of being stuck could translate into their experiences of being NEET. As outlined in Table 8, all young carers who left school early became NEET for several years, alongside eight other participants who had remained in school until at least Year 12. As such, over 50 percent of all NZ young carers were NEET for at least one year between the ages of 16 and 25. This figure is four times greater than the NZ average of 12.4 percent of young people aged under 25 who are not in education, employment, or training (Statistics New Zealand, 2018). Participants understood that their NEET status reflected educational qualifications that were unreflective of their actual ability, and thus a CV lacking breadth or depth, and the propensity for caring to end in their final years of high school, and during their transition to adulthood. This latter point appeared particularly impactful, with over 70 percent (n=17) of NZ former young carers' roles concluding between the ages of 14 and 25 (not including those whose roles continued into adulthood), in most cases when their care recipient passed away. Therefore, during a time already marked by great change, young carers could experience the loss of their loved one. Rachel described how her brother's death due to his muscular dystrophy

> was really dislocating, and really it threw me a loop … I missed him terribly and I became really unsettled. My life kind of just spun really (hands whirling), and I couldn't conceive of myself as settling down. I couldn't find direction. I was halfway through teachers college … but at the end of that year I went overseas … I actually had to get out … The world I was living in just felt like part of me was not there, and I wanted to go places where I didn't have that missingness.

Similarly, Lucy recalled "I left NZ a week after my mum died, like the day after the funeral, and just got on a plane … because I was too angry to be here … I needed [to] feel disconnected from everything". As a result of their caring, grief experiences, and NEET status, many young carers felt that they were falling behind their peers. For example, Lucy went on to explain:

> The choices that I've made were impacted by this experience, and they weren't always the best choices I could have made, and that has effected the way that I'm able to kind of live …

Table 8

NZ Young Carers who Were NEET for One or More Years When Aged 16-25

School status	Number of NZ young carers	Number of NEET NZ young carers	Percentage
Early school leaver	4	4	100%
Remained in high school until at least Year 12	21	8	38%
Total	25	12	52%

Note. Table 8 does not include the three young carers who were still in school at the time of their interviews.

> Like the trajectory of my life was different to a lot of my friends … I finished school, looked after mum, mum dies, [I] ran away … tried to enrol in a bunch of courses but just couldn't stick anything out, and … wandered around getting myself into trouble … And finally now [six years later], I have kind of settled into a course.

Existing research also identified that "young carers have a higher likelihood not to be in education, training or employment (NEET) between the critical ages of 16-19" (IARS, 2016, p. 77). Thus, there appears to be a real need for future-planning opportunities and scaffolding to support young carers' transitions through to adulthood.

When young carers did attend university, they found it challenging to commit fully and achieve well. Whilst eight young adult carers began university courses, 75 percent (n=6) left their studies prior to completion. Tilly said that at the time her twin sister became a tetraplegic following a car accident,

> I was at university: I was 18 … So I quit university to look after her, and then I cared for her fulltime for a couple years … At 21 I went back to university extra-murally, [and] got a job, but still doing other care and stuff for her (Adult, 44, Pākehā).

Her experience was shared by Lucy, who explained,

> I was at school for a lot of the time she was unwell, but when she was like actually dying, it was the year after I'd finished school. I had enrolled in university, but I dropped out after like two weeks, 'cause I couldn't do both: it was impossible. Which started a long career of dropping out of uni (laughs). So … I wasn't doing anything else, I was just looking after my mum, which was quite intense.

Kettel (2018) identified that "although YACs [young adult carers] are often highly motivated to undertake higher education, they may face a number of barriers and challenges in order to achieve this" (p. 9). The relative ease of placing studies on hold, however, appeared to be a significant protective factor when participants’ roles became intensive or overwhelming. All except one participant who stopped their studies due to caregiving returned to the same or a different course at a later date, often following the conclusion of their caring role. The remaining young carer was still undertaking care at the time of his interview, but planned to re-enrol in a different course once his caring role eased up. Overall, the findings suggest that maintaining university while caregiving was often not possible, with most young carers leaving university and returning once they had completed their caring roles.

In addition to higher education challenges, many young carers felt that their vocational undertakings were negatively impacted by their caring roles. Young adult carers often said that their vocation in early adulthood did not reflect their areas of interest or expertise. Specifically, participants commonly described their vocational opportunities being limited to the domestic, hospitality, and disability-, child-, and aged-care professions, which used their skills developed through caring. Whilst in several cases the caring professions were considered favourably, with Kelly stating “I grew the passion for looking after people from … those happy memories of looking after [grandpa]” (Former, 23, Māori, elderly grandfather, mother with bipolar, brother due to mother’s bipolar), and Louise recalling, “I’ve always wanted to do something in the health field growing up, with my parents in and out of hospital”, in all other cases, being pigeonholed into jobs that used caring-related skills exacerbated young carers’ feelings of being stuck. Grace said that she

> learnt how to make coffee (sounds bored), but that was about it really. But it was enough to get a foot in the door for hospo [hospitality] work … [But] I’m now getting shitty pay and slogging my guts out.

This was especially pertinent amongst young carers who had left school early and for whom their CV did not lend itself to their preferred areas of work, being in the arts, teaching, and business. McDonald, Dew, and Cumming (2010) asserted the importance of “young carers having dreams and plans for their future beyond a caring role alone” (p. 470). This was echoed by Ngākau, who recalled,

> In my seventh form year [School Year 13] we had a careers day and someone said, “Oh you are really good with people, you should become a social worker”, and so I did. I didn’t even know what it was! So not the greatest course advice … It’s been a good career, but I can really see those similarities between that caring environment of home, and extending that to care of others, sometimes too selflessly.

Ultimately, many former young carers had landed in their desired careers, which participants contributed to the skills gained young caregiving, being “resiliency” (Ngākau, Rachel), “confidence” (Louise), “duty” (Greg), “patience and passion” (Claire), and “being able to deal with … hardships” (Mele). Ngākau explained that she had been successful as a teacher because “I have a really good work ethic” gained via young caring, and likewise Mele felt that she had been successful as an academic, as young caring had prepared her for “being able to complete the job despite it being hard” (Former, 24, Tongan, grandmother with dementia/arthritis). Rachel wondered “if I would have had the resilience to keep going with [nursing] if I hadn’t have had these earlier experiences in life that taught me a lot of things?” Several former young carers identified the significant time it took to reach vocational success, however. For example, Rachel went on to describe how young caring for her brother with muscular dystrophy was “quite a disruption to my life”, and Melanie said that caregiving for her friend with schizophrenia “took a chunk out of my degree” (Former, 31, Pākehā, friend with schizophrenia), so that despite ultimately experiencing career success as a nurse and librarian respectively, both women entered the workforce later than anticipated. Likewise, Dan said that despite “travel[ling] the world being a photographer [and] getting well paid to do it … It’s taken a long time to get to this point. So, [young caring] did hold me back for a long time, it took a long time to catch up”. Service representative Tim explained that young carers are “held back” because “you are locked into [caring], and that’s your environment for years and years until something changes … and you are able to move out of it”.

Furthermore, young carers who were caregiving whilst employed described the challenge of balancing caregiving with their job. Mary explained that due to her caring role for her mother with cancer,

> my work performance [in marketing] definitely did go down, because I was so pre-occupied with other stuff, and coming in later here and there, and taking days off: I just wasn’t on top of it anymore … I felt like I was at a point where I had to make a choice. I couldn’t sustain working full-time and trying to look after my sick mother. And at the end of the day I knew what my priority was, and it was *her*.

Other researchers also highlighted the vocational difficulties experienced by young carers, as Becker and Sempik (2019) argued that “the early years of employment are especially important. This is the time when progress is made rapidly and young adult carers appear to be particularly disadvantaged in this respect” (p. 384). Despite former NZ young carers representing a group of vocationally successful individuals – for example, working in the marketing, artistic, nursing, education, and academic fields – participants highlighted the many years it took to reach their place of success, and the challenge of caregiving alongside work.

Health and Wellbeing

In this final section, I discuss the health impacts of young caring. The section begins with an overview of the physical health consequences of young caring, followed by an exploration of the mental health impacts, which were more commonly reported by the participants.

Many young carers reported experiencing **physical injuries** as a consequence of caregiving, a finding that reflects existing studies (Becker & Sempik, 2019; Nagl-Cupal et al., 2014; Szafran et al., 2016). Numerous participants described the difficulty of lifting or moving their loved one(s), who could be considerably larger than the young carers. Chloe said that as her mother’s multiple sclerosis “progressed a lot more, [she] was getting a lot weaker and harder to try and transfer. [My sister and I] were 12 and 13 at that stage … we could have easily injured ourselves”. Similarly Tilly explained, “I stuffed my back up … from lifting [my sister] and doing transfers … I still always had back problems after that [and] I still have to be really careful”. In other cases, participants perceived that the stress of providing care resulted in illness or sickness. Chun recalled that she experienced “tummy problems … acid reflux and all sorts” due to worry. Other participants reported developing poor sleeping and eating habits. Rachel said, “I developed very bad sleeping habits [and] I had a lot of insomnia … I worried a lot about [mum] … My sleeping patterns throughout my life are a bit dodgy [because] they really got trashed in those teenage years". Similarly, Mary said, "I had really bad nightmares 'cause I watched my mum dying. And it can be like fairly graphic … So I had trouble sleeping for a long time, so hence the weird nightlight thing (laughs)". Also speaking to the physical impacts of care, Terrence said that while

> I've always been an active person, I put on over 100kg in those first years … I think I was too busy taking care and being there for everyone else that I didn't pay attention to myself for anything … Then one day I looked at myself and I was like, "What the hell happened to me?"

The demands of caregiving could leave little time for self-care, as Lucy remembered: "there are certain tests that women start having at a certain age, [but] there just wasn't time for that … and also, not having your mum to take you along to those things [meant that] I just kind of ignored them, and there was no one to hassle me". Overall, young carers could sustain injuries, experience physical symptoms of stress and worry, develop unhealthy habits, and neglect self-care, as a result of their caregiving roles.

In line with previous studies (e.g., Watt et al., 2017), participants were most concerned with the **mental health impacts** of young caring. Almost all participants reported poor mental health at some point during caregiving, with over 60 percent (n=18) of young carers stating that they experienced anxiety and/or depression. Chun recalled, "I had a really bad spell of depression … and I would feel pain in the chest because [of] all my anxiety … [and have] panic attacks, [which] are terrible … you are lying on the ground and you can't breath and you think you are dying". Lucy also described her anxiety, explaining

> I can't go out a lot because … I just start packing and if I don't do something about it, it just gets really out of control. I mean it's really just panic attacks … but you definitely feel like you're going to die … For someone who doesn't ask for help, and someone who doesn't want to be seen as weak, [anxiety is] a very private way of like holding that stuff in, but allowing it to exist (hand in claw beating on her chest). But like, after I have a panic attack, I actually feel a sense of relief, 'cause I'm like, "*oh God*, it's out" (breathes out heavily).

The stressors of carrying out a young carer role appeared to contribute to participants' poor mental health. In particular, many participants whose care recipients had a mental illness or substance misuse described the mental health impact of dealing with their care recipients' adverse behaviours. For instance, Sally described how, due to her mother's bipolar disorder, her mother would threaten to commit suicide, which left Sally grappling with "that notion that I wasn't enough … How do I trust anybody when the woman who gives me life says, 'Fuck it, you don't matter'?" Likewise, Fleur said that her mother's mental illness related to her multiple sclerosis resulted in their relationship being

> quite challenging at times, especially [when] I feel like she was being quite emotionally manipulative (hands stiff and claw-like) … Like if I would say, "Look I'm going to move to [another city]", she would kind of withdraw from me, emotionally, and that was her way of saying she didn't approve, and that was her leverage. And so, if I came back or if I was to change my plans, then she would be warm and loving.

Mary said that when her father

> moved into alcoholism … he was this really dark, horrible person … [and] I haven't let go of that person yet … I'm angry at him … The thing that really pisses me off is when people go, "*Oh*, your *poor* dad" (said in sympathetic voice). And I almost want to *scream* … 'Cause I'm like, "*Not* poor dad! My mum's dead, he's an asshole: Look what he's done: he did that to himself" (said in a stern voice, hands in fists).

Echoing these young carers' experiences, existing research identified that mental illness "tended to be highest in children living with a parent with poor mental health" (Robison et al., 2017; Sadler et al., 2018, p. 18). The present study suggested that such poor mental health may occur due to the increase in adverse behaviors for individuals with a mental illness or drug misuse, which included suicide attempts and hurtful actions.

Disenfranchised grief.

Becker and Sempik (2019) highlighted the importance of considering "the circumstances in which caring occurs", which may underly young carers' poor mental health (p. 385). In addition to their overwhelming caregiving roles, the many significant losses of young carers in my study contributed to their poor mental health. Young carers' lack of address of their nonfinite and finite losses was representative of Doka's conception of "disenfranchised grief" (Doka, 1989, p. 1). Originally conceived to describe the grief experiences of gay men and woman, Doka (1999) described disenfranchised grief as "the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported. Isolated in bereavement, it can be much more difficult to mourn and reactions are often complicated" (p. 37). Such disenfranchisement was universally evident as almost all participants described "coping" (Mary) or being unable to "show any emotion" (Melanie) despite experiencing loss. Certainly, some young carers felt that they were "denied a socially recognised right to grieve" (Bruce & Schultz, 2001, pp. 12-13). This withholding of the expression of grief was poignantly reflected by caregivers at the time of death of their loved ones. For example, Lola said that when her fiancé died:

> His family didn't want to deal with the fact that their son or their brother had passed away … So I just hit the ground running … [because] if I was a mess in that corner rocking back and forth, there wouldn't have been a funeral … [So] I had to pick the handles for the casket, and had to pick the casket … and all of these things: it was weird (Former, 23, Pākehā, fiancé with brain tumour).

Likewise, Mary recalled how when her mother

> died, all of her friends just come like *swooping* in: they just smother you and show up at your house with baking … Especially at the funeral – it was *madness* … just like a revolving door of people … And then after a few weeks it just dies out, and you never hear from them again … So from my experience, the hardest time is after … when things go back to normal … and suddenly you've got nobody.

In other cases, young carers' grief was disenfranchised by their family/whānau/aiga's or caregiver's attitudes towards grieving. Dan said that he felt unable to grieve for many years following his mother being "committed into a mental institution" due to her schizophrenia when Dan was aged 13.

> The police put me into a social welfare home … and then my sister found out about it and a week later she drove up and got me … I was given no counselling, not a single sentence was uttered to me about it … I kind of had to quickly adapt to it, but I was in trauma for a long period of time after that … I was just withdrawn and cut-off, and not talkative.

A silent but embedded macrosystem and chronosystem-level blueprint regarding the appropriate reactions and timeframes for grief was disenfranchising for young carers' grief (Bronfenbrenner, 2005).

Alongside such social disenfranchisement, young carers could "actually disenfranchise their own right to grieve" (Bruce & Schultz, 2001, p. 13). Tilly described being uncomfortable speaking about her caring role, because

> When she's your sister, you can't moan … because her life is a lot worse than what yours is … and you feel disloyal to her if you moan about how crappy things were. So I felt it quite hard and didn't really talk to anyone much about it.

Self-disenfranchisement was especially pertinent among young carers' whose care recipients were their only source of support, or for whom their parents or caregivers were the primary *adult* carers, in which cases participants said that they did not want to add stress or burden. Lucy explained that she "didn't tell anyone" about her anxiety "because ... my mum [was] sick, I didn't want to put that burden on her". Likewise, Rachel said that she "never confided" in her parents when she was struggling,

> because I didn't want to add to their burden … and the older you get the more you see how much your parents carry with a disabled child in the family … and so rightly or wrongly, one way of relieving that burden is to not share your own stuff with your parents.

When their grief was disenfranchised, participants often self-medicated with drugs and alcohol, or coped using self-harm. Lucy recalled that she

> had little like ticks and things that I guess were fairly unhealthy coping mechanisms … Like, I was cutting myself or whatever, but mostly I'd hit myself really hard. Like it sounds a bit crazy, but I'd do this for ages (hits her forearm with her fist), because it felt quite nice (laughs in an embarrassed way).

On the other hand, several young carers described using drugs or alcohol. Dan recalled "some substance abuse, you know, getting drunk too often … But that was a way of me perhaps just dealing with things". Likewise, Grace said that she "did sort of dabble in substances [drugs]" because "it blocks out a lot of anxiety and depression … sort of a getaway in itself". However, she explained that, in the long-run, such drug-use worsened her mental unwellness "without realising … I still have anxiety today from it". In fact, several participants understood that the unaddressed nature of their poor mental health often resulted in ongoing depression and anxiety that, in fact, was exacerbated in adulthood. Wyn shared:

> It wasn't until I was much older [that a doctor] explained to me … that I had this clinical depression now and that this was the losses in my life that had been repressed all the way through. And I take anti-depressants to this day.

In particular, the disenfranchisement of grief at the specific time of finite loss could culminate in an intensified grief emerging years later. Most young carers who had seen their care recipient die experienced delayed grief, months or even years after the loss occurred. Participants described the confusing nature of such grief; instead of experiencing sadness, they had guilt, social anxiety, generalised depression, or suicidal thoughts. Mary recalled,

> I thought I was just a complete weirdo [because] almost a year or two on [from mum dying] … things seem to come out in different ways … I had total social anxiety [and] depression … I guess I wish I'd done more to save her … She was in my care, solely, and she died. I should have quit my job earlier … I should have picked up on it earlier, 'cause she was quite advanced when she was diagnosed. It's irrational, but it's there. You always wish you could have done things differently.

Anna also felt "regrets" years after the death of her boyfriend's father, as she found herself thinking "'If only we'd done this', and 'We should have said this' (holding her breath to stop herself crying) … I guess a sense of guilt closely associated with it all. I don't know if that's normal or not?" (Former, 27, Pākehā, substance misuse/cancer). The passage of time since the loss appeared to have little bearing on participants' continued loss and emotional distress. Instead, young carers' opportunities to express their grief with trusted others, often via counselling, was the key influencing factor in the state of their ongoing mental wellbeing. Mary explained that grief "does build up a little bit, and you have to let off the valve a bit … you just let it all out and you feel better". Bruce and Schultz (2001) pointed out that grief is "open to changing interpretations", so that over time, individuals attribute new meanings and understandings to their loss experiences (p. 129). In turn, a single loss can be iteratively redefined and thus re-grieved. Overall, most young carers experienced significant and unaddressed poor mental health, which could endure and even deteriorate in adulthood.

An interesting trend across the interviews was the absence of long-term anxiety and depression among Māori participants. It appeared that the expectation in Māori culture to grieve openly and over time allowed participants' acknowledgement of their losses. Kahurangi explained that "in a Māori context, it's natural to cry… like at tangi". Here, Kahurangi is referring to the traditional Māori tangi, a ceremonial wake, which acknowledges "that grief is not a process confined by time", with bereavement being "encouraged and expected to continue" (Nikora, 2016, p. 6). The process of Māori grieving acknowledged and encouraged participants' expression of loss and may have contributed to better mental health for Māori young carers following a death, compared with their non-Māori peers. Kelly explained:

> When [poppa] did pass, we kept him at the home for three days … That's not really a European type of thing … I actually fully spoke to him. So I said, "Okay poppa, I'm putting on your pants now". And once I'd done that, I said, "Okay, I'm putting on your shirt now" (said very gently). It just really helped me: it was a healing process to get him through that.

The difference in grieving practices between non-Māori and Māori participants is reflective of how “grieving rules differ between cultures … what is disenfranchised in one culture may be supported in another” (Doka, 2008, p. 227). Overall, enacting familial and culturally meaningful models of loss and grief, alongside having trusted individuals in which to confide, were integral factors to enfranchise young carers’ loss experiences and enhance their mental wellbeing.

This chapter has addressed key educational, social, vocational, and health impacts of young caring. The overarching theme of the three preceding chapters was continued; that impacts are not only due to being a young carer, but also as a consequence of the often overwhelming and unacknowledged nature of their roles. The ensuing and final chapter is the discussion and conclusions.

CHAPTER EIGHT

Discussion and Conclusions

This thesis has explored the experiences and needs of NZ young carers. Seven key findings, presented throughout the thesis, are discussed here. Four derive from the interviews, being: (1) a mismatch between participants' caregiving experiences and the prevailing definition of young caring, (2) holistic care aimed at meeting care recipients' physical, emotional, social, and spiritual needs, (3) experiences of nonfinite loss underlying young caring tasks, and (4) the value of young caring versus participants' overwhelming care roles. Additionally, three key methodological findings were: (5) the difficulty of recruiting NZ young carers due to their invisibility at all levels of Bronfenbrenner's BST model, (6) the importance of acknowledging the emotional impact of self-recognition when facilitating research with young carers, and (7) the value of enacting social justice throughout, rather than solely at the conclusion of the research process. The overarching finding is that it is the *overwhelming* and unsupported nature of participants' caregiving roles that needs to be addressed across the wider exosystem, macrosystem, and chronosystem levels, rather than simply at the level of the young carers supporting their loved ones.

In this chapter, I synthesize the findings to outline key ways in which young carers' insights can inform the persistent gaps identified in care and disability policies and services. First, I draw out the seven key findings, in order to weave together multiple argument threads to tell an overarching story of what it means to be a young carer in Aotearoa/NZ from the viewpoint of the participants. Thereafter, I consider the implications of the study, by providing key research, policy, and service recommendations, some of which extend beyond young carers to recognise their embeddedness within their family/whānau/aiga and wider communities. I then highlight the possible impact of the thesis beyond the young caring field, acknowledge the limitations of the study, and present my concluding statements.

Misalignment Between Experience and Definition

The first key finding is the misalignment between the definition of young caring used across research, policy, and practice, and young carers' own experiences of providing care. The thesis highlighted seven areas of discrepancy between the definition underlying young caring, and participants' understandings of their roles, being the incongruity between: (1) children and youth as vulnerable individuals socialised into care versus capable decision-makers; (2) providing care as an individual versus caring as part of a wider collective familial unit; (3) significant care versus the normality of young caring roles; (4) ongoing care versus episodic and intermittent caregiving realities; (5) caring for versus supporting; (6) family as a nuclear unit versus the wider notion of whānau/aiga; and (7) disability and illness as medical diagnoses versus being embedded in familial and cultural belief systems and historical or ancestral actions or events. Due to the misalignment of the definition of young caring and participants' experiences, the nature and extent of NZ young carers' roles could be underestimated, as participants often initially recognised only the aspects of their roles that reflected the prevailing definition. In particular, participants appeared more likely to identify their intensive physical caregiving, which fit the parameters of a dominant societal conception of care as significant and ongoing, than recognising their emotional, social, and spiritual tasks. Furthermore, physical care (e.g., nursing care) was more likely to be seen as *caring for* the care recipient, as the same support was unlikely to be received by the young carer in return. On the other hand, emotional, social, and spiritual care were often reciprocal between young carers and their care recipients, thus being less likely to be perceived as *caring for*. As such, incongruity between participants' understandings of their roles, and the definition of young caring, could result in participants initially largely identifying the physical care aspects of their roles. Overall, identifying as a young carer was challenging for the many participants who did not see their experiences reflected in the term. The impacts of this misalignment are teased out in more detail in the following sections.

A Holistic View of Care Provision is Necessary

Second, young carers enacted holistic care to meet four aspects of their care recipients' wellbeing: Taha Tinana (physical), Taha Hinengaro (mental and emotional), Taha Whānau (social), and Taha Wairua (spiritual). The holistic nature of care also extended to young carers' roles being embedded within the wider functioning of their entire family/whānau/aiga unit, including spiritual ancestors. Here, the fluidity of familial roles in order to meet a loved ones' four aspects of wellbeing – alongside other family members' needs – resulted in care often being understood by young carers as a holistic family effort.

The finding of the four dimensions of care speaks to participants' young caregiving identities, as the prevailing definition of 'providing care' does not include explicit reference to holistic support, and was thus often interpreted by participants only as physical and quantifiable caregiving. This tendency to recognise largely the physical (and sometimes emotional and social) aspects of care reflects a wider societal understanding of what 'counts' as care. The prevailing understanding that young caring involves significant care, or adult-like tasks not appropriate for a child, youth, or young adult, may result in young carers assigning a level or amount to their care. This could consequence in young carers only identifying their physical tasks, or in identifying their intensive care, often occurring during episodes or crises, which is unlikely to be reflective of their everyday caregiving realities. In turn, one or more elements of young carers' roles may be overlooked – especially their spiritual and everyday care – so that the prevalence, alongside the nature and extent of young caring in NZ could be underestimated. As such, young carers providing largely emotional care, for instance, may not identify as young carers according to the current definition. Specifically, young carers of loved ones with a mental illness or substance misuse for whom emotional and social support prevailed, and Māori and Pacific young carers whose spiritual care in the form of karakia, prayer, and song was fundamental to their roles, may also not 'see' themselves in the current definition. When the holistic nature of care espoused by family/whānau/aiga was not recognised by service agencies, then formal support was often perceived by participants and their families as being unable to meet care recipients' needs. In such cases, families and especially young carers 'filled in' for service inadequacies – largely in terms of undertaking emotional, social, and spiritual care – especially when a care recipient was in an out-of-home setting. In turn, the lack of services meeting the care recipients' four dimensions of wellbeing, which underlay the uptake and maintenance of many young carers' roles, could go unseen because a largely physical or quantifiable understanding of young caring was used.

Finally, when all four dimensions of young carers' roles are not considered, then the extent of the impact of caring on young carers could be underestimated. In particular, the overwhelming nature of young caring could be missed when the emphasis remained on the physical aspects of their roles. In turn, the risk is that young carers' roles could be interpreted as manageable or age appropriate according to their physical provision of care, when in fact a deeper understanding of the holisticity of care – enabling recognition of their significant emotional, social, and spiritual support – would reveal the propensity for physical care to be simply the tip of the iceberg. Here, for children and young people in compulsory schooling, the importance of their teachers having a firm understating of the holisticity of care and the impacts of such care on students' educational, social, vocational, and health outcomes will be important in order to address the educational inequalities faced by young carers.

Nonfinite Loss Underlies Care

A third unique finding of this study is the significant nonfinite loss experienced by young carers. Thus, the nature and extent of caregiving is defined not simply by the level and amount of care tasks themselves, but also by the meaning underlying those activities, being young carers' experiences of nonfinite loss. The discovery of nonfinite loss extends our understanding of what counts as care beyond tasks that are age inappropriate or substantial, to include all physical, emotional, social, and spiritual support. So, whilst domestic tasks can be discounted as everyday or age-appropriate chores, such activities can be a constant reminder for young carers of the gap between what their care recipient could or should do, and their reality in light of ill health or disability. In addition, such tasks can represent for young carers what they were once able to do, and their reality of caregiving. As such, nonfinite loss added meaning to care activities over and above simply enacting tasks themselves. The nonfinite loss underscoring young carers' roles could add new understandings of young caring internationally, because such losses likely transcend diverse demographics, countries of origin, and care recipient disabilities or illnesses.

The finding of nonfinite loss offers unique insights into the circumstances creating and maintaining young caring roles. Participants' nonfinite loss resulted in an overarching aim of care being to close the gap between loved ones' as they were or should be, and their current reality. In order to close these gaps, young carers sought to maintain their care recipients' key familial and community roles and relationships. In turn, young carers considered that effective care (that which maintained who their loved one was prior to their ill health) could only be provided by those who knew the unwell individual intimately before the onset or progression of their disability or illness. As such, service providers were most often perceived as unfit to carry out the role, especially in light of the high turnover of care staff. In addition, young carers' nonfinite loss experiences maintained their caregiving roles, as the enactment of care fulfilled their yearning to remain close to their loved ones. In turn, the threat of services requiring their care recipient to leave home could be understood by participants to outweigh the benefits of recruiting support.

Nonfinite loss also affected participants' perceptions of their young caring identities. Care could be central to keeping family/whānau/aiga life as it was or should be, not only for the care recipient but for the participants and other family members. In essence, care could become a family effort to protect against one another's many losses. A three-tiered care model was evident when, for instance, a child sought to maintain their unwell parent's existing familial role, not only in order to decrease their loved one's sense of loss (tier one), but in an effort to reduce the participant's own loss experiences by ensuring that their mother or father could continue to care for them (tier two). Furthermore, participants could also protect against their siblings' loss (tier three), by concealing the extent of their parent's disability or illness, thus facilitating their brothers' and sisters' normal parent-child relationships and childhood experiences. Such levels of care were not reflected in the current definition of the term 'young carer'.

Finally, the health impacts of young caring could also be underestimated when the significant nonfinite loss in which participants' roles were embedded was unrecognised. So, whilst the "haunting and inescapable quality" (Bruce & Schultz, 2001, p. 8) of nonfinite losses meant that young carers were constantly confronted by grief as they enacted care, the losses themselves were often overlooked or misunderstood due to the widespread dissociation of grief when a death has not occurred. In turn, young carers' experiences of anxiety, depression, and anger – whilst being normal grief reactions (Bruce & Schultz, 2001; Kübler-Ross & Kessler, 2005) – were not understood through a lens of grief by young carers. The unaddressed nature of loss could continue into adulthood, and result in ongoing poor mental health, and unhealthy coping mechanisms such as drug-use and self-harm. The need to enfranchise grief, and especially non-death related loss and grief experienced by young people, individuals with a disability or illness, and carers, is essential to address the poor mental health impact of young caring.

The Value of Caring Versus the Issue of Overwhelming Roles

The fourth key finding is NZ young carers' conceptualisations of providing care in childhood, adolescence, and young adulthood as being normal. The normality of care was demonstrated in participants' desires and insistence to undertake their culturally and relationally informed care responsibilities. The normality of care was also shown in the fluidity of household roles that resulted in blurred lines between 'carer of' and 'cared for' among family/whānau/aiga members. Young carers' conceptions of the normality of care aligned with Bronfenbrenner's (1985) curriculum of care, which espoused the importance of participants' caregiving 'for', reinstating "the concern of one generation for the next" (Bronfenbrenner, 1970, p. 216), and supporting the wellbeing of families and the effective development of children and youth.

The finding contributes to a key debate in young caring literature about whether it is appropriate to investigate and address 'young caring' (outlined in Chapter Two), with Children's Rights researchers having advocated for studies examining young carers' experiences and needs (e.g., Aldridge & Becker, 1996), and Disability Rights researchers having conceived that such a focus could challenge the rights of parents with disabilities (e.g., Parker & Olsen, 1995). While in recent years the debate appears to have largely subsided, the "question as to whether it is appropriate for children to be involved in significant care work at all" (Becker, Dearden, & Aldridge, 2001, p. 15) remains pertinent. Participants' conceptualizations of their roles as an integral part of growing up in Aotearoa/NZ adds a key consideration to this debate of children, youth, and young adults enacting care, as young caring roles were identified as being culturally significant. Certainly, the interviews suggested that many participants wanted to care due to the familial and cultural importance of young caring, reflecting their right under Article 30 of The United Nations Convention on the Rights of the Child (UNCROC) to enjoy and enact their family/whānau/aiga and cultural customs (United Nations Human Rights Office of the High Commissioner, 2020). Instead, my results identified that it was the *overwhelming* nature of young carers' roles – rather than simply the existence of such support – that required attention. Such an overwhelming model of care – brought about largely by inadequate services for individuals with disabilities or illnesses and their family/whānau/aiga – resulted in many of the negative impacts stemming from participants' roles, including poorer educational outcomes, limited opportunities to socialise, difficulties attending higher education, and poorer mental health. This was because overwhelming roles changed young carers' initial decisions to undertake familial-, relational-, and culturally-informed care into forced choices regarding the level and type of support undertaken. In turn, participants' roles often no longer reflected their 'normal' family/whānau/aiga models of care, and could instead be in tension with familial and cultural beliefs, such as when the young person was enacting intimate care for an elder. As such, the findings reflect elements of both the Children's Rights and Disability Rights perspectives of young caring. On the one hand, the findings identify that children, youth, and young adults may want to enact care, and thus a focus on young caring is imperative. On the other hand, the thesis highlights the inadequacy of services for individuals with disabilities and illnesses – especially with regards to support for parents to maintain their roles when they experience ill health or disability – that results in overwhelming care undertaken by family/whānau/aiga and young carers. As such, a focus on support for individuals with disabilities and illnesses is also essential. This wider focus beyond young carers reflects a shift in the literature towards the examination of circumstances underlying young caring roles, such as the poverty, marginalisation, and service inadequacies experienced by individuals with ill health or disability (Gaffney, 2007; Moore & McArthur, 2007; Newman, 2002).

Participants' belief in the normality of care suggests a possible high prevalence of young carers, especially among Māori participants who highlighted the naturalness of undertaking whānau care. In turn, the absence of a shared NZ young caring identity, and widespread societal-level lack of awareness despite the normality of children, youth, and young adults providing care, suggests that the number of NZ young carers may be larger than estimated, most of whom may be unsupported in their roles. Furthermore, it was difficult for participants to define the nature and extent of their young caring roles when care tasks were often conceived as a normal part of growing up in a familial unit experiencing ill health or disability, or as a natural component of childhood regardless of the existence of disability or illness in their own family/whānau/aiga. This was apparent when Māori participants described the normality of children and youth enacting care within a te ao Māori (Māori world) framework, and especially for the many kaumātua (elderly) at the marae. As such, when care and childhood or adolescence were blurred, participants had difficulty teasing out which aspects of caregiving were young caring, and which elements were normal childhood or adolescent experiences. This blurring could help explain the inconsistency between the normality of care and the lack of a shared NZ young carer identity. Certainly, participants found it more challenging to identify as young carers when they conceived of their roles as normal. In many cases, participants only identified as young carers when they considered the overwhelming aspects of caring, rather than their everyday caregiving. As such, participants often only identified young caring as activities related to crisis-related care, rather than representing the overall experience and everyday realities of undertaking care in childhood, adolescence, and young adulthood. In turn, a primarily negative conception of young caring could develop in NZ, if the term solely reflects young carers' overwhelming roles, and overlooks the normal and more positive elements (or pull factors) of care. This would make establishing a positive, shared NZ young carer identity more challenging.

Participants' perceptions of the normality of care often resulted in their uptake of a young caring role. Furthermore, the many positive outcomes of undertaking such normal roles, including the development of deep familial bonds, sustained young caring. Even when care became overwhelming and no longer reflected normal support, young carers' roles endured because families sought to hold onto their integral familial and culturally-relevant models of care, especially when formal services did not reflect the care recipients' and family/whānau/aiga's preferred care model. Finally, the impacts of young caregiving could be overlooked when participants conceived that their roles were normal. Here, participants could downplay or accept adverse outcomes, further embedding the silence surrounding their overwhelming care, when they assumed that such impacts were also normal. However, participants were often unaware that such negative outcomes were largely as a result of the *overwhelming* nature of their caregiving, rather than being due to carrying out care in itself.

Reaching Young Carers Where They Are: The Benefit of Social Media

The need for innovative means to recruit and facilitate research with NZ young carers is the fifth key finding. The following discussion highlights key methodological findings that explain the challenges I faced recruiting young carers and outlines the unique insights that I gained. Recruiting young carers without using gatekeepers was a significant challenge not undertaken in existing NZ research and not commonly enacted in international research. The difficulty of supporting young carers to self-identify was evident when numerous young carers described initially overlooking the research call for participants, as they did not conceive that the study related to their experiences. Now, with hindsight and deeper understanding of young carers' conceptualizations of their roles, it is evident that the divergence between participants' experiences and the definition used in my initial, traditional recruitment methods washed over many potential participants, as they did not identify as young carers. For example, using a poster call for participants with the heading "Are you are young carer?" and accompanied by the prevailing definition of the term was not effective, possibly because of young carers' lack of identification with the label or definition. Thus, even when young carers saw the poster, they were unlikely to self-identify and come forward for the study. Bronfenbrenner's (2001) BST concept of interdirectionality was apparent because the definition I used limited the relevant parameters of care and failed to reflect the potential participants' understandings of their roles.

The difficulty of recruiting and facilitating research with a hidden population of young carers was certainly not unique to my study. However, my experience offers insights for researchers of future national and international studies to recruit young carers without using gatekeepers. My experience highlights the value of digital storytelling to encourage young carers' self-identification. The video, in which I described my young carer experiences, shared on social media, was the most effective recruitment method. The dissemination via social media reached geographically distant young carers and could be shared with other possibly interested parties.

The Importance of Acknowledging the Emotional Impact of Self-Recognition

Sixth, storytelling was vital for participants, who discussed their young caring experiences through stories of their childhood, adolescence, and young adulthood. In particular, as most young carers had not spoken about their roles at all or in-depth prior to the interviews, they required a safe space and time to describe what caring meant to them, and to make meaning of their experiences. Consequently, *time* (Bronfenbrenner, 2001) was essential for participants to unpack their experiences. Time and space were offered in the phenomenographic interviews, which allowed participants to speak about their experiences beyond the confines of young caregiving and explore many avenues of their roles that may not have otherwise been identified as young caring. Furthermore, the participant-led and loosely-structured nature of phenomenographic interviews revealed deep meanings and emotions attached to caregiving that may not have been realised via traditional time-constrained and researcher-led interviews, case studies, or quantitative methods.

Discussing such deep meanings and emotions unlocked raw emotions for participants. As the interviewer, I had to be well-prepared to support my participants. I had to deeply engage with literature regarding interviews about sensitive topics to support the interviewees' during the process and to fully engage as the interviewer. It was imperative for me to recognise the possible enduring impacts of these individuals not only telling but reimagining their intimate stories. I prepared and provided take-home information at the conclusion of each interview that outlined relevant counselling and support services that participants could contact if they felt distressed.

Due to participants engaging in active meaning-making during interviews, the narrative pathway of their transcripts was never linear. Instead, each interview revealed multiple interpretations of a single event or phenomenon. In turn, the phenomenographic whole of transcript analysis was essential to gather and analyse the many facets of participants' discourse related to a single idea within the context in which they were delivered, in order to construct an overall picture of their experiences and needs. Without the whole of transcript approach, I could have extracted a single response from scripts, which would not have accurately or fully represented a participant's experiences, especially when additional or alternative meanings were added later in the interview.

The Significance of Accepting Opportunities to Improve the Situation of Young Carers

Finally, a key social justice aim of this research was to engage young carers' own voices to affect policy and service initiatives (Bronfenbrenner, 2001). However, although I originally anticipated that social justice initiatives would occur at the end of the thesis, the interest from government agencies, alongside a lack of support for young carers, meant that social justice action was undertaken throughout the research process. This included my involvement in the re-establishment of YCNZ (including the social media platform and Young Carers Advisory Group) shaped by participants' requests for information, respite, connection, and their voices being heard in decision-making that concerned them. A key contribution of the Advisory Group (under the guidance of Carers NZ) was raising over $15,000 that, alongside MSD funding, was used to produce and disseminate resources to young carers and key stakeholders, including GPs, principals, and school teachers. The resources were aimed at raising awareness and meeting the expressed needs of young carers, and were informed by participants' educational, socialisation, vocational, health, and service experiences. Other initiatives were my contributions to the updating of the University of Auckland Equity Office (2015) Toolkit for Student Carers to include young carers, with a key focus on effective awareness-raising and dissemination of the document among possible young adult carers at the university. In addition, young carers' experiences and needs were translated to the governance level through my 2014 address to key Government Ministers and stakeholders at the NZ Parliament, and via two Evidence Briefs (Donnan, 2014, 2018) commissioned by the MSD. The address to Parliament and second Evidence Brief (Donnan, 2018) presented young carers' direct quotes in order to advocate for and inform their inclusion in NZ policy, via the Carers' Strategy Action Plans (MSD, 2014, 2018). As such, my research enabled multiple ways of contributing to social change throughout the research process, using participants' own voices, in order to meet the needs of NZ young carers. However, it was essential not to overstep the boundaries of what my research had found, and to retain copyrighting and control of the material throughout the process.

Recommendations

The study's key findings have resulted in research, policy, and service recommendations that are outlined in this section. In order for these recommendations to be achieved, the definition of young caring will require updating to reflect the experiences of Aotearoa/NZ young carers. That is because the definition used in existing NZ policy, services, grassroots organisations, and research (including my study) does not reflect many young carers' holistic understandings of their roles as meeting their loved ones' physical, emotional, social, and spiritual needs, and maintaining their roles within the family. As such, research, policy, and practice implemented using the current definition of young caring may only include and meet the needs of some young carers, with others possibly being excluded from much-needed support. For instance, young carers providing largely intangible and intermittent care, who were supporting a non-family member, or who were enacting a familial and culturally normative role, might not identify as a young carer as their experiences are not reflected in the definition. A redefinition would not only enfranchise young carers' abilities to self-identify and thus access support, but could facilitate the effectiveness of the young carer prevalence survey proposed in the latest NZ Carers' Strategy (MSD, 2019). Certainly, prevalence data collected according to the existing definition of young caring could be an underestimate as young carers' emotional, social, and spiritual care may not be recognised and counted. Considering that the need for further research, policy, and service initiatives are often based on prevalence measures, then the inclusion of young carers under the guidance of a more inclusive NZ definition of young caring could have a significant impact. My proposed definition, based on young carers' experiences in my thesis, is:

> Young carers are children, youth, and young adults aged 25 years and under who physically, emotionally, socially, and/or spiritually support individual(s) who may be experiencing ill health, disability, substance misuse, mental illness, or advanced age. Such support can be enacted within or outside the home, alone or as part of a wider family/whānau/aiga or friendship unit, provided to the unwell individual or another person(s)/child, and undertaken continuously or intermittently.

Further targeted research into the sub-groups of young carers – such as Māori young carers, or those supporting a care recipient with a mental illness – and their role conceptualisations will be essential in order to continue refining the definition so that it truly reflects diverse Aotearoa/NZ young carers' experiences.

Research recommendations.

A series of pathways to future research have emerged from this study. First, the experiences of young carers representing major cultural groups in NZ, especially from the collectivist Māori, Pacific, and Asian cultures, can deepen and inform the existing international studies of the experiences of young carers from Black, Asian, Minority, and Ethnic (BAME), and culturally and linguistically diverse (CALD) backgrounds. Second, the findings related to NZ young carers of loved ones with a mental illness or substance misuse, who appeared to have particularly challenging caregiving roles due to the nature of their care recipients' ill health, and the lack of mental health support in NZ, may make important contributions to the literature on Children of Parents with Mental Illness (COPMI). Third, the identification of nonfinite loss among young carers can contribute to the broader research on (*adult*) caregiver grief. It also suggests the value of further in-depth examination into young carers', their loved ones', and family/whānau/aiga's experiences of nonfinite loss and grief, alongside the disenfranchisement of grief experienced by children and individuals with disabilities and illnesses. This research could also examine loss and grief with regards to the type of disability or illness experienced by the care recipient, for instance, Alzheimer's disease or terminal cancer. Fourth, the findings of my study suggest the value of exploring young caring through a whole family/whānau/aiga approach that recognises the impact of services on their and their family's 'choices' regarding young caregiving. Finally, the finding of wider factors influencing the uptake of young carers roles, including financial hardship, may suggest that an examination of the interface between young carers and vulnerable children policies in NZ is needed, while being mindful of the low-profile young carers are likely to have within the larger umbrella of vulnerable children.

Such research might adopt loosely-structured and creative methodologies such as video storytelling, which could be effective in gaining deep insights into young carers' experiences, especially when participants are making meaning of experiences that they have not spoken about previously. Another key recommendation for further research is a holistic model of analysis, that can enable the gathering of many descriptions of a singular event or idea in order to refine participants' meanings. Finally, given that many young caring studies appear to stem from the researchers' own experiences of young caring, then it is imperative that future studies implement protective measures regarding researcher emotionality. One such measure could be seeking counselling to learn effective means of supporting participants while setting appropriate boundaries, and learning strategies for managing and respecting their own emotional responses. Overall, such research would not only further our knowledge and understanding of NZ young carers, their care recipients, and their family/whānau/aiga's experiences and needs, but could facilitate further policy, research, and grassroots actions stemming from these experiences and needs. Furthermore, research carried out in NZ will continue to add NZ voices to the existing literature and, as argued in this chapter, potentially extend and deepen current understandings and definitions of young caring. In order for the key areas of future young caregiving research to be realised, then applications could be made to the Mahi Aroha Carers' Strategy Action Plan 2019-2023 Carer Research Fund (MSD, 2019).

Policy recommendations.

Effectively implementing the actions outlined in the Mahi Aroha Carers' Strategy (MSD, 2019) offers the most promising NZ policy initiative at the moment. These actions were guided by the participants' own expressed experiences and needs and my consequent recommendations, as outlined in my second Evidence Brief (Donnan, 2018). However, it is important that the actions are implemented in line with young carers' expressed needs, and as outlined in the strategy. Furthermore, it will be important to ensure that the actions remain at the forefront of the government's agenda if the party in power changes. One area requiring address is Action Four of the Carers' Strategy, wherein the MACA-YC18 (Joseph, Becker, Becker, & Regel, 2009) questionnaire will be used to gather more in-depth and precise data on NZ young caring activities. Linking back into the redefining of young caring outlined at the start of this section: while the MACA-YC18 questionnaire does enquire about physical, emotional, and social care, the spiritual element of care is not recognised. Adjusting the survey to include spiritual care will be an essential consideration prior to its implementation in NZ, where spiritual care has been identified as a key element of young carers' roles, especially for Māori young carers. In addition, adding further questions regarding social care could be advantageous, since this element of care was also highlighted by NZ young carers, but is only briefly addressed in the MACA-YC18 questionnaire. Furthermore, accompanying the MACA-YC18 survey with the YC-QST-20 questionnaire will be pertinent. The YC-QST-20 is a screening tool recently developed by the UK-based Young Carer Research Group, that assists researchers to estimate the prevalence of young carers in a population and to identify their needs (Young Carer Research Group, 2020). Used in combination with the MACA-YC18 survey, NZ will be able to both identify young carers and their needs (YC-QST-20), and assess the caring activities being carried out by identified young carers (MACA-YC18).

Service recommendations.

Service recommendations are divided into two sections, the first of which addresses young carer-specific services. The second outlines service provision to address inadequacies in formal disability support. Several key **young carer-specific service outcomes** have been highlighted by participants. Firstly, young carers identified their need for support but a lack of time and opportunity to leave home in order to access it. As such, participants wanted an effective social network established for young carers, that included opportunities to connect with one another, and to organise and attend events and activities. The social network was also posited as a platform to share stories, worries, and successes with one another, and to access information and advice about young caregiving-related issues. The YCNZ Facebook page has begun to meet this need, but a website could be more effective. A young carer buddy service between current and former young carers was also mentioned, which could use the same online platform as the social network, or be implemented via phone or face-to-face conversations. Such a network and buddy system could be especially impactful for young carers who are geographically or socially isolated, or resistant to identifying and reaching out for formal support. It is important to highlight that in all cases of young carers converging and sharing their experiences – whether virtual, via phone, or in-person – qualified social workers would be needed to moderate conversations and support young carers in distress, reflecting proven protocols and policies, in order to protect children and youth using the services.

Secondly, participants advocated for services that gave opportunities for respite, access to counselling, care-related training, and support to access services for themselves, their care recipients, and family/whānau/aiga. The training aspect was particularly emphasised, which participants understood could acknowledge their time caregiving, and build new and transferable skills that could enhance their CV and improve their chances of entering higher education and employment. A young carer payment was also requested, to cover education-related costs and to reduce students' need to miss out on their education in order to financially support their families.

Thirdly, participants identified the need for young carer awareness-raising at a societal level, and specifically amongst their peers, teachers and lecturers, and service staff with whom young carers often came into contact (e.g., formal carers). Participants also hoped that, as a result, their teachers and lecturers would be better equipped to support them by offering flexibility in learning, understanding when they could not complete work or were absent, and support them with future-planning. Participants also perceived that their peers would be more understanding of their home lives, thus facilitating the establishment of deeper friendships. In addition, young carers understood that key medical practitioners and service staff commonly interacting with young caring families (such as GPs, social workers, and needs assessors) would be better able to identify and support young carers and their family/whānau/aiga. Awareness-raising of young carers' experiences and needs was thought to be most effective if peers, teachers, and service staff had a better understanding of the impact of disability and illness, and of the existence and impact of nonfinite loss, on family life and on young carers. Such a shift in understanding should include a deeper societal understanding that grief often endures for many years as individuals enter different life-stages, make new meanings, and thus continually re-grieve.

Whilst NZ is relatively late in formally recognising the existence of young caregiving, a benefit is our ability to learn from other countries' successes and challenges, with key international stakeholders being generous in their willingness to share resources to facilitate the implementation of effective services in Aotearoa/NZ. However, it will be important to keep in mind the uniqueness of the NZ population, and to adjust any services to meet NZ young carers' own expressed needs.

Finally, the findings identified the need for a deep examination of the **service inadequacies existing for individuals with disabilities and illnesses**. Young carers often described their, their care recipients', and their family/whānau/aiga's lack of trust in services, which resulted in resistance to, or refusal of, formal support. Such mistrust came about due to five key elements: the need to fight for the support to which they were entitled; a fear of familial disjunction or care recipient loss of identity if services were accessed; previous negative service experiences or hearsay surrounding the quality of care provided; cultural inappropriateness of services; and the tendency for staff to take over care, thus undermining a collective familial model of support. In particular, young carers highlighted the lack of service holisticity, as formal services often failed to address their loved ones' emotional, social, and spiritual wellbeing, or recognise the continued reciprocity of roles and relationships among unwell loved ones, young carers, and their family/whānau/aiga. Considering that young carers' overwhelming roles were largely bought about by such service inadequacies, and that participants were often open to formal support if it reflected their family's preferred care style and unique needs, then ameliorating the many participant-identified service inadequacies and building young carer, care recipient, and family/whānau/aiga trust in services is vital. Specifically, careful consideration of the current model of service delivery and providers of care is needed, so that services can mitigate against the inadequacies that currently prevent young carers and their family/whānau/aiga from accessing or accepting their support.

Participants' interviews suggest several levels that should be considered if we are to adopt an approach to support that addresses the inadequacies that they identified, and which reflects the holistic Te Whare Tapa Whā vision of young caring that emerged in my study. First, carers, unwell loved ones, and family/whānau/aiga need to be engaged in the design of future services, so that support planning and implementation is a collective architecture, undertaken in consultation between, and taking into consideration the needs of, carers, care recipients, and families. Second, in order to address the piecemeal, static, and narrowly-focused services outlined by participants, then such a collective approach would aim to create personalised support that flexes with the individual and family/whānau/aiga's holistic and dynamic support needs. Such support would aim to meet all four dimensions of care recipient, young carer, and family/whānau/aiga wellbeing, which underscores young carers' holistic conceptions of effective care. Consideration of all members' ongoing investment in their wider bioecological networks (e.g., work, school) would be imperative, alongside regular review to allow adjustment to meet each party's dynamic needs, rather than allowing initial decisions to persist even when they no longer fit. Tapping into the existing Whole Family Approach described earlier in the thesis (Chapter Two) could be advantageous, as the model enables a holistic understanding of an individual's support needs that takes into account their wider support network (Frank & Thompson, 2015). Third, young carers' understanding of care as maintaining their unwell loved ones' identity, roles, and relationships aligns with a strengths- and hopes-based orientation, reflecting the earlier discussed Māori principle of mana, or "pride, honour and esteem" (Webber, 2019, p. 119). Webber's (2019) discussion of a strengths- and hopes-based orientation "grounded in humility, care and a determination to whakamana (esteem)" (p. 119) the lives of individuals, could thus be a key framework underlying the collective architecture and effective delivery of future services.

Keeping in mind the existing piecemeal services model highlighted by participants, then a coordinator or advocate assigned to individual families could be essential, to build their trust in services, and to avoid families having to continually navigate an unfamiliar and confusing services landscape. The advocate would be able to identify, and discuss with the care recipient and their family/whānau/aiga, which specific services they need, and where possible, ensure consistency in care staff.

This service process has the capacity to enfranchise care recipients', young carers', and wider family/whānau/aiga members' continued choices regarding care, by placing them firmly in the driver's seat, collaborating with an advocate with in-depth knowledge of the available systems and services to help, plan, and individualise the services that they receive. In this final section, the impact of the thesis beyond young caring is outlined.

Impact Beyond Young Caring

Some research findings could extend beyond young carers, to impact other societal groups, and add areas of interest to further key bodies of research. Firstly, the study addressed the failure of services to meet the needs of not only young carers, but individuals with disabilities and illnesses and their family/whānau/aiga, especially given a services model in which individuals fought to access support. In particular, the research challenged and extended the dominant conceptions of care, disability and illness, family, parenting, and childhood underlying formal services and policies, which could have significant impact beyond young carers to other service users. The research also highlighted the misalignment of the definition of young caring and young carers' own understandings of their roles, which could extend to other groups of carers, wherein the definition of informal or familial care may not reflect caregivers' lived experiences. As such, *adult* carers may not identify as carers, access support, nor become counted. Here, the notion of voice was pertinent with regards to *whose* understandings of key concepts underlying caregiving are being heard in policy and services decision-making, and thus shaping the support offered. The disregard of familial and culturally informed means of providing care and experiencing disability or illness highlighted throughout the thesis could suggest a wider aversion to services not only by young carers but also by *adult* carers.

Secondly, the research highlighted the lack of awareness, or misunderstanding of individuals' experiences of grief and loss. Specifically, the study extended the prevailing understanding that grief plays out in a short window of time immediately following a death, to include nonfinite loss experiences across the lifespan, reflecting the findings of the wider grief literature (Bruce & Schultz, 2001; Kübler-Ross & Kessler, 2005). In addition, the research demonstrated the loss experiences of children and youth, and their care recipients, which could be disenfranchised when such grief was not recognised or respected (Doka, 2000). Once again, the finding of nonfinite loss and disenfranchised grief has impact beyond young carers, by adding a unique lens through which the experiences of vulnerable or at-risk children, individuals with disabilities and illnesses, and their caregivers and family/whānau/aiga can be interpreted. In particular, the study highlighted key mental health impacts of the oversight of nonfinite loss and disenfranchised grief (such as anxiety and depression), which might also be found in other children and youth, for instance, children whose parents have a disability or illness, but who are not young carers.

Finally, the findings have further impact for the wider area of vulnerable or at-risk children and youth. In the Children's Action Plan Vulnerable Children and Families Green Paper (Statistics New Zealand, 2012), 11 factors considered to adversely affect children's development or well-being were identified – the accumulation of which resulted in vulnerable children. Four of those factors are key to many young carers' experiences, being sole-parent households, low economic standard of living, poor mental health, and income from a benefit. Furthermore, both periods when children are identified as being especially vulnerable can apply to young carers, being when children are very young (up to early primary school-aged), and when youth enter adolescence (Statistics New Zealand, 2012). It is important to note, however, that not all vulnerable children will be young carers, nor will all young carers be vulnerable children. It is imperative that research and policies regarding children in caring roles is not subsumed into 'vulnerable children', because then young carers' unique needs will not be met. However, it could be advantageous to consider the existence of young carers among the NZ vulnerable child population, where a lack of support for their family member experiencing ill health or disability could have resulted in the factors underlying the child's status as vulnerable (e.g., low economic standard of living).

Limitations

My research had several possible limitations and constraints, identified earlier in the thesis (Chapter Three). One limitation was that, within the time frame of a PhD, I was not able to undertake long-term study to examine young carers' roles over time (Bronfenbrenner, 1979, p. 14). However, by accessing the experiences of both current and former young carers at all bioecological levels, I was able to hear stories of NZ young carers told across diverse ages and contexts, and extending into adulthood. In fact, my inclusion of former young carers was integral to the original finding of nonfinite loss, as participants, after time to reflect on their roles after their young caring ended, attributed deeper meanings to their care activities and experiences.

Another possible limitation was being a young carer myself, which undoubtedly shaped my interpretations of the findings. Employing autoethnography so that I was constantly reflecting on my positionality, alongside phenomenographic interjudge reliability (Van Rossum & Hamer, 2010) whereby I continually justified my categories of description to my supervisors, helped me address this possible limitation. Having been a young carer also resulted in the research having a greater-than-expected emotional impact on me, as memories resurfaced and like the participants, I attributed new meanings to my adolescent experiences. As such, taking time out to reflect throughout the research process, alongside regular counselling, autoethnographic writing, and honest conversations with my supervisors, friends, and family, were integral to the research process. My own experiences and vulnerabilities were a powerful motivation for my study, however, and enabled me to connect with young carers that I might not have otherwise have reached, through sharing my story. My experiences also facilitated my ability to empathise and connect with the participants, and may have increased their level of trust in me as a researcher to understand their experiences.

Researching a hidden population that I did not know about prior to my PhD presented several challenges. I learned about young caring several months into my PhD, which was initially intended to explore the community participation of individuals with disabilities. I faced a significant dilemma as I chose to move away from my original topic – which grew out of my experiences with my brother Beefy and his limited opportunities to make friends and invest in community activities – to a focus on myself, and my time as a young carer. I found the metaphor of an oxygen mask – commonly used during in-flight emergency demonstrations – particularly helpful in my decision, as I considered that addressing the experiences of young carers (putting on my own oxygen mask first), would assist in effective support being implemented so that care could be a more positive experience for young carers and their care recipients (putting on Beefy's oxygen mask). In addition, entering into a new field and body of literature that was previously unknown to me was time consuming and confronting, but also presented a wealth of opportunities to learn about an integral facet of my life, and the lives of many NZ children, youth, and young adults, of which little was known.

Concluding Statements

Despite an estimated 40,000 young carers aged 15-24 in Aotearoa/NZ (MSD, 2019), and the challenges inherent in caring during childhood, adolescence, and young adulthood, the topic and experiences of NZ young carers remains understudied. Several fundamental gaps and limitations exist in NZ research that have resulted in a dearth of policies and services to meet young carers' unique needs. The result is a hidden population of young carers often enacting overwhelming caregiving roles with little support or guidance. My study has begun to address many of the gaps in NZ research, by giving agency to diverse young carers to share their own perceptions of their care roles, experiences, and identified needs, in the context of their immediate and wider social and institutional environments, during young caring and in their transitions to adulthood. The subsequent rich data has resulted in key findings that can inform the way that young carers are identified, their roles understood, and their needs met. Participants' deep narratives have also led to key policy and practice implementations being enacted throughout the thesis process intended to address young carers' needs. Nevertheless, these implementations are only the start. This thesis should be seen as a step in opening up the conversation about young caring in Aotearoa/NZ, and identifying possible pathways for further research, policy, and service actions.

By embarking on this journey and listening to the voices of hidden young carers, you, the reader, have been placed in a unique position of understanding. This is a position not inhabited by the majority of New Zealanders, including many young carers themselves. This knowledge gives you the capacity to support the changemaking that has begun alongside my research. Sharing participants' stories will amplify young carers' voices beyond these pages, and in doing so, may enfranchise young carers', their care recipients', and their family/whānau/aiga's needs. The experiences of the participants reveal that current young carers in Aotearoa/NZ are willingly providing care and deepening relationships with loved ones, but often feel alone, overwhelmed, and unsupported without recognition from external services. The results of this thesis identify a range of vital but unmet needs of young carers, and the importance of shifting the dominant narrative to one of autonomous, supported young carers carrying out their natural familial and culturally informed roles, within a context and with resources that support the current and future goals of the young carers, their care recipients, and their wider family/whānau/aigas. After all, in the words of young carer participant, Lucy,

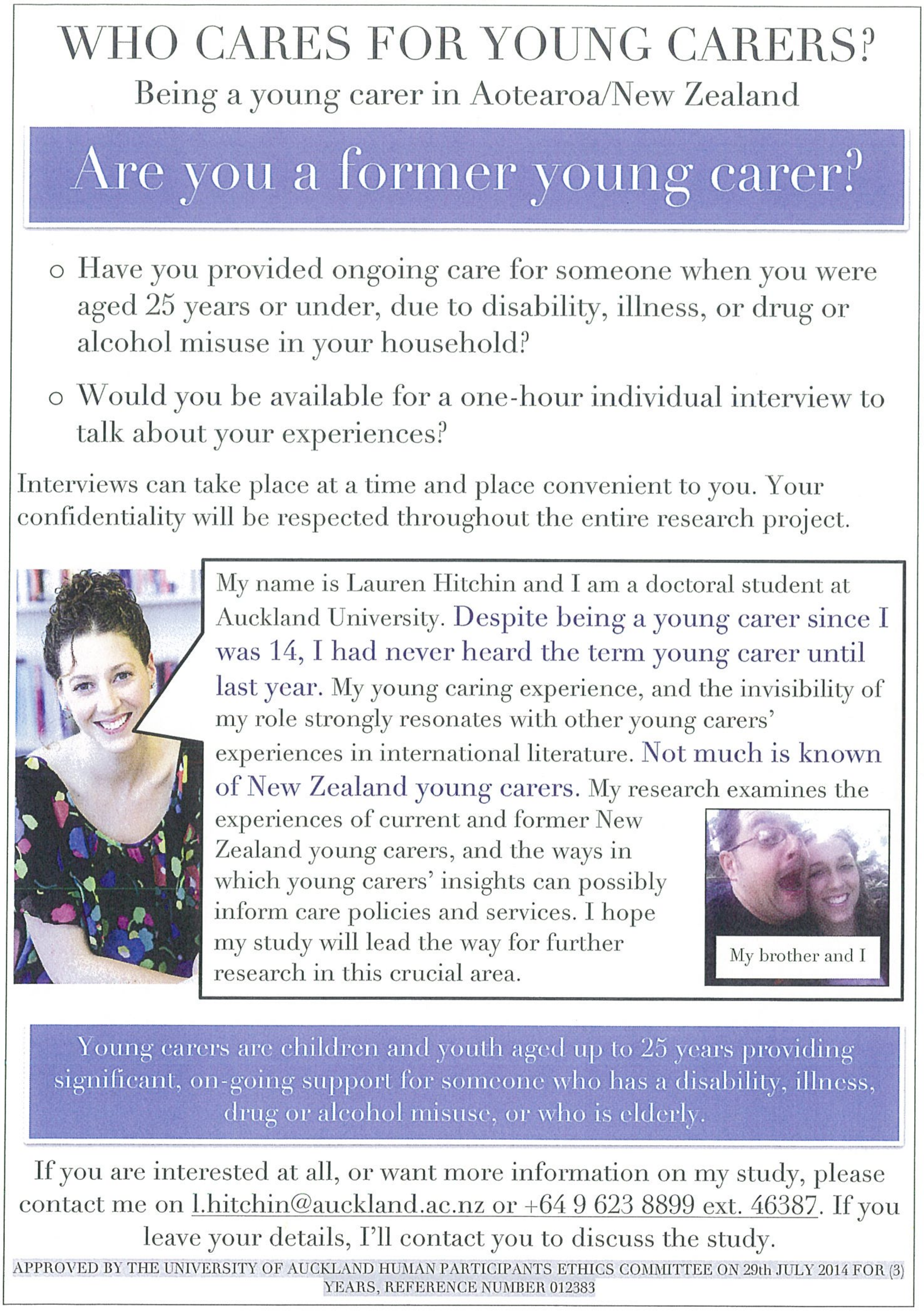
> If we don’t talk about young carers then we continue not to service their needs. And the most important thing is to have our voices heard: to make silent voices louder … Sharing our stories *is* the most important way to be heard (Former, 25, Pākehā, mother with cancer).

Nau te rourou, nāku te rourou, ka ora te manuhiri.
With your basket of knowledge, and my basket of knowledge, the people will prosper.
(Anon, whakataukī).

APPENDICES

Appendix A: Participant Recruitment

Poster call for participants example (former young carer).



WHO CARES FOR YOUNG CARERS?

Being a young carer in Aotearoa/New Zealand

Are you a former young carer?

- Have you provided ongoing care for someone when you were aged 25 years or under, due to disability, illness, or drug or alcohol misuse in your household?
- Would you be available for a one-hour individual interview to talk about your experiences?

Interviews can take place at a time and place convenient to you. Your confidentiality will be respected throughout the entire research project.

My name is Lauren Hitchin and I am a doctoral student at Auckland University. Despite being a young carer since I was 14, I had never heard the term young carer until last year. My young caring experience, and the invisibility of my role strongly resonates with other young carers' experiences in international literature. Not much is known of New Zealand young carers. My research examines the experiences of current and former New Zealand young carers, and the ways in which young carers' insights can possibly inform care policies and services. I hope my study will lead the way for further research in this crucial area.

My brother and I

Young carers are children and youth aged up to 25 years providing significant, on-going support for someone who has a disability, illness, drug or alcohol misuse, or who is elderly.

If you are interested at all, or want more information on my study, please contact me on l.hitchin@auckland.ac.nz or +64 9 623 8899 ext. 46387. If you leave your details, I'll contact you to discuss the study.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 29th JULY 2014 FOR (3) YEARS, REFERENCE NUMBER 012383

Family Care magazine column call for participants example (Carers New Zealand, 2014).

Hey!

YOUNG CARERS

Are you a current or former young carer?
Do you work with young carers?

Young carers are children and youth aged up to 25 years providing significant, ongoing support for someone who has a disability, illness, drug or alcohol misuse, or who is elderly.

I am studying what it's like to be a young carer in Aotearoa/New Zealand, and I need YOUR help!

- My name is Lauren Donnan (nee Hitchin).
- I am a doctoral student at Auckland University.
- I have been a young carer for my brother since I was 14.
- My brother has autism and an intellectual disability.
- I didn't even know I was a young carer until last year.
- Not much is known about New Zealand young carers.
- My research aims to learn the experiences of young carers in New Zealand.
- Would you be available for a 1 hour individual interview to talk about your young caring experiences, or your experience helping young carers?

My brother Beefy and I!

If you are interested, or want more information about my study, please contact me on l.hitchin@auckland.ac.nz or +64 9 623 8899 ext. 46387

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 29th JULY 2014 FOR (3) YEARS, REFERENCE NUMBER 01238

New *Lives!*

READER STORY!

Beefy wanted his own space. **Lauren Donnan** and their Dad Rob Hitchin were protective. Then they had 'the conversation'.

I think the hardest conversation a parent can have with their children is:"what will happen when I'm no longer here".

This conversation is made even more difficult when you have a child with a disability who needs ongoing support.

It's a conversation we may think about but often avoid, yet it's such a crucial conversation to have. Our family had that conversation a year and a half ago about the future of my brother Beefy, who has autism and an intellectual disability.

It's a conversation that led us to a truly wonderful outcome.

I guess I felt that as his sister, I would provide full-time support to Beefy when Dad got older.

But after opening up the conversation as a family, we discovered that there are plenty more options, which are much better for Beef.

At 32 years old, my brother is starting his own life, and he is surprising us all with what he can achieve. Let me explain.

'THE TALK'

About a year ago my family was in a tough place. My brother was ruling Dad's life, demanding his time and attention and using very negative language to get what he wanted. He was unhappy; he needed space and freedom, but didn't know how to get either. Also, Dad was tired, physically and emotionally worn out.

I had lost my fun-loving, always happy brother, and my supportive, optimistic Dad. Their relationship was suffering, and so was my relationship with both of them, as I was caught in the middle. Something had to be done.

So we had 'the talk': what would happen when Dad was gone?

I knew Dad thought that he would have to deal with my brother's behaviour until he could no longer manage – but I don't think he was aware that his breaking point was not far away.

Sometimes it takes an outsider to see that you are in way over your head.

FIRST STEPS

We talked about where my brother might live if he wasn't with Dad, who was shocked when I suggested that Beefy could live with me.

"No way," he said, "I would never expect that."

Where then might Beefy like to live?

Dad, Beefy, and I decided to apply for residential care.

This was in no way a small decision, as we knew that getting government funding can be a lengthy and emotionally involved experience, one that I guess we had been unintentionally putting off.

Knowing that we'd have to describe in great detail the worst parts of Beefy's behaviour over and over again to different people over the coming months was almost enough to put us off.

Also, Beef put up some significant resistance at first.

But we were determined to show him that this could be a great opportunity for him, and that we had each other to lean on.

ADJUSTING

We had several meetings over the course of a few months where we looked through numerous service options for Beefy – from supported community living to residential care facilities.

For the first time in many years, I witnessed my father break down as he told of the difficulties he was facing with my brother.

I think the hardest part for me was seeing the guilt that my Dad felt. I just couldn't understand it.

My Dad is the kind of person who will always put others first, especially his children. Anytime we need a lift, a hand, or some advice, Dad is there. So I just couldn't fathom why he'd feel guilty after he'd done so much for us.

What I now realise is that Dad felt that he'd failed my brother by not helping Beefy make the transition to a more independent life sooner – he felt it was his fault that my brother did not have a job, or a purpose for his days.

This of course was absolutely not true – in the 11 years since Mum passed away and Beef had been living with my Dad, he wasn't ready to move out or go to work.

Beef needed that time to process everything, and deal with Mum's loss and the changes this brought for him.

For Beefy, Dad was not just a Dad, but also his companion, biggest advocate, his confidante, and best friend.

Moving him out during that time would have been a disservice to my brother as he was not ready. Instead of guilt, my Dad should feel immense pride and a sense of achievement for how he has supported Beefy for so long.

INDEPENDENCE

Beef told us, in his own way, when he was ready to move out.

His behaviour changed over the course of a year – he became very bolshy with Dad, and started taking his frustrations out on him.

Most days Beef came home after his morning walk and yelled, in an accusing tone, "have you been in my room"?

Or when Dad asked him to shower or brush his teeth he'd respond: "Why don't you go back to Australia?" (Dad is Australian.)

But it had nothing to do with any dislike for Dad. Instead, Beef was struggling with his lack of autonomy. He was displaying hostile behaviour that he'd never shown before, and became extremely protective of his belongings - anything he could have control over, he took. ›

He became a hoarder, storing bags of rubbish in his room so Dad wouldn't throw anything away, and he became very convinced that he not only ran Dad's house but also owned it.

Despite Beef displaying obvious signs that he needed his own space, the decision to start the process to get him into residential care was a really hard one.

But it was the right thing to do: we have our old Beefy back, and Dad is slowly learning that he can finally relax.

AMAZING COMMUNITY

I think sometimes it seems easier to keep loved ones who have disabilities close by.

I see how much my Dad loves my brother. He's spent so many years caring for him, in fact his whole life has revolved around supporting Beef.

But now my brother is settling into a place that he chose, and which he absolutely loves – something my family was doubtful could ever happen.

I think we all had visions of a dull, tired place, with staff enforcing strict rules on my brother, and not giving him freedom and the love that he needs.

Instead we have found the most amazing community where he's making friends, where the staff are genuinely interested in him, and where my brother is extended beyond what he even thought that he could do. He's the happiest and most confident I have seen him in years.

Last year I wrote in *Family Care* that I was frustrated with people never giving my brother the time of day; I was so upset that no one got to know what a great guy he is.

Now Beef is in a community of people who have time to spend with him and get to know the kindhearted, outgoing Beef that we know and love.

HANG IN THERE

In our family, things are changing.

Dad's been left with an empty nest, and recently I got married and live with my husband. My middle brother is living in Rome with his wife, and Beef is off making his own life in his new community.

My worry now is that Dad is lonely and may struggle with this transition. He's asked John and I to move into his house with him so we can save money, but we decided that wasn't best for Dad.

He's spent his whole life taking such good care of all of us, and now it's his time to look after himself. He deserves time to travel, visit my brother and his wife, and indulge in his hobbies.

FAMILY JOURNEY

This has been a hard article to write, because it shows a side of my family that perhaps we're not so proud of.

But it also shows the emotional reality of decisions about assisting a family member into residential care or community supported living.

My advice to families discussing these options is: hang in there!

It's a tough journey; I had to continually remind myself that the process was to make sure that we found the best possible place for Beefy – somewhere that was right for him.

My other suggestion is to get the whole family involved. We attended all meetings together, and had my brother Rob on Skype from Rome so that he could take part too.

In the end the process of helping Beefy find and adjust to his new home has brought my family closer; we can all share in the joy of helping Beef find a place where he is truly happy.

ADVICE

To young carers – it's a funny feeling when your day to day support role 'ends' and you have more time to live an independent life yourself. Sometimes you feel guilty, just as Dad and I both did, and I wondered whether I had done enough to support Dad. But you can take comfort that you've done your best, and it's time to let your loved one move on with their life.

Remember, you have the right to move on with your life, too!

To those of you shifting to a residential home or supported community living: I know it can be scary.

I saw my brother was anxious and uncertain about going to a place where he didn't know anyone, and where he'd be away from Dad and I. But his bravery has paid off, and he's making a life of his own – he's independent and in charge.

QUALITY TIME

It's true that sometimes the things that scare you the most are the best things you will ever do. Growing up and moving out of home doesn't mean you won't have your family anymore, it means that the time you do spend with your family is quality time, and you'll have so much more to talk and laugh about together.

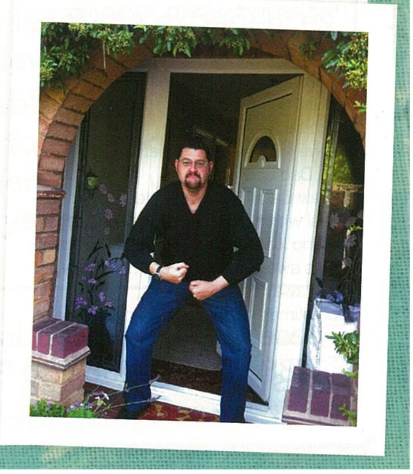
PROUD SISTER

My final words are for Beefy. I'm such a proud sister!

You've made friends so easily and you fit right in because of the awesome person that you are.

I love being able to call you and find out about all the fun things going on in your life, and that John and I can come down and stay for the weekend and be part of the cool life you've made for yourself.

I cannot wait to see all the amazing things you achieve now that you have the courage and the space to go ahead and do them!



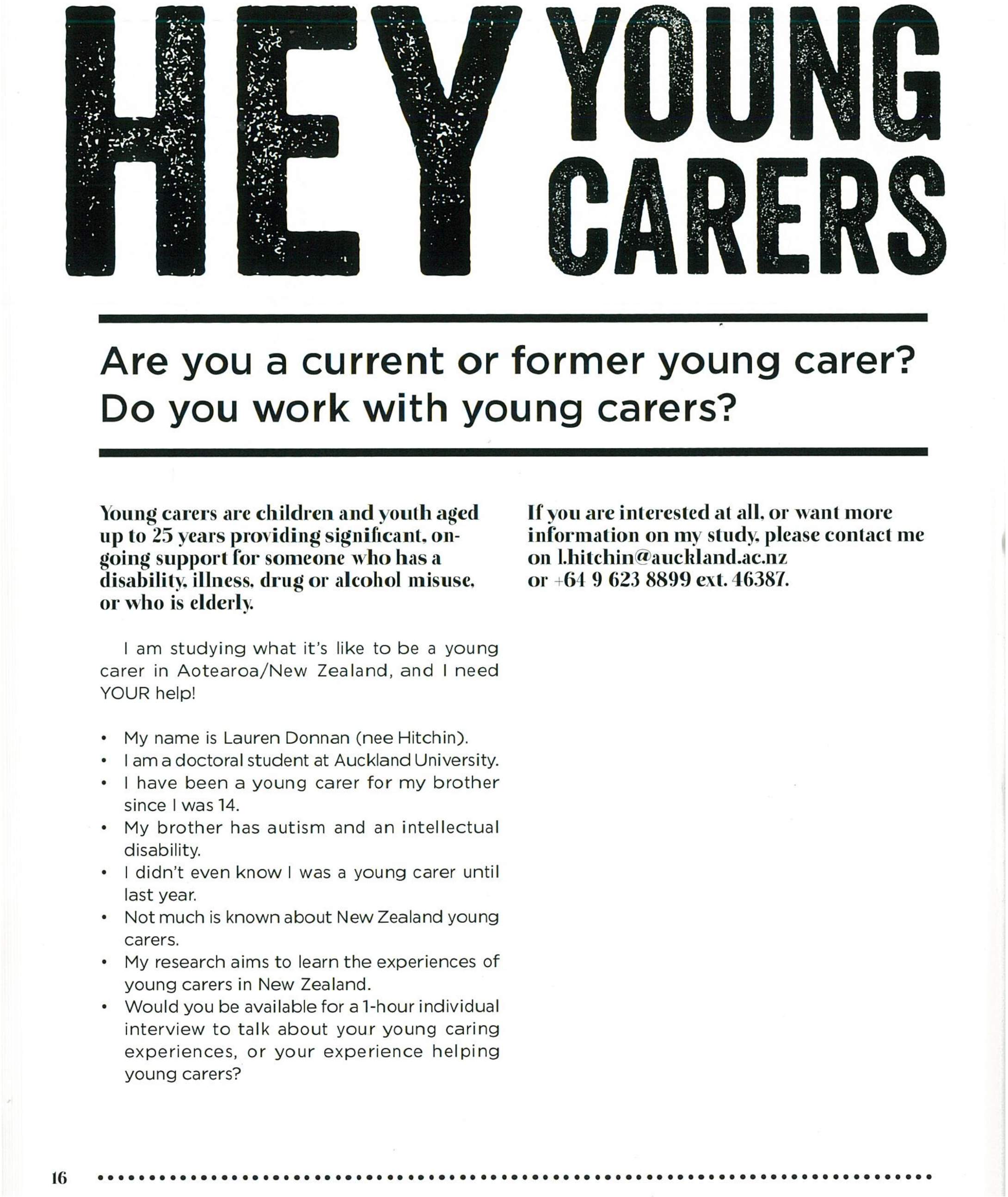
Magazine call for participants example (New Zealand Down Syndrome Association [NZDSA], 2014).

COMMUNICATION | HOLISTIC | ADVOCACY | TAONGA

CHAT 21

ISSUE 62 SPRING 2014

NZDSA



HEY YOUNG CARERS

Are you a current or former young carer? Do you work with young carers?

Young carers are children and youth aged up to 25 years providing significant, on-going support for someone who has a disability, illness, drug or alcohol misuse, or who is elderly.

I am studying what it's like to be a young carer in Aotearoa/New Zealand, and I need YOUR help!

- My name is Lauren Donnan (nee Hitchin).
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- Would you be available for a 1-hour individual interview to talk about your young caring experiences, or your experience helping young carers?

If you are interested at all, or want more information on my study, please contact me on l.hitchin@auckland.ac.nz or +64 9 623 8899 ext. 46387.

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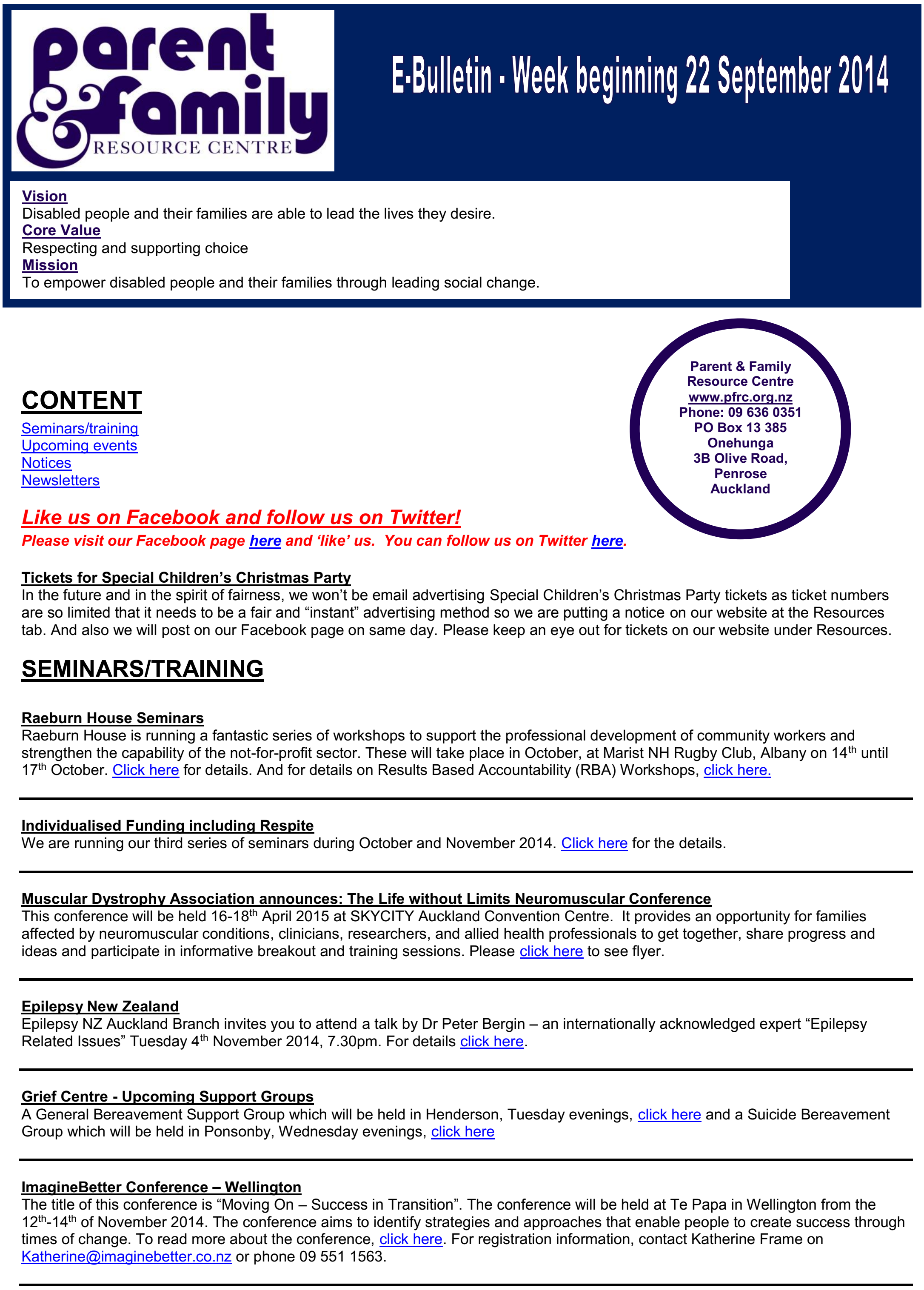
Newsletter call for participants example (Parent & Family Resource Centre, 2014).



parent & family RESOURCE CENTRE

E-Bulletin - Week beginning 22 September 2014

Vision
Disabled people and their families are able to lead the lives they desire.
Core Value
Respecting and supporting choice
Mission
To empower disabled people and their families through leading social change.

Parent & Family
Resource Centre
www.pfrc.org.nz
Phone: 09 636 0351
PO Box 13 385
Onehunga
3B Olive Road,
Penrose
Auckland

CONTENT

Seminars/training
Upcoming events
Notices
Newsletters

Like us on Facebook and follow us on Twitter!

Please visit our Facebook page here and 'like' us. You can follow us on Twitter here.

Tickets for Special Children's Christmas Party
In the future and in the spirit of fairness, we won't be email advertising Special Children's Christmas Party tickets as ticket numbers are so limited that it needs to be a fair and "instant" advertising method so we are putting a notice on our website at the Resources tab. And also we will post on our Facebook page on same day. Please keep an eye out for tickets on our website under Resources.

SEMINARS/TRAINING

Raeburn House Seminars
Raeburn House is running a fantastic series of workshops to support the professional development of community workers and strengthen the capability of the not-for-profit sector. These will take place in October, at Marist NH Rugby Club, Albany on 14th until 17th October. Click here for details. And for details on Results Based Accountability (RBA) Workshops, click here.

Individualised Funding including Respite
We are running our third series of seminars during October and November 2014. Click here for the details.

Muscular Dystrophy Association announces: The Life without Limits Neuromuscular Conference
This conference will be held 16-18th April 2015 at SKYCITY Auckland Convention Centre. It provides an opportunity for families affected by neuromuscular conditions, clinicians, researchers, and allied health professionals to get together, share progress and ideas and participate in informative breakout and training sessions. Please click here to see flyer.

Epilepsy New Zealand
Epilepsy NZ Auckland Branch invites you to attend a talk by Dr Peter Bergin – an internationally acknowledged expert "Epilepsy Related Issues" Tuesday 4th November 2014, 7.30pm. For details click here.

Grief Centre - Upcoming Support Groups
A General Bereavement Support Group which will be held in Henderson, Tuesday evenings, click here and a Suicide Bereavement Group which will be held in Ponsonby, Wednesday evenings, click here

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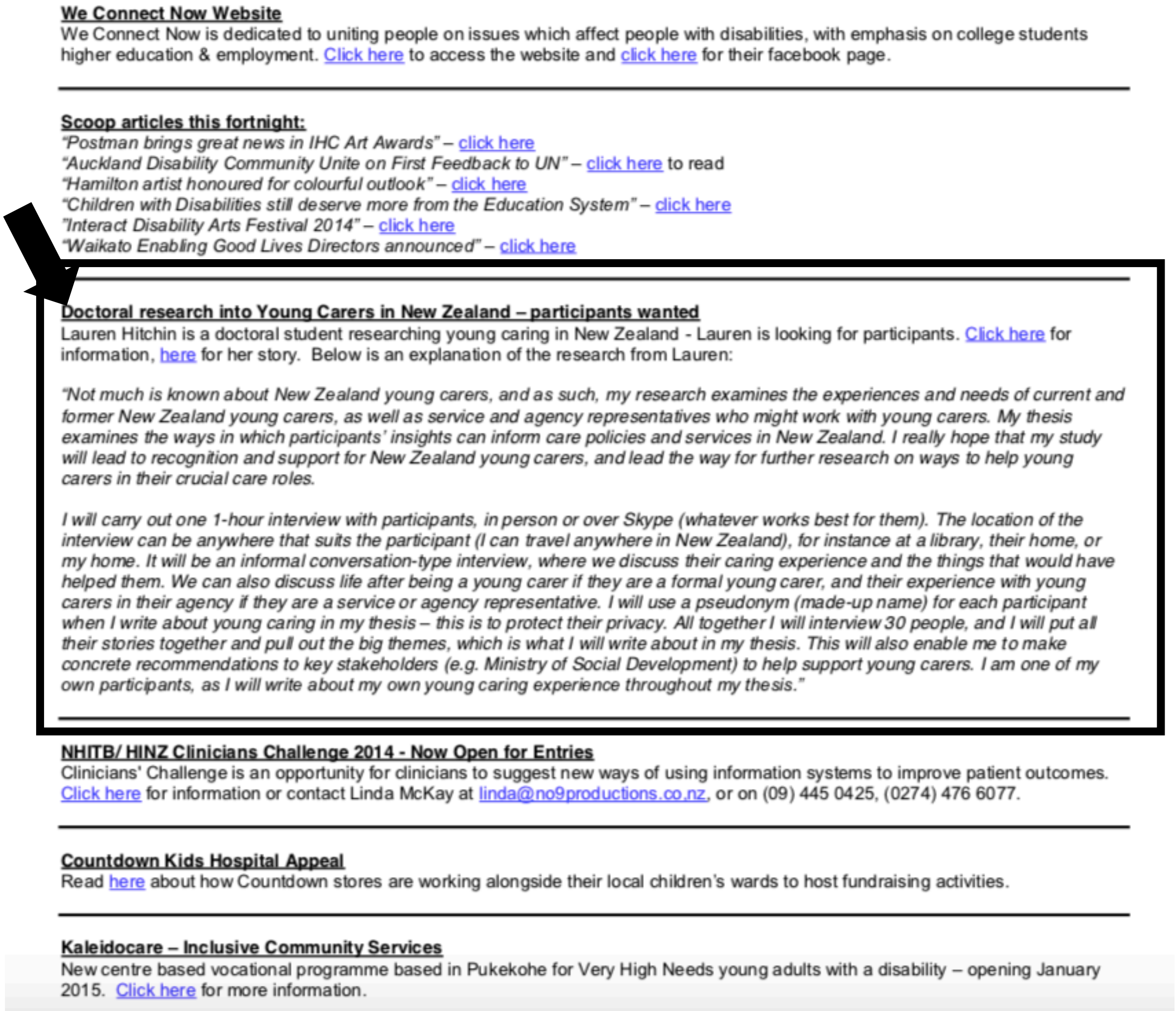
ImagineBetter Conference – Wellington
The title of this conference is "Moving On – Success in Transition". The conference will be held at Te Papa in Wellington from the 12th-14th of November 2014. The conference aims to identify strategies and approaches that enable people to create success through times of change. To read more about the conference, click here. For registration information, contact Katherine Frame on Katherine@imaginebetter.co.nz or phone 09 551 1563.



We Connect Now Website
We Connect Now is dedicated to uniting people on issues which affect people with disabilities, with emphasis on college students higher education & employment. Click here to access the website and click here for their facebook page.

Scoop articles this fortnight:
"Postman brings great news in IHC Art Awards" – click here
"Auckland Disability Community Unite on First Feedback to UN" – click here to read
"Hamilton artist honoured for colourful outlook" – click here
"Children with Disabilities still deserve more from the Education System" – click here
"Interact Disability Arts Festival 2014" – click here
"Waikato Enabling Good Lives Directors announced" – click here

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Doctoral research into Young Carers in New Zealand – participants wanted
Lauren Hitchin is a doctoral student researching young caring in New Zealand - Lauren is looking for participants. Click here for information, here for her story. Below is an explanation of the research from Lauren:

"Not much is known about New Zealand young carers, and as such, my research examines the experiences and needs of current and former New Zealand young carers, as well as service and agency representatives who might work with young carers. My thesis examines the ways in which participants' insights can inform care policies and services in New Zealand. I really hope that my study will lead to recognition and support for New Zealand young carers, and lead the way for further research on ways to help young carers in their crucial care roles.

I will carry out one 1-hour interview with participants, in person or over Skype (whatever works best for them). The location of the interview can be anywhere that suits the participant (I can travel anywhere in New Zealand), for instance at a library, their home, or my home. It will be an informal conversation-type interview, where we discuss their caring experience and the things that would have helped them. We can also discuss life after being a young carer if they are a formal young carer, and their experience with young carers in their agency if they are a service or agency representative. I will use a pseudonym (made-up name) for each participant when I write about young caring in my thesis – this is to protect their privacy. All together I will interview 30 people, and I will put all their stories together and pull out the big themes, which is what I will write about in my thesis. This will also enable me to make concrete recommendations to key stakeholders (e.g. Ministry of Social Development) to help support young carers. I am one of my own participants, as I will write about my own young caring experience throughout my thesis."

NHITB/ HINZ Clinicians Challenge 2014 - Now Open for Entries
Clinicians' Challenge is an opportunity for clinicians to suggest new ways of using information systems to improve patient outcomes. Click here for information or contact Linda McKay at linda@no9productions.co.nz, or on (09) 445 0425, (0274) 476 6077.

Countdown Kids Hospital Appeal
Read here about how Countdown stores are working alongside their local children's wards to host fundraising activities.

Kaleidocare – Inclusive Community Services
New centre based vocational programme based in Pukekohe for Very High Needs young adults with a disability – opening January 2015. Click here for more information.

Appendix B: Participant Information Sheet and Consent/Assent Forms

Participant information sheet example (current young carers aged 16 years and under).

THE UNIVERSITY
OF AUCKLAND
FACULTY OF EDUCATION
Te Kura Akoranga o Tāmaki Makaurau
Incorporating the Auckland College of Education

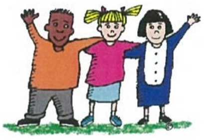
Epsom Campus
Gate 3, 74 Epsom Avenue
Auckland, New Zealand
Telephone 64 9 623 8899
Facsimile 64 9 623 8898
www.education.auckland.ac.nz

The University of Auckland
Private Bag 92601, Symonds St
Auckland 1150, New Zealand
School of Curriculum and Pedagogy

WHO CARES FOR YOUNG CARERS?
BEING A YOUNG CARER IN AOTEAROA/NEW ZEALAND

Researcher: Lauren Elaine Hitchin
Degree: Doctor of Philosophy (PhD)
Department: Faculty of Education, School of Curriculum and Pedagogy
Supervisors: Associate Professor Toni Bruce and Professor Janet Gaffney

PARTICIPANT INFORMATION SHEET (CURRENT YOUNG CARERS AGED 16 YEARS AND UNDER)



What is a young carer?

A young carer is:

- Aged up to 25 years old.
- Providing significant and on-going care.
- Caring in a house where someone has a disability, illness, or drug or alcohol misuse.

What does the researcher want to find out?

The researcher:

- Wants to understand what it is like being a young carer.
- Will interview and possibly observe young carers to find out about their young caring experiences.
- Will interview service workers to find out about their experiences with young carers.
- Wants to know how young carers' voices can make a difference for policies and services.

The researcher has a question

What will it mean for me?

- You will take part in an interview at a time when you are free.
- Your parent or guardian can come along if you would like.
- The interview will be one hour long.
- If you want to speak for longer than one hour, you can.

Interview with your parent/guardian

[49]

- You can be observed in your caring tasks if you want.
- Observation is your decision.
- Your decision to be observed will in no way affect your chance of being chosen for the study.

You can be observed if you want to

- Your answers during the interview and observation will be voice recorded.
- You can turn off the voice recorder at any time, without giving a reason.
- You can withdraw from the study at any time, without giving a reason.
- You can withdraw your data from the study at any time, without giving a reason, until you have approved your transcript of the interview and observation.

Voice recorder

- The interview and observation will be written out by the researcher.
- Only the researcher and her two University supervisors – Associate Professor Toni Bruce and Professor Janet Gaffney – will have access to the written-out interview and observation.

The researcher will write out the interview and observation

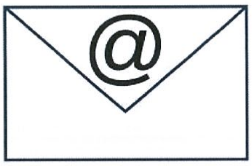
---

[49] I initially considered participant observation as a data source, but my continual reading of young caring literature uncovered many young carers' reluctance to draw attention to their caring roles due to fears of child removal, embarrassment, or not wanting the intrusion of outsiders in their home (Aldridge et al., 2016; Banks et al., 2002; Rose & Cohen, 2010). Consequently, whilst participant observation was a desirable method, I deemed it not appropriate with my participants.

- You will get a copy of the written out interview and observation.
- You can change parts and add more detail to the written out interview and observation.

You can change parts or add details

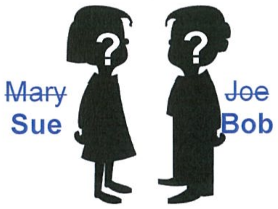
- You can have a digital (computer) copy of the interview and observation for free.



Free digital copy

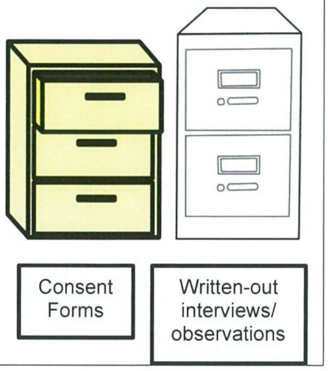
Will people know that it's me?

- Your real name will never be used.
- You can choose a different name, which you can write on the Consent Form.
- Any of your words used will be under your different name, or some other information like your age or gender.

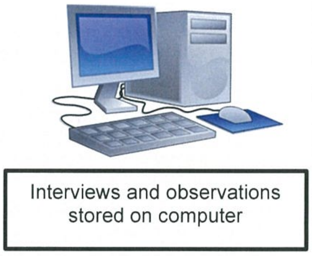


Different names will be used

- The Consent Form that you sign will be kept in a separate place to the written-out interview and observation.



- The written out interview and observation will be stored on computer with your different name, some information such as your age, and your own number that I will give you.



What if I decide that I don't want to answer a question or be observed doing something?

- You don't have to answer every question.
- You can choose not to have some of your answers recorded.
- You can choose not to have particular care tasks observed.

- You can end the interview and observation at any time.

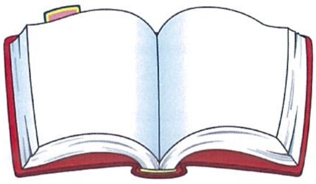
You can stop at any time

What if I decide that I don't want to do it anymore?

- You can choose not to participate at any time, until you agree to the written-out interview and observation.
- You should not feel like you have to take part in the study because you know the researcher.
- If you feel like you have to take part in the study, your parents or guardians can contact the principal investigator Toni Bruce to talk about your worries.
- If you become distressed at any time during the research, the researcher will direct you to some support services that can help young carers.

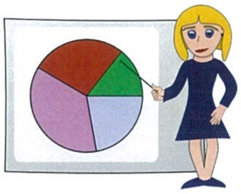
What will be done with the interviews and observations?

- The interviews and observations will help the researcher write her thesis (a big book) about young caring.
- The interviews and observations will help the researcher write articles about young caring.



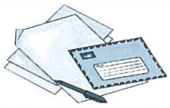
Help with researcher's thesis and articles

- The interviews and observations will help the researcher make presentations about young caring.
- The interviews and observations will help the researcher teach students about young caring.
- But remember, any shared quotes or snippets will *not* be under your real name.



Help with researcher's presentations and teaching

- You can have a copy of any articles or presentations if you want them. The researcher can email them or post them to you.



A copy of any articles and presentations can be sent

- The written out interviews and observations will be kept for at least 6 years.
- When written out interviews and observations are not needed anymore, your Consent Form and written out interviews will be shredded, and computer data will be deleted.

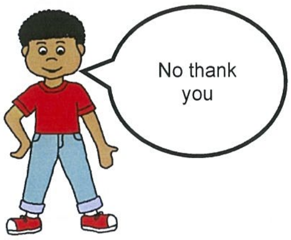
Interviews and consent forms will eventually be shredded

What if I have questions about the research?

- If you have any questions please contact the researcher or principal investigator at any time:
- **Researcher:** Lauren Hitchin (l.hitchin@auckland.ac.nz), phone 09 623 8899 extension 46387
- **Principal Investigator:** Associate Professor Toni Bruce (t.bruce@auckland.ac.nz), phone 09 623 8899 extension 48646

Contact the researcher if you have any questions

What now?

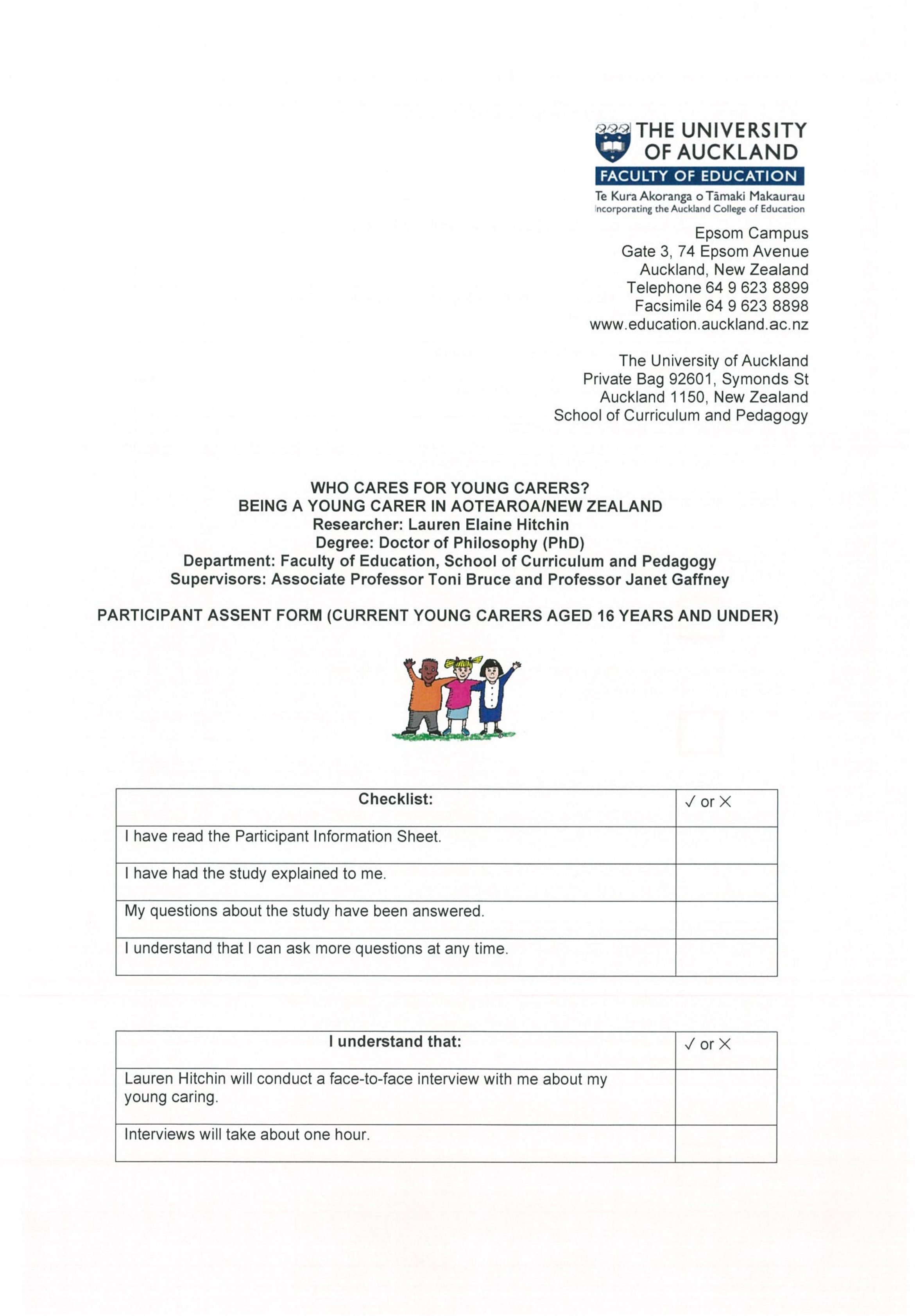
• If you want to take part, please fill out the attached Consent Form and return it to the researcher.	 If you want to take part, fill out the Consent Form
• If you do not want to take part, that is absolutely fine, and no further action is needed.	 If you don't want to take part, no further action is needed.

Thank you for helping me to research young carers.

If you have any queries regarding ethical concerns of this research, you may contact the Chair, The University of Auckland, Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1142. Telephone: 09 373 7599, extension 83711.

This study has been approved by the UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 29th JULY 2014 for three years. Reference number 012383.

Participant assent form example (current young carers aged 16 years and under).



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WHO CARES FOR YOUNG CARERS?
BEING A YOUNG CARER IN AOTEAROA/NEW ZEALAND
Researcher: Lauren Elaine Hitchin
Degree: Doctor of Philosophy (PhD)
Department: Faculty of Education, School of Curriculum and Pedagogy
Supervisors: Associate Professor Toni Bruce and Professor Janet Gaffney

PARTICIPANT ASSENT FORM (CURRENT YOUNG CARERS AGED 16 YEARS AND UNDER)

Checklist:	✓ or ✕
I have read the Participant Information Sheet.	
I have had the study explained to me.	
My questions about the study have been answered.	
I understand that I can ask more questions at any time.	

I understand that:	✓ or ✕
Lauren Hitchin will conduct a face-to-face interview with me about my young caring.	
Interviews will take about one hour.	

I can be observed in my caring tasks if I want, if I tick this red box: ☐ ✓ or ✕	
The observation will be done during care tasks that myself and my family decide.	
The observation will be done at a time and location that myself, my care recipient, and my family decide.	
Interviews and observations will be voice recorded.	
I can choose not to talk about any topic or issue.	
I can choose not to answer any questions.	
I can choose not to have particular care tasks observed.	
I can choose to have the audio recording turned off at any time.	

I will get a copy of my transcript, and this will be emailed or mailed to me, if I tick this red box: ☐ ✓ or ✕	
I have the right to request parts of my transcript to be deleted and changed, if I tick this red box: ☐ ✓ or ✕	
I can withdraw from the study at any time, without giving a reason.	
I can withdraw my data at any time, without giving a reason, until I have approved the transcript of my interview and observation.	
The audio recording will be kept in a safe place during the interview, and for at least 6 years after the interview and observation.	
All research information will be kept for six years or until after the study is finished (if longer than 6 years), then destroyed.	
Quotes and snippets from my interview and observation will help Lauren Hitchin write her thesis and articles, make presentations, and teach students. My real name will not be used for quotes and snippets from my interview and observation.	
I will receive a copy of work and presentations produced from this study, and these will be emailed or mailed to me, if I tick this red box: ☐ ✓ or ✕	

Any use of my interview and observation audio recordings, such as in teaching, will not happen without my permission.	
No-one but Lauren Hitchin and her two University supervisors will hear my interview and observation audio recording.	
I can request a copy of my interview and observation audio recording for free, and this will be emailed or mailed to me, if I tick this red box: ☐ ✓ or ✕	
I can choose not to participate at any time, until I agree to the final written-out interview and observation.	

Yes I want to be part of the study	

If you want to be part of the study:

Complete the relevant details below.

My name is____.

My research name is__________________________________.

This is the name the researcher will use for you so no one knows who you are. The researcher can choose a name for you if you do not complete this section.

My age is____.

I started caring when I was__________________________years old.

I finished caring when I was__________________________years old.

Leave blank if you are still caring.

My care recipient is___________________________________.

e.g., mother/father/sister/brother/cousin/aunty/neighbour/friend

I live in____.

e.g., Auckland, Christchurch

My email and/or postal address are *(if you have requested copy of transcript/audio*

recording):____

____

____

____.

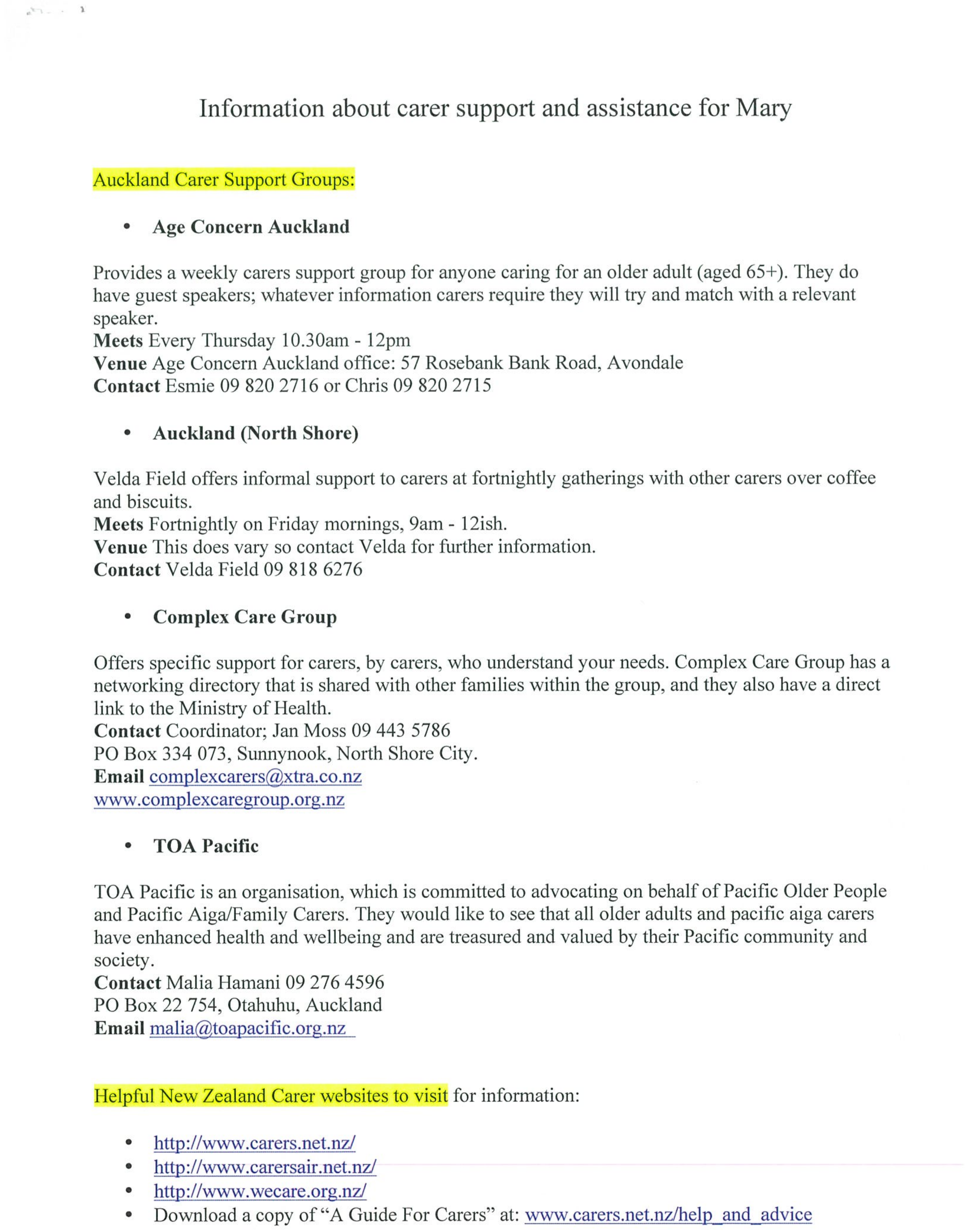
Signed: ____.

Date: ____.

This study has been approved by the UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 29th JULY 2014 for three years. Reference number 012383.

Appendix C: Post Interview Support Services Sheet

Example of a support services sheet (given to Mary following her interview).



Information about carer support and assistance for Mary

Auckland Carer Support Groups:

- **Age Concern Auckland**

Provides a weekly carers support group for anyone caring for an older adult (aged 65+). They do have guest speakers; whatever information carers require they will try and match with a relevant speaker.
Meets Every Thursday 10.30am - 12pm
Venue Age Concern Auckland office: 57 Rosebank Bank Road, Avondale
Contact Esmie 09 820 2716 or Chris 09 820 2715

- **Auckland (North Shore)**

Velda Field offers informal support to carers at fortnightly gatherings with other carers over coffee and biscuits.
Meets Fortnightly on Friday mornings, 9am - 12ish.
Venue This does vary so contact Velda for further information.
Contact Velda Field 09 818 6276

- **Complex Care Group**

Offers specific support for carers, by carers, who understand your needs. Complex Care Group has a networking directory that is shared with other families within the group, and they also have a direct link to the Ministry of Health.
Contact Coordinator; Jan Moss 09 443 5786
PO Box 334 073, Sunnynook, North Shore City.
Email complexcarers@xtra.co.nz
www.complexcaregroup.org.nz

- **TOA Pacific**

TOA Pacific is an organisation, which is committed to advocating on behalf of Pacific Older People and Pacific Aiga/Family Carers. They would like to see that all older adults and pacific aiga carers have enhanced health and wellbeing and are treasured and valued by their Pacific community and society.
Contact Malia Hamani 09 276 4596
PO Box 22 754, Otahuhu, Auckland
Email malia@toapacific.org.nz

Helpful New Zealand Carer websites to visit for information:

- http://www.carers.net.nz/
- http://www.carersair.net.nz/
- http://www.wecare.org.nz/
- Download a copy of "A Guide For Carers" at: www.carers.net.nz/help_and_advice

Some help lines:

Lifeline 0800 543 354

Youthline 0800 376 633

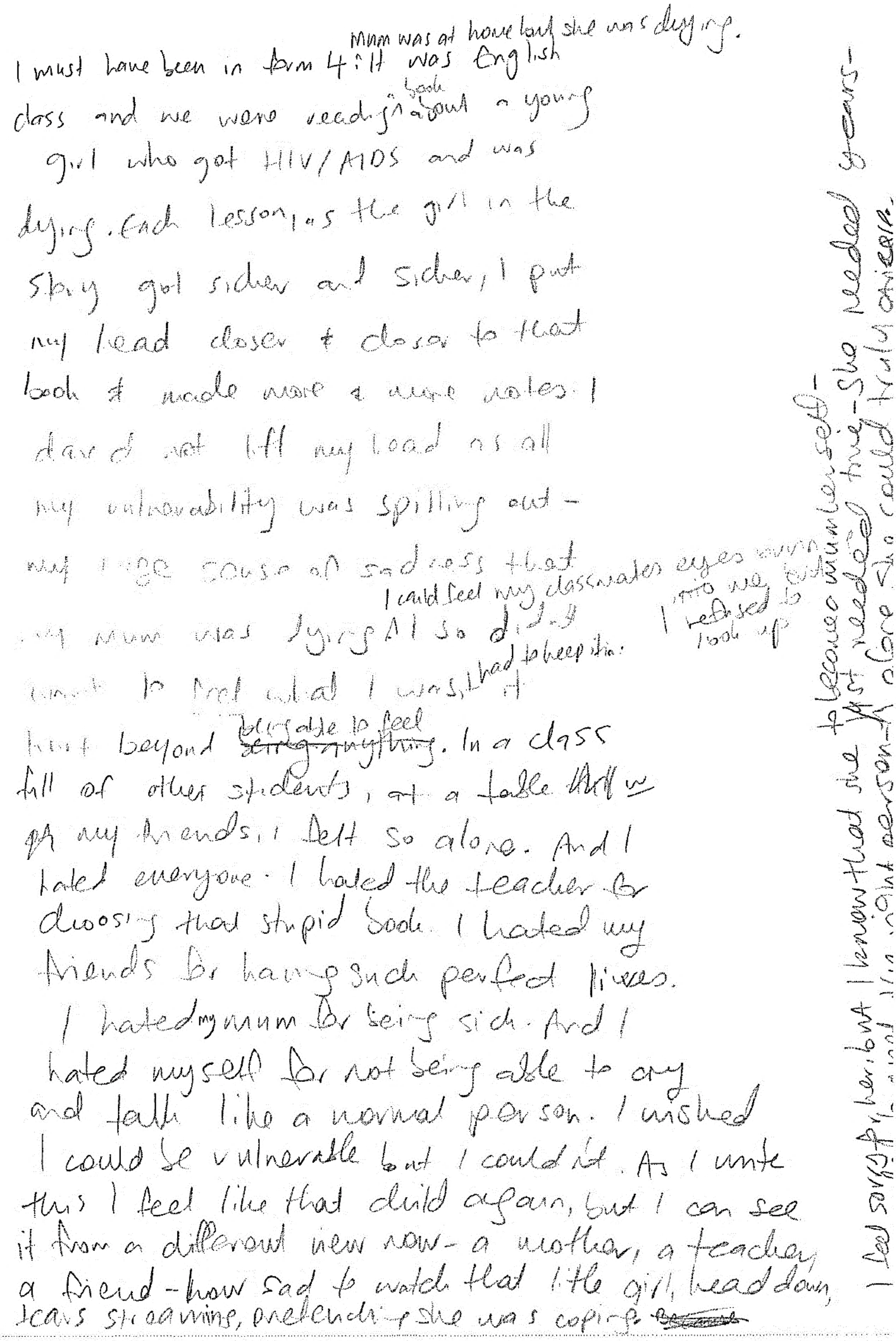
Depression Helpline 0800 111 757

Some people you could talk to:

- Friends or family
- Church support services - you could talk with a pastor, priest, or minister and some churches provide counselling and pastoral support
- Your local Citizen's Advice Bureau may be able to tell you about support services in your area
- Marae based community support services
- Cultural group based community support services
- The guidance counsellor or public health nurse at your school
- Your local drop-in centre for youth

Appendix D: Autoethnographic Vignette

Example of an autoethnographic vignette, written post Leah's interview, 2014.



Mum was at home but she was dying.
I must have been in form 4: It was English
class and we were reading a book about a young
girl who got HIV/AIDS and was
dying. Each lesson, as the girl in the
story got sicker and sicker, I put
my head closer & closer to that
book & made more & more notes. I
dared not lift my head as all
my vulnerability was spilling out –
my huge sense of sadness that
I could feel my classmates eyes on me but I refused to look up
my mum was dying. Also didn't
want to feel what I was, I had to keep it in:
it hurt beyond ~~seeing anything~~ being able to feel. In a class
full of other students, at a table ~~full~~ w
all my friends, I felt so alone. And I
hated everyone. I hated the teacher for
choosing that stupid book. I hated my
friends for having such perfect lives.
I hated my mum for being sick. And I
hated myself for not being able to cry
and talk like a normal person. I wished
I could be vulnerable but I couldn't. As I write
this I feel like that child again, but I can see
it from a different view now – a mother, a teacher,
a friend – how sad to watch that little girl, head down,
tears streaming, pretending she was coping ~~because~~

I feel sorry for her, but I know that she ~~just~~ needed time – she needed years – to become a mum herself –
and the right person – a place she could truly grieve.

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