Experiences of Neurotypical Siblings of Neurodiverse people with high and complex needs in Aotearoa, New Zealand.

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Abstract

This study aimed to explore the childhood and adolescent experiences of neurotypical siblings of neurodiverse people with high and complex needs. A review of literature in this area identified a range of gaps and limitations in current research, particularly a lack of contemporary studies within Aotearoa. Drawing on Doka's theory of disenfranchised grief and trauma, this small-scale exploratory study adopted a qualitative interpretive design to sensitively inquire into people's distressing or disturbing experiences of growing up with a neurodiverse sibling.

Five participants were recruited across the Tāmaki Makaurau region, each with a sibling with high and complex needs relating to their neurodiversity. The interview data was transcribed and analysed through reflexive thematic analysis. The analysis provided four overarching themes of experience: 1) a socially nullified existence which was comprised of social invisibility, a cycle of silence and feeling boxed-in by shame; 2) the shaky pillars of growth such as chaos, defence, emotional turbulence, unpredictable development and enduring grief; 3) a yearning for connection through siblinghood, a need to be seen, and a need for understanding; 4) the ingredients needed for growth, such as protective factors and post-traumatic growth.

The experience of siblings was marked by an undercurrent of anxiety, which was soothed by an overwhelming feeling of love towards the neurodiverse sibling and reverence and respect for the efforts of their parents to manage an, at times, unmanageable situation. Suggestions are made for community services, counsellors, and educators regarding this population.

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Introduction

This research project aimed to explore the experiences of neurotypical siblings of neurodiverse people with high and complex needs in Aotearoa, an often under-researched and under-valued group in New Zealand society (Smyth & Michail, 2010). This research aspired to foster a broader understanding and acknowledgement in wider society and the counselling and education communities of this group's needs throughout childhood and adolescence. Neurotypical siblings of neurodiverse people with high and complex needs are an often-isolated demographic of tamariki and rangatahi who undertake roles within their families that are often not assumed by their peers (Hanna & Chisnell, 2019). By focusing the study on neurodiverse people with high or complex needs, this research was centred on the experiences of neurotypical siblings of neurodiverse people who require a higher level of support or accommodations due to the severity or complexity of their cognitive differences.

Different terms and definitions have been used regarding this topic across previous literature. The following sections explore and clarify key terms and the social and cultural contexts ascribed to this terminology. A theoretical focus on disenfranchised grief and trauma is then presented to provide a trauma-informed lens for the study. This is followed by a brief overview of both the professional rationale and personal reasons for undertaking the study.

Key Terms and Definitions

Numerous terms have been used to describe individuals with different ways of thinking and processing information (Berry, 2022). These differences can be related to attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, dyslexia, and other neuro-based conditions (Den Houting, 2019). In contrast, *intellectually disabled* has historically been ascribed to individuals with cognitive impairments and diagnoses such as fragile X syndrome, foetal alcohol spectrum disorder and Down syndrome (Berry, 2022). The following subsections critique the Western diagnostic framework often used to define intellectual disability against a more contemporary understanding of neurodiversity. The specific focus on “high and complex needs” is clarified, followed by a brief discussion of the varying cultural understandings around neurodiversity in relation to Te Ao Māori.

Diagnostics and Intellectual Disability

Widely recognised as a Western framework, the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) is a valuable tool for clinicians, offering a foundation to classify behavioural patterns and formulate treatment plans to promote individuals' wellbeing and ongoing development (American Psychiatric Association, 2013). In the DSM-V, intellectual disability was categorised as a cognitive impairment involving deficiencies in planning, problem-solving, reasoning, judgement, and abstract thinking, as well as experiential and academic learning (American Psychiatric Association, 2013). These deficits often manifest in a lack of adaptive functioning, hindering individuals from meeting the daily requirements of personal independence and social reciprocity (American Psychiatric Association, 2013). The American Psychiatric Association (2013) considered personal independence and social reciprocity to involve communication, social engagement, academic or occupational functioning, and personal autonomy within the home or community settings.

Intellectual functioning deficits can lead to challenges across cognitive skills such as learning, logical reasoning, verbal, and visual abilities, problem-solving, and information processing speed. Additionally, deficits in adaptive behaviour indicate difficulties in social, conceptual, and practical skills (American Psychiatric Association, 2013). Due to these challenges, individuals with intellectual disability often need ongoing support throughout their lives. Further to intellectual disability, the DSM-V also specifies global developmental delay (GDD) (American Psychiatric Association, 2013). GDD is defined as occurring when an individual does not meet expected milestones in several areas of intellectual functioning and is unable to undergo systematic mental and cognitive functioning assessments (American Psychiatric Association, 2013). These specific diagnoses are just some examples of the deficit model held in the Western framework, highlighting the need for more strengths-based terminology, such as *neurodiversity*.

Neurodiversity

Neurodiversity is a term that describes the natural variation in how human brains work and recognises that different people have diverse ways of thinking and processing information, which is not necessarily a pathology or disorder (Berry, 2022). Neurodiversity is based on the idea that the human brain is a complex and diverse organ and that there is no one “normal” or “right” way to function (Pantazakos, 2023). A prominent critique of the Western DSM-V model was that *intellectually disabled* was a medical term based on a deficit model, which focused on what an individual cannot achieve or perform in their daily life, as opposed to a strengths-based model that refocused on the adaptive abilities these diagnoses may have fostered (Den Houting, 2019). For example, an individual with Down syndrome may experience advantages in visual learning, a high capacity for empathy and social understanding, and a strong visual short-term memory (McGuire & Chicoine, 2006). Approaching from a deficit-focused framework may ascribe individuals with these diagnoses to a lesser status in families, the wider community, and society (Den Houting, 2019). In contrast, *neurodiverse* offers a strengths-based framework that acknowledges and celebrates individuals' unique talents and abilities with diverse ways of thinking (Berry, 2022).

Reframing the dialogue from the term “intellectually disabled” to “neurodiverse” is also consistent with the broader research and societal movement towards person-first language (Chellappa, 2023). Person-first language emphasises the individuality and humanity of individuals with neurodiversity rather than defining them solely by their condition and promotes a more inclusive and equitable society (Pantazakos, 2023). For these reasons, the term “neurodiverse” is used throughout this study instead of “intellectually disabled.”

High and Complex Needs

To adequately frame this study, it was crucial to recognise that neurodiversity can be a wide-ranging concept. Using the terms high or complex needs helped to focus on the experiences of neurotypical siblings of neurodiverse people who required a higher level of support or accommodations due to the severity or complexity of their cognitive differences. Neurodiverse individuals with high or complex needs tend to require more intensive support in various areas, including education, employment, social interaction, and independent living such as one-on-one assistance or specialised programs (Chellappa, 2023). In contrast, others may require more moderate support, such as accommodations in the classroom or workplace (Den Houting, 2019). For example, individuals with autism may require support in social communication and interaction, sensory processing, and executive functioning; an individual with ADHD may require organisation support, time management, and impulse control; or someone with a traumatic brain injury may require daily assistance with personal hygiene and independent living (Chellappa, 2023). Overall, it is essential to note that high or complex needs do not imply a deficit or pathology in the individual. In this study, high or complex needs reflected that the individual required additional support or accommodations to succeed and thrive.

Māori Perceptions of Neurodiversity/Kanorau ā-roro

Aotearoa New Zealand upholds a bi-cultural context, meaning it is important to consider the understanding of Māori around neurodiversity. As per Opai and Severne (2020), in their Māori dictionary focusing on mental health terminology, *kanorau ā-roro* has emerged as a prevalent term in Te Reo Māori for neurodiversity. The term “kanorau” is used to convey the notions of diversity and variety, both as a verb and a noun (Opai & Severne, 2020). The word “roro” is used to describe the nervous system and neurological aspects such as brain matter or marrow.

Information and research on Māori perspectives of Kanorau ā-roro are scarce (Bevan-Brown et al., 2015). Durie's (1977) Te Whare Tapa Whā model of wellbeing identifies the importance of spiritual influence which informs the formation and development of Kanorau ā-roro people. Durie (1977) described that "without a spiritual awareness, the individual is considered to be lacking in wellbeing and more prone to disability or misfortune" (Durie, 1977 p. 92). This reflected some traditional beliefs around spirituality and how this can potentially form Kanorau ā-roro. A central belief was that the wairua leaves the body during sleep and wanders about the land, and the memory of the wandering constitutes a dream (Welch, 2021). If a person were ever awakened suddenly, and the body is awakened before the wairua returns, this could leave the person "half-witted" (Welch, 2021, p.23).

Collins and Wilson (2008) identified the importance of collective wellbeing rather than personal dysfunction within a Māori holistic health perspective. This collective perspective was centred first around whānau, who were socially and morally obliged to look after all their members, irrespective of their apparent neurodiversity (King, 2019). Furthermore, there are historical accounts of Kanorau ā-roro people being revered as tāonga, welcomed with amusement, and appreciated as an integral part of the community (King, 2019). In pre-European eras, children with neurodiversity were often under the charge of the Kaumātua and offered special protection by the iwi (King, 2019).

Contemporary Māori views of Kanorau ā-roro people have been investigated by Bevan-Brown et al. (2015). This study conducted sixteen in-depth face-to-face interviews with eight male and eight female participants from varied Māori backgrounds. There were variations in iwi (tribe), socio-economic backgrounds, and suburban and urban spread (Bevan-Brown et al., 2015). Participants were asked about their interpretation of neurodiversity in a modern Te Ao Māori context. Responses varied between perceptions of Kanorau ā-roro as slow thinkers, “doers” and “learners”, and with limited ability to look after themselves and cope with everyday life (Bevan-Brown et al., 2015, p. 152). Respondents also noted differences in mental and chronological age, degree of neurodiversity, and possible causes (Bevan-Brown et al., 2015). A participant noted differences between Pākehā and Māori concepts of Kanorau ā-roro based on severity, spiritual components, and time and development. "People come to different stages of development through their own time… Māori do not measure that time as Pākehā do" (Bevan-Brown et al., 2015, p. 153). The most dominant view among the study's younger participants was that Kanorau ā-roro was "a fact of life." (Bevan-Brown et al., 2015, p. 153). People with Kanorau ā-roro were accepted on the same level, offered equal opportunities, and regarded as having as much mana as anyone else (Bevan-Brown et al., 2015).

Disenfranchised Grief and Trauma

Disenfranchised grief and trauma refer to experiences of grief and trauma that are not recognised or validated by society, communities, or peers and, as such, are not incorporated into the individual's narrative of their life experiences (Henshaw, 2019). This theory provided a trauma-informed lens for this study to help understand the experiences of neurotypical siblings of neurodiverse people, for example, experiences of witnessing violent outbursts, witnessing medical emergencies, and the experiences of living with added emotional and mental stress in the whānau and home.

Kenneth Doka, Grief, and Trauma

Disenfranchised grief and trauma were defined by Kenneth Doka (2008) as intertwined distressing experiences that often leave individuals feeling isolated and invalidated. This perspective expanded on common conceptualisations of trauma as life-altering moments that change how people think, feel, and interact with the world, including the death of a loved one, sexual assault or a natural disaster. Disenfranchised grief and trauma extend to include less acknowledged experiences of grief and trauma that are not typically recognised or socially supported, including the loss of a pet, a miscarriage, the death of an ex-spouse, or the grief experienced by members of marginalised communities after societal tragedies (Doka, 2002). These losses or experiences may be trivialised, dismissed, or met with silence, leaving individuals to navigate their grief in isolation (Doka, 2008). Recognising and understanding these phenomena is essential for providing appropriate support and healing opportunities.

Doka (2008) identified various forms of disenfranchised grief and trauma, each characterised by unique challenges and complexities. Ambiguous loss or trauma is a loss or distressing experience that lacks closure or a clear understanding, such as when a loved one goes missing or is diagnosed with a chronic illness (Doka, 2002). Stigmatised grief and trauma encompassed losses or experiences that were shrouded in social stigmas, like death due to suicide, a loved one’s substance abuse, or the diagnosis of HIV/AIDS (Doka, 2002). Invisible grief and trauma referred to losses or experiences that were not readily apparent to others, such as losing fertility or ending a non-traditional relationship, like an affair (Doka, 2002). Lastly, secondary grief and trauma involved the ripple effects and subsequent losses that emerged from an initial loss or experience, such as the loss of financial stability after the death of a breadwinner (Doka, 2002).

Impacts of Disenfranchised Grief and Trauma

Disenfranchised grief and trauma can have profound emotional, psychological, and physical consequences for individuals (Doka, 2002). The lack of acknowledgment and support can lead to feelings of isolation, shame and guilt, and grief or trauma may become complicated or prolonged, with individuals struggling to find closure or meaning in their loss (Doka, 2008). The inability to openly mourn can also hinder the healing process and impede adaptive coping strategies, potentially leading to the development of mental health disorders (Doka, 2008).

Doka's (2008) work was instrumental in raising awareness about disenfranchised grief and trauma, and his research emphasised the importance of validating all forms of grief and trauma and promoting inclusive mourning practices. Doka (2002) encourages professionals and society to listen to those mourning compassionately, offer support without judgement, and create safe spaces for individuals to express their grief openly. Recognising and addressing disenfranchised grief and trauma is essential for facilitating healing and supporting individuals experiencing these losses (Cloitre et al., 2009). Cultivating empathy and understanding within communities can foster a more compassionate response to those grieving disenfranchised experiences (Cloitre et al., 2009).

Research Rationale

The basis for this study was formed partly after evaluating Aotearoa New Zealand's literature on the experiences of neurotypical siblings of neurodiverse people with high and complex needs, which yielded few or outdated results. Considering the lack of contemporary literature, the strategy for this research project was adapted to focus on an updated and modernised view of siblings' experiences in Aotearoa. Further investigation into international literature provided analyses of siblings' experiences from Italy, Dutch Flanders, and the United Kingdom. While this literature was formative to understanding core themes of experience in the international sphere, it left a dearth of understanding of the unique experiences in Aotearoa, where much of the literature and support available has focused on the experience of parents of neurodiverse individuals. Although these supports and narratives are vital, they leave a precarious gap for neurotypical siblings, which could increase perceived isolation within this group.

Alongside this academic rationale, the study was born from reflection on my own experiences as a sibling of a neurodiverse individual. For me, there was a feeling of isolation and loneliness during adolescence, extra responsibilities, anxiety, and several distressing experiences. I was interested in what these experiences tell us about the shared experiences of neurotypical siblings, their unmet needs and how they could have been supported better retrospectively.

My younger sister suffered a perinatal stroke and was diagnosed with GDD at age two. This GDD diagnosis was comorbid with epilepsy, added developmental delays and cognitive differences around understanding, and autistic traits emerging with age. Additionally, she was gifted with high emotional intuition and was able to notice slight changes in tone and language.

The desire to conduct this study came from self-examination through my own counselling, where I noticed a correlation between current anxieties and some experiences involving my sister's neurodiversity growing up. I engaged in finding support for neurotypical siblings of neurodiverse people with high and complex needs. However, these resources were sparse, and provoked queries regarding the social and academic discourse around this (often overlooked) experience.

Literature Review

The literature collected for this study ranged from 1987 to 2022 and was mainly identified through searches conducted via the University of Auckland Library website. These searches returned articles, theses, dissertations, and various social work, counselling, and psychology journals. Searches were also conducted through Google Scholar, which offered some policy documents and books on relevant topics. The literature search utilised different international and national terms regarding neurodiversity and siblings with truncations to increase search results. For example: "siblings of*" (to capture various diagnoses), "intellectually disabled*" (to capture various definitions), "neurotypical siblings of neurodiverse people", "high and complex needs", and "family experiences of intellectual disability". These search terms were then updated as additional terms surfaced.

Furthermore, to expand the reach, these search terms were combined with a variation of Boolean operators ('AND', 'OR', 'NOT', 'SAME', brackets and quotation marks), for example, "siblings" AND "intellectual disabilities" AND "counselling" AND "experience". These searches identified approximately a hundred relevant and appropriate sources which offered a wide breadth of established international knowledge on the subject and a sampling of the established knowledge in Aotearoa.

Refining the searches to Aotearoa based publications produced minimal results, older publication dates, and a specific focus on educational outcomes. Expanding the search to international studies gave access to works that provided varied theories on the experiences and needs of neurotypical siblings of neurodiverse people throughout Europe, Israel, and the United States. Discovering more leads for research involved examining reference sections in selected articles to find other literature. The selected papers ranged in paradigm from positivism to interpretivism to radicalism. The studies included phenomenological analysis, quantitative standardised measures, literature reviews, and narrative analysis. Several research articles focused on an interpretive phenomenological analysis of the experiences of neurotypical siblings of neurodiverse people at various stages of life.

Caregivers of People with High and Complex Needs

In order to provide a broad overview of people’s experiences of others with high and complex needs, the search for literature and research for this study included caregivers of individuals with mental illness diagnoses, cancer patients and primary caregivers in military families.

Several qualitative studies have delved into the challenging experiences of caregivers who supported individuals with high and complex needs outside of the scope of neurodiversity. These studies provided a nuanced comprehension of the experiences, coping mechanisms, and potential interventions applicable to caregivers. Weiss et al. (2022) focused on the experiences of family caregivers of individuals with cancer within the scope of ambiguous loss. This study engaged a qualitative synthesis of primary literature published between 2008 and 2021. The findings indicated that appreciating changes in primary relationships, uncertainty in reconciling losses, a static existence in time, and living with paradoxes were paramount (Weiss et al., 2022). The authors highlighted the necessity of recognising and addressing ambiguous loss as a universal aspect of the human experience in caregiving, surpassing specific illnesses. Moreover, they demonstrated importance of therapeutic interventions to foster caring, healing, and resilience among caregivers of individuals with high and complex needs emphasises the impact of tailored interventions on caregiver wellbeing.

O'Dowd (2003) used a reflective observation approach to reflect on the complexities associated with the grief and loss of people with mental health issues and their carers, including non-finite loss and ambiguous loss. Families and caregivers of people living with a mental illness reported an ongoing 'fear of loss' that stemmed from the increased risk of their loved one dying by suicide and said this was rarely addressed. Through a group process, participants were offered a chance to process “dual grief experiences” of both their physical loss and the psychological loss of their loved one to their mental illness (O’Dowd, 2003, p.27). Participants recalled their self-questioning when receiving the diagnosis for their loved one, their search for meaning, and deep feelings of sadness, anger, guilt, and self-criticism. Further recognised were the numerous secondary losses, such as their long-standing beliefs about their “assumptive world” being shattered by the diagnosis (O’Dowd, 2003, p. 29). The researcher also observed that the participants found the emotional toll of losing a loved one to mental illness to be more distressing than their physical demise (O’Dowd, 2003).

The nature of the losses around mental illness was further complicated by stigma surrounding the causes of mental illness and feelings of blame, shame, and failure, both for individuals living with a mental illness and their caregivers. Stigma was identified as a barrier to this type of grief being openly spoken about and acknowledged by participants (O'Dowd, 2003). As emphasised by Doka (2008), neglecting to recognise feelings of grief can strengthen negative emotions individuals might harbour regarding their losses. O'Dowd (2003) proposed a need to develop rituals that acknowledge and validate people's loss experiences. For example, validating feelings could come through simple questioning, connecting, acknowledging, and inviting people to reflect on their experience of loss. This awareness and focus can address some of these feelings around this disenfranchised grief for caregivers of someone living with a mental illness (O'Dowd, 2003).

Furthermore, Ramchand et al. (2014) provided a perspective centred on young carers within military families aged eighteen to forty, revealing the often-unacknowledged burdens and added caregiving responsibilities endured in this context. Ramchand et al. (2014) found that most carers in military families were caring for individuals with mental health or substance use conditions and were not connected to support networks. Typically, these carers helped their loved one’s cope with stressful situations or other emotional and behavioural challenges. Their findings also found that these carers consistently experienced worse health outcomes, more significant strains in familial relationships, and more workplace problems than non-caregivers (Ramchand et al., 2014). The authors highlighted the shared disenfranchisement, grief, and trauma for carers in military families, which came from aspects such as societal ignorance and insufficient social and emotional support (Ramchand et al., 2014). The suggestions to mitigate the long-term ramifications of caregiving were the need for long-term planning assistance for carers, critically around financial, legal, residential, and vocational or educational planning. Additionally, this study suggests that carers should be empowered to build their skills and confidence in caregiving, mitigating caregiving's potential stress and strain and raising public awareness of their value (Ramchand et al., 2014).

Aldridge and Becker (1993) have offered a comprehensive exploration into the lives of young caregivers, providing insight into their roles, challenges, and potential impacts on their wellbeing. The responsibilities these young people shouldered often involved the care of family members facing chronic illnesses or disabilities. By presenting in-depth narratives and qualitative insights, the researchers offered a glimpse into the emotional and psychological toll caregiving can have on young minds, the potential for trauma and stress in the daily lives of young caregivers and the intricate dynamics of their caregiving roles. Aldridge and Becker (1993) highlight the need for increased awareness and support systems to address young caregivers' unique challenges. Giving a voice to these young carers made a significant contribution to the discourse on youth caregiving, emphasising the importance of recognising and understanding the impact of such responsibilities on the wellbeing of the individuals involved.

Correspondingly, Joseph et al. (2020) revealed in their review of the relevant literature, that young caregivers often grapple with elevated levels of stress, emotional strain, and heightened risks of anxiety, depression, and trauma-related symptoms. The review underscored the socioemotional consequences, disruptions in social and educational pursuits, and resilience of young caregivers, emphasising the need for targeted interventions and support structures (Joseph et al., 2020).

Collectively, these works centre youth caregivers' complex challenges, underscoring the hidden nature of their contributions and the need for increased societal awareness and support. Disenfranchised grief and trauma emerged as a central theme, reflecting society's tendency to marginalise or ignore this group (Aldridge & Becker, 1993). Moreover, the interplay of caregiving in military contexts, caregiving dynamics, and sibling relationships adds complexity to our understanding. Collating insights from these diverse studies helps construct a foundation for targeted interventions and support systems such as support groups, further education opportunities, and community building. In navigating the complexities of caregiving in diverse contexts, understanding, and addressing disenfranchised grief and trauma becomes crucial to fostering a more compassionate and supportive society for caregivers of neurodiverse individuals with high and complex needs.

Siblings of People with High and Complex Needs

The literature regarding neurotypical siblings of people with autism spectrum disorder (ASD) and chronic disabilities provided a comprehensive exploration of the unique challenges, dynamics, and coping mechanisms experienced by siblings who provide care to others. Each study contributed valuable insights into sibling relationships, emotional wellbeing, and the long-term impacts of having a family member with high and complex needs.

The literature review by Meadan et al. (2010) identified twelve articles published from 1997 to 2008 regarding the social, emotional, and behavioural adaptations of siblings living with siblings with ASD. Specifically, the literature selected for this review delved into the experiences of neurotypical siblings of people with ASD, offering a glimpse into the intricate dynamics within neurodiverse families. Meadan et al. (2010) scrutinised these siblings' emotional and psychological wellbeing, revealing potential stressors and challenges that impact their mental health. The studies analysed through this literature review showed that some siblings were positively affected, such as experiencing elevated levels of self-concept and social competence or no perceived ill effects. Conversely, other siblings reported adverse effects, including low levels of pro-social behaviour, increased internalising and externalising problem behaviour, feelings of loneliness, and hinderances in acquiring socialisation skills (Meadan et al., 2010). These findings highlight the specific stressors and their effects in siblings of people with ASD and gave an insight into the coping strategies employed to manage these situations.

The research investigated siblings' perceptions of their family roles and the coping mechanisms siblings employed to navigate the distinct challenges of having a sibling with ASD (Meadan et al., 2010). The study explored these siblings' overall quality of life, considering various social, educational, and personal dimensions (Meadan et al., 2010). The research considered the long-term impact on sibling relationships as they progressed through different life stages, offering a nuanced understanding of how early experiences shaped their development (Meadan et al., 2010). This study shed light on siblings' complex challenges, providing a foundation for understanding the emotional landscape within these families.

Similarly, Orsmond and Seltzer (2007) took a longitudinal approach and explored the long-term impact of having a sibling with ASD or Down syndrome. They recruited siblings from families of 406 adolescents and adults with ASD and collected data on an 18-month basis. Their findings came through positivist measures and questionnaires covering topics such as social support and behaviour problems, coping skills, psychological wellbeing, and sibling relationship quality. Findings touched on emotional wellbeing and the evolving role of siblings in caregiving (Orsmond & Seltzer, 2007). Considering that the sibling relationship is often the longest one can have, this study offered a comprehensive perspective on the challenges siblings may encounter over time. The key recommendations emphasised the need for comprehensive support programs across the life course, such as longitudinal support initiatives tailored to siblings' evolving needs at different life stages (Orsmond & Seltzer, 2007). The authors suggested the provision of mental health resources, such as counselling or support groups, to address the emotional challenges associated with having a sibling with ASD or Down syndrome (Orsmond & Seltzer, 2007). Educational interventions are recommended to help siblings understand and cope with their sibling's ASD-related behaviours, and respite services are recommended to alleviate caregiving responsibilities (Orsmond & Seltzer, 2007). Additionally, Orsmond and Seltzer (2007) advocated for sibling-inclusive research and advocacy efforts and emphasised the importance of policies supporting siblings' unique needs within the ASD and Down syndrome communities. Communication training and transition planning are crucial, along with establishing peer support networks to foster a sense of community and shared coping strategies among siblings (Orsmond & Seltzer, 2007).

Macks and Reeve's (2007) comparison of 51 siblings of children with ASD and thirty-five siblings of neurotypical children between the ages of seven and seventeen. The researchers investigated the psychosocial adjustment of neurotypical siblings of individuals with ASD through several scaled questionnaires that involved Children’s Depression Inventory-Short Form (CDI-S) (Kovacs, 2015) and the Piers-Harris Children’s Self-Concept Scale (Piers, 1984). This study contributed to understanding how siblings navigate the challenges associated with neurodiversity as they transition into adulthood (Macks & Reeve, 2007). The key findings of the study revealed that neurotypical siblings often faced unique challenges in adjusting to the presence of a sibling with ASD, such as heightened levels of stress, anxiety, and behavioural difficulties (Macks & Reeve, 2007). Additionally, the study suggested that the adjustment difficulties of neurotypical siblings were associated with the severity of the autistic symptoms (Macks & Reeve, 2007). The findings underscored the importance of considering the wellbeing and adjustment of neurotypical siblings within the broader context of supporting families with a member on the autism spectrum (Macks & Reeve, 2007). The study emphasised the need for understanding the dynamics within these families and targeting interventions and support systems to address the specific challenges faced by neurotypical siblings of children with autism.

Dyke et al. (2009) discussed the profound challenges families face when raising a neurodiverse child with high and complex needs, encompassing all aspects, including financial, emotional, and lifestyle. The article highlighted that over the past fifty years, there has been a paradigm shift in service delivery, transitioning from focusing solely on medical and therapeutic needs to an approach that acknowledges the entire family's requirements (Dyke et al., 2009). The article noted the importance and effect of early intervention programs in the United States. It also recognised the crucial role of families in optimising outcomes for neurodiverse people with high and complex needs. While early studies primarily focused on the adverse psychological effects on siblings of neurodiverse children with high and complex needs, contemporary research suggested that overall family functioning played a pivotal role in sibling adjustment (Dyke et al., 2009). The study explicitly explored families with a Down or Rett syndrome child, revealing both positive and negative effects on siblings (Dyke et al., 2009). Positive outcomes included increased tolerance, awareness, and maturity, while disadvantages encompassed limited recreational opportunities, financial constraints, and potential feelings of embarrassment (Dyke et al., 2009).

Interestingly, there were implications that the impact of having a neurodiverse sibling varied with birth order and the number of children in the family (Dyke et al., 2009). Dyke et al. (2009) emphasised the importance of understanding and supporting siblings, suggesting interventions such as respite care and age-appropriate information resources. Medical practitioners were encouraged to advocate for families, promote positive aspects, and facilitate access to support networks for siblings, acknowledging their vital role in the overall family dynamic (Dyke et al., 2009). The study's ultimate recommendation urged service providers and policymakers to embrace the challenge of working with the entire family, particularly siblings, to enhance their experiences and contributions to society (Dyke et al., 2009).

Furthermore, the qualitative study by Yang et al. (2017) explored the lived experiences of siblings of individuals with schizophrenia in a Chinese context. This study provided a rich understanding of siblings' challenges in caregiving roles (Yang et al., 2017). The findings suggested that mental healthcare professionals should involve caregiving siblings in the care plan and offer psychoeducation for all family members, reducing tensions increased by caregiving and future care anxieties (Yang et al., 2017). The findings offered transferable insights applicable to siblings in various caregiving situations and reinforced the importance of emotional support and tailored interventions (Yang et al., 2017).

The combination of these studies collectively deepened the understanding of the experiences of siblings in families with neurodiverse individuals with high and complex needs. These works contributed to the broader discourse on the emotional complexities within neurodiverse families and provided a foundation for future research and supportive interventions.

Sibling Experiences of Neurodiversity

The following section of the literature review discusses varying aspects relevant to the experiences of siblings of neurodiverse people with high and complex needs. The literature reviewed covered various topics such as complex emotions, gender, behaviour, attitudes, and practitioner perspectives.

Guilt and Fears for the Future

Jacobs and MacMahon (2017) used interpretive phenomenological analysis to uncover themes of experience among six neurotypical siblings of neurodiverse people, focusing on those who had a neurodiverse sibling in residential care. The study highlighted the core themes of the neurotypical sibling experience in England and Belgium through in-depth and semi-structured interviews. A core theme discovered was the added weight of responsibility in the participant's lives (Jacobs & MacMahon, 2017). While neurotypical siblings noted the inherent benefits of their neurodiverse sibling being in residential care, this was often accompanied by feelings of guilt (Jacobs & MacMahon, 2017). Jacobs and MacMahon (2017) noted that the neurotypical sibling's fears for the neurodiverse sibling's future are reduced in previous studies where the siblings lived together. This could have correlated to the lessened physical distance between siblings and the accessible facilities and funding for families, rather than an accurate appraisal of the siblings' sentiments regarding the neurodiverse sibling's future care needs. The selection of participants from a single organisation could limit the study and may have failed to reflect the experience of neurotypical siblings based in Aotearoa. For example, there may be cultural differences in approach or understanding and differences in facilities or accessibility to long-term care. Therefore, questions regarding the neurotypical siblings' sentiments about their neurodiverse sibling being in care may be ap really good well done plicable for further study in Aotearoa.

Unmet Needs and Desires of Neurotypical Siblings

Inquiries into the quality of life for siblings of neurodiverse people with high and complex needs have been primarily centred in research conducted throughout the United Kingdom. The literature reviewed by Moyson and Roeyers (2012) highlighted core needs and supports that can increase the quality of life for this group. The aim of the qualitative and in-depth phenomenology-based interviews in the study was to investigate how young neurotypical siblings of neurodiverse people with high and complex needs define their quality of life as siblings.

Moyson and Roeyers (2012) recruited fifty neurotypical siblings from thirty-seven families with a neurodiverse child with high and complex needs. Participant recruitment involved approaching organisations such as family support services, rehabilitation centres and respite care facilities in Flanders (Dutch-speaking Belgium). By adopting interpretive phenomenological analysis, the researchers attempted to identify key themes and meanings of the experiences of siblings of neurodiverse children (Moyson & Roeyers, 2012).

Moyson and Roeyers (2012) focused on neurotypical siblings of neurodiverse people aged six to fourteen and their quality of life. The results found potential unmet needs of neurotypical siblings, for example, the desire for a mutual understanding of needs, the need for private time, exchanging experiences and social support, better resilience, and a lack of confidence in their sibling's wellbeing. The interviewees were from middle- to high-socioeconomic families, which limited the scope of needs from expanding on the compounding issues affecting families and neurotypical and neurodiverse siblings, such as class, socio-politics, and socioeconomics. The authors noted the limits and offered the idea for future research to focus on both these contributing factors and expanded criteria for 'disabilities', for example, physical disabilities and chronic illness (Moyson & Roeyers, 2012).

Parallel to Moyson and Roeyers (2012), Hanvey et al. (2022) interviewed sixteen participants between twenty and sixty-eight years old recruited through various organisations and respite care facilities in the United Kingdom. Hanvey et al. (2022) approached recruitment through Twitter and shared the study criteria with several local support organisations. The study examined the reflections and experiences of neurotypical siblings of neurodiverse people through semi-structured interviews that focused on childhood experiences, supports, friendships, schooling, mental health, and wellbeing (Hanvey et al., 2022). Similarly, Hanvey et al. (2022) highlighted themes of guilt, internalisation stemming from adverse life experiences, a sense of invisibility and a need for social support from family, friends, and a more comprehensive network of people with similar experiences. Furthermore, Hanvey et al. (2022) highlighted common themes, such as invisibility, internalisation, and guilt that neurotypical siblings encountered in the United Kingdom by examining how these themes play out through the sibling's lived experiences.

While Hanvey et al. (2022) could directly recruit participants to engage in their study, Moyson and Roeyers (2012) were ethically bound to contact participants via their parents. This was an ethically safe method for engaging with minors, however, this may have limited the researchers' access due to the topic's sensitive nature (Moyson & Roeyers, 2012). Interpretive phenomenological analysis for these studies could be suitable as it engages the interviewee's 'cognitive inner world' (Smith et al., 2022). By capturing the interviewee's inner cognitive world in these studies, the researchers captured the fluctuation of the lived experience of neurotypical siblings of neurodiverse people with high and complex needs while identifying the inherent subjectivity of the interviewees (Jacobs & MacMahon, 2017).

Invisibility

Hanvey et al. (2022) pinpointed themes of psychological impact that could cause further mental health issues, providing one of the most impactful studies in the construction of this research project. These themes included feeling invisible, psychological difficulties, internalisation, guilt and self-blame, and a tendency to disregard or fail to recognise their needs (Hanvey et al., 2022). In a similar study, Connors and Stalker (2003) interviewed twenty-four neurotypical siblings of people with neurodiversity, aged between six and nineteen, across Britain. They ascertained that the accounts of life and wellbeing were predominantly positive, with a sense of subjective “ordinary-ness” and reciprocal relationships between neurotypical siblings and siblings with neurodiversity (Connors & Stalker, 2003, p.13). However, there were reports of internalisation, not “bothering” parents, loss of time and attention, and some psycho-emotional damage (Connors & Stalker, 2003, p.13). On the contrary, investigations into the families of individuals with neurodiversity from the standpoint of positive psychology suggested that, while their experience may not be inherently easy, it could contribute to a more fulfilling and prosperous life (Leidenhag & King, 2023).

Gender

The international literature found during this review also highlighted a potential gender disparity among responding siblings. In Leane’s 2019 study, the gender disparity in caregiving was highlighted, where females are more likely to be the “key carers” in later life (Leane, 2019, p. 268). This imbalance was also reflected in Hanvey et al. (2022), who noted the gender disparity in their sample size, as fourteen of the sixteen respondents identified as female.

Leane (2019) examined the narratives of twenty-five predominantly female caregiving neurotypical siblings of neurodiverse people with high and complex needs aged eighteen to forty-five. Consistent with the phenomenological research, Leane's (2019) narrative analysis highlighted the close emotional bonds made in childhood between siblings that fostered a higher sensitivity to the other's feelings and needs. These narratives highlighted social issues not often identified in the discourse, such as gender and gendered expectations. The researcher identified that the predominantly female voice in the narrative reflected a need for support that is representative of the responsibilities and ambitions of the population (Leane, 2019). The study implied that emotion and connection impacted the decisions made around caregiving, how the neurotypical sibling made sense of it, and how they managed and negotiated care (Leane, 2019).

Seltzer et al. (2005) supported the significance of gender in the inter-sibling relationship. They discovered that the sibling most engaged in the family dynamic was more frequently a female sibling. Their study also revealed that neurotypical brothers were more likely to have distant relationships when their neurodiverse sibling was a sister and closer to a brother. Conversely, the gender of the sibling with the neurodiversity did not impact the sisters' emotional or practical contributions. Qualitative research suggested that gender plays a crucial role in the extent and nature of neurotypical siblings' interactions with their neurodiverse sibling, with sisters often assuming a more supportive role compared to brothers (Zetlin, 1986).

Moreover, a notable gap in the literature was found surrounding representation of male neurotypical siblings of neurodiverse people, as they are not adequately vocalised (Leane, 2019). These studies and the highlighted gender disparity of respondents raised the need for future studies to engage in gender-diverse recruitment styles and focus.

A Lifelong Relationship

Seltzer et al. (2005) investigated how the sibling relationship distinguished itself when one sibling of the pair was neurodiverse. The researchers focused on the adult sibling relationship, as past research on neurotypical siblings and people with neurodiversity had focused on the sibling pair during childhood (Seltzer et al., 2005). Considering the longevity of these relationships, the authors noted a need to extend the investigation of the sibling relationship when one has neurodiversity across the life course to explain better whether and how this relationship changes when the siblings grow up. Seltzer et al. (2005) analysed self-reported and qualitatively designed comparative research, which showed that the most involved sibling in the family had a high level of contact with the neurodiverse sibling. Thirty percent of respondents reported weekly or more frequent phone contacts, 41% reported in-person visits at least weekly, and 58% lived within a 30-minute radius of each other's home. Forty-four percent of the adults with neurodiversity had an overnight visit with a neurotypical sibling the previous year. Shared activities were reported between siblings, such as going to a restaurant (63%), shopping together (56%) or going to the movies (44%) (Seltzer et al., 2005).

The research on sibling relationships when one sibling was neurodiverse revealed that these bonds were characterised by supportiveness, concern, and involvement. A central question that arose from Seltzer et al. (2005) was whether the uniqueness of the relationship was shaped by the specific diagnosis of the neurodiverse sibling or if the primary fact of the diagnosis had affected the sibling experience.

Behaviour and Quality of Sibling Relationships

Furthermore, in their review of studies between 1990 and 2004, Stoneman (2005) found that emotional reactions, internal resources, and behaviour problems that affected sibling relationship quality did not differ for neurotypical sibling pairs. Moreover, evidence suggested sibling relationships involving a person with neurodiversity might have been more positive. In a similar study, Hastings and Taunt (2002) found parents of children with neurodiversity reported positive impacts on the neurotypical child, including a changed perspective on life, increased sensitivity, learning opportunities, improved family dynamics, and strengthened religious faith (Hastings & Taunt, 2002). However, further studies have found that behaviour problems can affect the socialisation of siblings and their relationship.

The study by Travers et al. (2020) assessed 155 sibling pairs aged eighteen to thirty on how the neurotypical siblings spent time with their neurodiverse sibling. Among the participating young adult neurotypical siblings, all participants reported through a questionnaire that they engaged in at least one of the sixteen activity items with their neurodiverse sibling. The questionnaire listed sixteen activities (for example going to the movies, going to the mall, and volunteering) and asked siblings how often they participated in these activities with their neurodiverse sibling in the preceding year. Everyday activities occurring in the home, such as talking on the phone and watching TV were most frequent, while community-based activities like art, music, or dance lessons were less frequent.

Factors associated with spending less time together included limited speech and increased problematic behaviour of the neurodiverse sibling, making participation in community activities more challenging, particularly with higher support needs where participants might not have felt equipped to support their neurodiverse siblings independently.

Despite challenges, most siblings viewed their overall relationships with their neurodiverse siblings positively. When asked about the positivity of their relationship, 86.9% of siblings responded with "pretty much," "very much," or "extremely" (Travers et al., 2020, p. 32). This aligned with above studies indicating optimistic views of neurodiverse siblings. The study demonstrated that understanding the quality and closeness of sibling relationships over time can contribute to a smoother transition from sibling to caretaker for individuals with disabilities and their siblings.

Culture and Socioeconomic Challenges

Regarding cultural impacts on the experiences of neurotypical siblings of neurodiverse people with high and complex needs, the vast majority of studies have centred on Western, English-speaking perspectives and are not reflective of Aotearoa cultural context, making it unclear whether it is appropriate to generalise their findings to our bi-cultural society. To illustrate, in the literature review by Marquis et al. (2019), the peer-reviewed and published papers were from 1970 to 2017 and were dedicated to English-speaking neurotypical siblings' physical and mental health from zero to nineteen years old. While the bulk of current literature assumes a Eurocentric lens, the cultural and socioeconomic challenges found from a more expansive perspective will be explored.

Marquis et al. (2019) reviewed the literature through a radical paradigm and reduced existing literature into a narrative structure to affect policy development and support service change. The researchers utilised the narrative literature review method to note the factors that may affect the neurotypical sibling's ongoing physical and mental health (Marquis et al., 2019). The review highlighted that the neurotypical sibling's mental health impacts were akin to poverty or belonging to an ethnic minority group (Marquis et al., 2019). Marquis et al. (2019) found similarities through various factors: the impacts of income inequality, family structure, educational background, socioeconomic locations, race, caregiving, and worries concerning shame, embarrassment, and internalisation. The assertion of a comparable experience is flawed, as the life experiences of poverty and minority ethnic groups are complex and are derived from vastly different socio-political constructs.

Furthermore, these experiences are focused solely on English-speaking participants, which may neglect participants from sub-societies more frequently associated with these minority groups. Marquis et al. (2019) note that further research is required into a larger population and life course study to separate and examine these effects. An analysis of the stories and experiences of this group while also considering socioeconomic factors could better explain these correlations.

Growth

Findler and Vardi (2009) examined the impact of self-differentiation, perceived stress, and parental preference on neurotypical siblings' spiritual personal, and social growth. Findler and Vardi (2009) studied the differences between neurotypical siblings of people with neurodiversity and typically developing sibling pairs regarding differentiation of self, perception of parental treatment, stress, and growth. For this study, 190 participants aged thirteen to eighteen lived in “intact” families in the centre of Israel (Findler & Vardi, 2009, p. 8). Of these, 101 were neurotypical siblings of neurodiverse children with mild to moderate needs and diagnoses who lived at home, and eighty-nine had siblings with no neurodiversity.

Findler and Vardi (2009) investigated the comparative influence of these variables on neurotypical siblings of neurodiverse children with high and complex needs, analysing their respective contributions to the psychological development of the siblings. The participants were asked to complete the adapted Stress-Related Growth Scale (Park et al., 2013) for this study, which assessed the positive outcomes of a stressful event relating to spiritual, personal, and social consequences. The Perceived Family Relationship Questionnaire (Anthony & Bene, 1957) was part of the self-report family relations test administered for the study. The study used twenty items examining the perceived level of their parents’ preference. Five items indicated a positive attitude toward the sibling, for example, "My mother never complains about my sibling in comparison to other children in the family," (Findler & Vardi, 2009, p. 8). Five items indicated a negative attitude; for example, "Of all children in the family, my mother is always willing to punish my sibling" (Findler & Vardi, 2009, p.9). Throughout the analysis of the survey response, there were signs suggesting that neurotypical siblings of individuals with neurodiversity demonstrated elevated levels of personal development, with self-differentiation and perceived maternal preference emerging as the primary factors driving this progression. Interestingly, their results showed families of individuals with neurodiversity to have more children, have higher engagement with religion, and report lower economic status. The researchers acknowledged the limitations of relying solely on self-reports. They recommended that future studies incorporate additional measures, including observations and data from diverse sources such as parents, teachers, or professionals, as this would attain a more comprehensive understanding of neurotypical siblings' adaptations (Findler & Vardi, 2009). Additionally, while Israel is representative of Western society in many aspects, the authors identify that culture-specific factors may have influenced the findings (Findler & Vardi, 2009). Replicating the study in different cultures would provide valuable cross-cultural validation.

Attitudes

Sommantico et al. (2020a) focused on the relationship between attitudes and psychosocial outcomes of the neurotypical siblings of people with neurodiversity in the Italian context. Recruited through the internet, the 133 neurotypical siblings of people with neurodiversity indicated through a questionnaire that they experienced fewer positive emotional, behavioural, and cognitive attitudes towards their relationships and less frequent contact than the 140 typically developing people with typically developing siblings also questioned (Sommantico et al., 2020a). The positivist survey method can be limiting, as relationships are nuanced and subjective, and these answers offer only a quantifiable result rather than a holistic understanding of the relationship itself.

Furthermore, Sommantico et al. (2020b) developed the Siblings' Experience Quality Scale (SEQS) to measure the cognitive, emotional, and behavioural experiences of adult siblings of neurodiverse individuals with high and complex needs through five primary subjects: closeness, conflict, jealousy, self-marginalisation, and worry. The results indicated varying levels of intimacy depending on the placement of the neurodiverse sibling and the neurotypical sibling in the familial structure; for example, older siblings of neurodiverse individuals reported more closeness, and first-born siblings of neurodiverse individuals with high and complex needs experienced greater marginalisation (Sommantico et al., 2020b). Although a helpful self-report tool, the SEQS again does not advocate for the complexity and nuance of the sibling relationship.

Contrastingly, Granat et al. (2012) gave the sibling relationship questionnaire pre- and post-intervention and, after six weekly, two-hour sibling workshops, noted significant differences in the sibling relationship. The workshops educated the neurotypical siblings of children with neurodiversity on their neurodiverse sibling's conditions to increase their ability to regulate themselves in their environment (Granat et al., 2012). Additionally, the workshops provided tools to navigate the sibling relationship more effectively (Granat et al., 2012). Granat et al. (2012) reflected that, due to the self-selecting of participants, it was difficult to say whether these results were generalisable to the broader public. Most participants were from well-resourced, highly motivated families, and the number of participants was restricted (Granat et al., 2012). Likewise, there were no examinations of the experiences in the sibling relationship; thus, it was unknown whether the available tools were genuinely effective.

Finally, Petalas et al. (2009) measured behavioural and emotional regulation for neurotypical siblings of people with neurodiversity and neurodiverse siblings with comorbidity of ASD. Of the 49 respondents, the data summarised that these respondents were more likely to be within the high abnormal range for emotional distress and prosocial behaviour problems when compared with the neurotypical siblings of neurodiverse people and the typically developing sample (Petalas et al., 2009). The limitations and reduction of experiences of relationships between neurotypical siblings and their siblings indicated a need for further research into the stories and experiences of this population to enhance an already under-researched discourse in counselling.

Practitioner Perspectives

Burke's (2004) book intended to inform practitioners of the needs of neurotypical siblings of people with neurodiversity. This desire to inform practitioners comes from his parental experience of having a child with Spastic Quadriplegia and his other daughter's experience as a neurotypical sibling. This book focused on life at home for neurotypical siblings of people with neurodiversity, change, adjustments, and resilience, siblings as young caregivers and the different family experiences concerning neurodiversity.

To discern the main concerns of neurotypical siblings of people with neurodiversity, Burke (2004) interviewed neurotypical siblings of people with neurodiversity separately from their parents alongside two sibling-led support group meetings. The sibling-led format fostered open conversation and highlighted the need to consider siblings' feelings and needs equally within the family. Burke (2004) highlighted central experience themes, including neurotypical siblings receiving less attention from their parents than their neurodiverse siblings and neurotypical siblings’ hesitancy or reservation in sharing their concerns with their parents. Furthermore, this perspective reminded practitioners to be mindful of the neurotypical sibling's self-management, coping and self-esteem. Additionally, Burke (2004) implored practitioners to broker informed choices as part of the assessment to empower neurotypical siblings to have a chance at control.

The Power of Group Work in Aotearoa

The search for literature about the neurotypical sibling experience produced some theses regarding the neurotypical sibling experience from 1987 to 1998 through the former Auckland College of

Education: School of Special Education. One of the first published theses produced by these searches was Nel's (1987) thesis, *Brothers and sisters of people with special needs: Their needs and concerns*, which utilised qualitative and interpretive review measures to explore the needs and concerns of young neurotypical siblings of young people with neurodiversity through group counselling processes. This methodology was used to "present a general overview of some of the problems, concerns and frustrations associated with siblings of the children with special needs: how the handicapped child affects siblings in their everyday life" (p. iii)[1]. Nel's (1987) study considered the sibling relationship and focused on the question, "when a brother or sister has a handicap, will the effects on the non-handicapped sibling be negative or positive?" (p. IV). Nel's (1987) study found that most participants benefited from the group counselling process and workshops that were provided. The participants reflected that the 'group' processes and structure assisted in fostering a sense of community with other participants and better feelings towards their sibling's prospects. This study highlighted the need for neurotypical siblings to have a constructive and open space with other young people in similar situations to share, relate, and connect.

Likewise, McGibbon's (1994) thesis *Sibling workshops: For young children who have siblings with special needs* used the group process intervention method. Participants were invited to engage in workshops to examine and reflect on the neurotypical siblings' experiences. McGibbon's (1994) study used a qualitative and interpretive approach to the data collected through sibling workshops to provide an overview of the sibling relationship and the needs and issues that arose for those with a neurodiverse sibling. McGibbon's (1994) study used six sibling workshops for young children, after which information was shared with parents, teachers, and other professionals. These workshops enabled a better understanding of the sibling experience and the needs of neurotypical siblings. One of the central findings was that the participants did not regard neurodiversity as a deficit and that their concerns focused on the immediate future of their neurodiverse siblings (McGibbon, 1994). The study also found that neurotypical siblings felt that their neurodiverse sibling was favoured by the adults in their lives. The workshops addressed this issue by allowing neurotypical siblings to meet the core need of "being seen" through drama games and dressing up, emphasising fun and free play (McGibbon, 1994). The researcher reflected that future studies and workshops should emphasise free play, giving neurotypical siblings autonomy and control over their environment, which they often lacked in their home lives. Like Nel's (1987) study, the results of McGibbon's (1994) workshops showed that meeting and making new friends, meeting other people with neurodiverse siblings, and emphasising fun were the key highlights of the workshop experience.

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[1] The author notes the use of ableist language in Nel's (1987) thesis.

An Unfocused Lens

While Nel (1987) and McGibbon (1994) focused on the experience of the neurotypical sibling, Mair (1997) took the opportunity to explore the stories of both parents and neurotypical siblings. Mair (1997) used an interview format and interpretive phenomenological analysis to identify the neurotypical siblings' needs, stress factors, and emotions. Using interview prompts, siblings and parents shared their life stories and indicated what was essential to meeting their needs. The interviews allowed whānau to express individual experiences, feelings, and to voice what was most important in meeting their needs. A critique of this study is the integration of both parents and siblings in the interview, where there could have been some resistance for the participants, especially siblings, to vocalise their opinion or experience authentically. This highlighted the need for a reflective piece for siblings to be able to air their experiences anonymously and constructively. The critical points in Mair's (1997) study were that there was a need for better information regarding the neurodiverse sibling diagnoses, communication with the neurotypical sibling, and more attention from parents on family relationships and family life. This study highlighted the need for neurotypical siblings to be more involved in communications regarding their neurodiverse siblings, a common thread of experience in other international studies.

Through narrative analysis, emotions can be treated as objects, illuminating the various needs and experiences of the subjects (Leane, 2019). Similarly, the voices heard concerning the discourse around neurotypical siblings of neurodiverse people are of paramount influence. One of the prominent support agencies for families with a neurodiverse person in Aotearoa is the podcast and organisation Parent2Parent. Parent2Parent's (2018) podcast episode interviewed the mother of a neurotypical sibling and neurodiverse person with autism spectrum disorder (ASD) and researcher Rebecca Armstrong. The mother reported that for her neurotypical child, "it is just his life" and that the effect of having a neurodiverse sibling with complex needs was a formative experience, leading the neurotypical sibling to be "more accepting and open towards all people" (Parent2Parent, 2018, 5.37). However, the researcher approached the experience from a clinical perspective and offered that neurotypical siblings of neurodiverse people with high and complex needs have noted common themes of increased anxiety, depression, perfectionism, a sense of duty and responsibility, and internalisation. The researcher also highlighted the positives of the neurotypical sibling experience, such as strengthened resilience, fostering profound empathy, loyalty, tolerance, and maturity (Parent2Parent, 2018).

While the podcast advised the listener regarding the parent's role and the community's responsibility, it was pertinent to observe that the neurotypical sibling's voice was muted in this narrative. The central narrative is vocalised by a parent, who can only observe the neurotypical sibling's experience from a distance, and by an expert who approached the experience as a pragmatic observer. For this discourse, it was paramount to give space to neurotypical siblings of people with neurodiversity and high and complex needs to explore their truth.

The Weight of Responsibility and Care

Shaw's (1998) thesis, *What about me? The effects on siblings who have brothers and sisters with special needs* was conducted through semi-structured interviews and narrative analysis, focusing on understanding the specific needs of neurotypical siblings of people with neurodiversity to develop further education programs. The programs this study assisted in developing were aligned with supporting siblings and strengthening family units (Shaw, 1998). This study offered an opportunity to develop an understanding of the needs of the neurotypical siblings within their families. This was through an examination of the family environment and sibling subsystems and their effect on interwoven family networks. The sibling's responses to the semi-structured interviews were recorded and subjected to rigorous narrative analysis. Shaw (1998) summarised that the main concerns of these neurotypical siblings were worry, anger, tension, and embarrassment, as well as the stress and arguments caused by caregiving responsibilities. However, a theme of unselfishness, acceptance, and pride ran through the interviews.

Adding to this research, the narrative analysis and semi-structured interviews studied by Littlejohn (1998) inquired about adult neurotypical siblings. They asked them to reflect on their experiences and the impact of neurodiversity on their lives related to caregiving, support, and family life. The impact of the sibling relationship between neurotypical and neurodiverse siblings was central due to factors such as ongoing caregiving, the lifespan of neurodiverse people, the ageing and death of caregivers, and the reintegration of previously institutionalised persons. To do this, Littlejohn (1998) investigated the roles of three adult siblings with siblings with a range of neurodiversity, such as intellectual, sensory, and psychiatric differences. The researcher found that families had expectations that siblings would take on the responsibilities of the parents after their passing and that this responsibility weighed heavily on the sibling. Littlejohn's (1998) study highlighted that the weight of responsibility throughout the life span of the neurotypical sibling was an experience that needed further exploration.

Research Gaps

The undertaken literature review evidenced a range of gaps and limitations to the current state of research on neurotypical siblings of neurodiverse people with high and complex needs. While providing the groundwork for this population's experiences, the publication dates, vocabulary, and philosophical undercurrents of these theses could be considered outdated. The discourse regarding the experiences of this part of society requires an updated exploratory study to understand the modern sibling experience. Furthermore, the contexts of these theses were in the school of education, which highlighted the need for a counselling-focused approach to explore the needs of neurotypical siblings of neurodiverse people. A current account would also provide base knowledge for further examination of the sociocultural aspects of the experiences of neurotypical siblings of neurodiverse people in Aotearoa.

One of the notable findings in the reviewed literature was the impact of community-based supports for neurotypical siblings. One of the closest studies was published in 2012 and considered the needs and supports offered to siblings of neurodiverse people. Moyson and Roeyers' (2012) study highlighted the importance of exchanging experiences, receiving social support, and engaging more with the outside world to maintain the wellbeing of neurotypical siblings. In the study, neurotypical siblings stated that stories from people who shared similar experiences provided avenues for understanding, acceptance, and different perspectives on their journey with a neurodiverse sibling (Moyson & Roeyers, 2012). Some neurotypical siblings expressed appreciation for the opportunity to offer camaraderie or support to others in a familiar situation (Moyson & Roeyers, 2012). Furthermore, this study highlighted those siblings often required more emotional support throughout their development and adulthood than typically developing siblings.

Further to this, internalisation was highlighted as a prominent finding that could be explored further in the Aotearoa context. Moyson and Roeyers (2012) highlighted that neurotypical siblings would first expect this support from their parents. However, they often held back from seeking support as they perceived their parents to be under immense stress (Moyson & Roeyers, 2012). Hence, neurotypical siblings often self-invalidated their needs to keep from adding to their parents' stress, exacerbating a sense of aloneness in their experiences (Burke, 2004). Although neurotypical siblings were aware of and respected the needs of their neurodiverse siblings, Moyson and Roeyers (2012) recommended that parents provided extra support or attention to neurotypical siblings as much as they were capable.

Finally, the community support systems that could be validating and offering care to neurotypical siblings was highlighted as lacking. Neurotypical siblings in this study described the *outside world* as a source of support and distress (Moyson & Roeyers, 2012, p. 12). The outside world comprised the broader social and societal circles around neurotypical siblings who know they have an "extraordinary sibling" (Moyson & Roeyers, 2012, p. 88). A concurrent theme from Moyson and Roeyers' (2012) analysis was that the outside world can be supportive if it appreciates the neurodiverse sibling but also accepts the "sometimes difficult situations that (neurotypical) siblings go through" (Moyson & Roeyers, 2012, p. 100). For siblings, an outside world that could not accept their neurodiverse sibling was distressing (Moyson & Roeyers, 2012). Without recognition or validation from their community and support systems, neurotypical siblings of neurodiverse people with high and complex needs struggled in the future to understand their experiences or seek help for the adverse impact that these experiences have had on them emotionally or mentally (Moyson & Roeyers, 2012).

This literature review formulated a base of knowledge for the research question: What are the experiences of neurotypical siblings of neurodiverse people with high and complex needs in Aotearoa? Through this literature review, it became evident that the experiences of neurotypical siblings of neurodiverse people with high and complex needs, specifically in Aotearoa, are under-researched in a modern context.

Methodology

As a small-scale exploratory study, this project adopted a qualitative interpretive design. A qualitative interpretive paradigm positions the researcher in an intersubjective relationship with participants, acting as a listener and interpreter of data, necessitating reflexivity (Cocks, 2013). Grant and Giddings (2002) categorised four overarching research paradigms: positivism, interpretivism, radicalism, and post-structuralism. Interpretivism in research emphasises understanding human experiences from diverse perspectives, contributing to a rich comprehension of the complexities inherent in human existence (Grant & Giddings, 2002). While sharing assumptions about truth and understanding human experience, interpretive methodologies vary in theoretical perspectives and data collection methods (Grant & Giddings, 2002). For the current study, reflexive thematic analysis was chosen as a method as it emphasised researcher reflexivity and positionality. This was important as the researcher had lived experience with the research topic.

The primary aim of reflexive thematic analysis is to concentrate on the creation, examination, and understanding of patterns within a dataset (Braun & Clarke, 2022). Reflexive thematic analysis is frequently associated with the phenomenological or experiential qualitative research tradition, which is prevalent in counselling and psychotherapy research (Morrow, 2007). The *reflexive* base of this method involved the practice of critical reflection on the researcher's role, the research practice, and the process (Braun & Clarke, 2022). Reflexive thematic analysis aligned with the core values of the research question, which were to explore the common themes of experience for neurotypical siblings of people with neurodiversity.

Reflexive Thematic Analysis

As a method, reflexive thematic analysis provided a toolkit comprised of tools, concepts, techniques, practices, and guidelines for organising, examining, and interpreting a dataset (Braun & Clarke, 2022). Reflexive thematic analysis differentiates from other qualitative analyses, such as content analysis which often relied on pre-existing frameworks or theories to guide the analysis process (Braun & Clarke, 2022). Reflexive thematic analysis can be conceptualised as a method that offers theoretical flexibility rather than being constrained by specific theoretical frameworks (Braun & Clarke, 2021). However, various approaches to reflexive thematic analysis are influenced by the paradigms that inform this method (Braun & Clarke, 2021). Reflexive thematic analysis assumes that there is meaning within the data that can be identified and analysed through a careful process of coding and interpretation, and places inherent value on the subjective, situated, and aware researcher (Braun & Clarke, 2017).

It is necessary for the researcher to reflect on the predominant assumptions ingrained in their cultural context as both an observer and a cultural participant (Braun & Clarke, 2022). In this approach, researchers should desire to understand nuance, complexity, and even contradiction rather than finding a simple explanation. Researchers should prefer the long answer over the short answer, requiring tolerance for some uncertainty (Braun & Clarke, 2022).

Development of Reflexive Thematic Analysis

Over the years, several theorists have contributed to developing and refining reflexive thematic analysis. Virginia Braun and Victoria Clarke were two psychologists who were central in developing reflexive thematic analysis (Braun & Clarke, 2006). Their first co-authored paper highlighted guidelines to start a thematic analysis or conduct it more deliberately and rigorously while considering potential pitfalls in this research style (Braun & Clarke, 2006). Their method for thematic analysis comprised six stages: one, initially becoming acquainted with the data; two, creating initial codes; three, identifying themes; four, reviewing these themes; five, defining and labelling the themes; and sixth, crafting the final report (Braun & Clarke, 2006). This method was widely used because it was easy to follow, transparent, and flexible. Braun and Clarke's (2006) work helped to make thematic analysis more accessible to researchers across various fields and emphasised the importance and usefulness of the researcher's reflexivity in interpreting the data. Braun and Clarke (2022) proposed that the researcher's positioning inevitably shapes the researcher's engagement with the data and the research.

Similarly, Uwe Flick (2017), a German social scientist, contributed to the development of various qualitative research methods, including thematic analysis. Flick (2009) had written extensively on qualitative research methods and emphasised the importance of reflexivity in qualitative research, meaning that researchers should be aware of their biases and assumptions and how they may influence the analysis (Flick, 2018). Flick also highlighted the importance of context in thematic analysis and argued that themes should be analysed with consideration of the broader social and cultural contexts through which they emerged (Flick, 2018).

Similarly, Catherine Kohler Riessman (2008) was an American sociologist who emphasised the importance of studying narratives in qualitative research and using thematic analysis to identify themes within the narratives. Riessman (1993) also developed a method for analysing personal narratives, which involved identifying the plot, setting, characters, and themes. Riessman's (1993) work had helped to make thematic analysis more accessible to researchers who were interested in studying personal narratives while maintaining a vested interest in the themes of experience and meaning making.

The theorists discussed have contributed significantly to developing and refining reflexive thematic analysis. Their work has helped to make thematic analysis more accessible, rigorous, and transparent. As qualitative research continues to grow in popularity, the contributions of these theorists will continue to shape and influence the field of qualitative research.

Why Reflexive Thematic Analysis

Reflexive thematic analysis, narrative analysis, and interpretive phenomenological analysis (IPA) are distinct qualitative research approaches each with unique strengths and limitations. Reflexive thematic analysis offers a flexible framework, emphasises reflexivity, and encourages researchers to acknowledge their preconceptions and biases throughout the analysis process (Braun & Clarke, 2022). However, this subjectivity could be disadvantageous, as interpretations of data may vary based on the researcher's perspective.

Comparatively, narrative analysis focuses on storytelling and constructing meaning through narratives, capturing the richness of individual experiences, and fostering a deep understanding of the context (Delve & Limpaecher, 2020). A potential drawback is maintaining objectivity as the researcher engages with subjective narratives. IPA explores the lived experiences of individuals, aiming for an in-depth understanding of phenomena (Spiers & Smith, 2019). The advantage of IPA lies in uncovering the essence of experiences, but its disadvantages involve potentially overemphasising individual perspectives and not addressing broader social or cultural contexts (Spiers & Smith, 2019).

Ultimately, reflexive thematic analysis was chosen for this study as it exceled in flexibility and reflexivity (Braun & Clarke, 2022). As the researcher has a personal experience like the participants, richness would be added through the engagement of researcher subjectivity. Through this process, the researcher examined, analysed, and reflected on their own experience while uncovering broader social and cultural aspects of the experiences presented (Braun & Clarke, 2022).

Ten Assumptions of Reflexive Thematic Analysis

Braun and Clarke (2022) listed ten core process assumptions for reflexive thematic analysis. The first pillar was researcher subjectivity. Researcher subjectivity in reflexive thematic analysis was a primary tool, as knowledge generation was viewed as inherently subjective (Braun & Clarke, 2022). The researcher's subjectivity was not a problem to be managed or mitigated but treated as a central resource for robust analysis (Braun & Clarke, 2022). The second assumption was the acceptance that data analysis and interpretation cannot be accurate or objective. Integrating researcher subjectivity and reflexivity into data analysis and interpretation makes outcomes more robust, compelling, and insightful. However, this process should be cautiously approached, as a flippant approach to researcher subjectivity can make analysis and interpretation weaker, unconvincing, underdeveloped, and superficial (Braun & Clarke, 2022).

Good coding was the third assumption of reflexive thematic analysis. It can be achieved alone or through collaboration if collaborative coding improves understanding, interpretation, and reflexivity instead of reaching an agreement (Braun & Clarke, 2022). This led to the fourth assumption, the high-quality codes and themes that resulted from immersion in the data. High-quality codes materialise when the researcher takes some distance from the developing analysis, often requiring time and breaks from the analytical process (Braun & Clarke, 2022).

The fifth assumption was the themes and patterns moored by a collective concept, rather than synopses of all aspects concerning a subject. Initial themes, which are analytic outputs built from high-quality codes, were the sixth assumption, as they could only be identified after the analytic process. The seventh pillar concerned the expansion of these themes. Themes do not inactively 'emerge' from data but are crafted by the researcher through their systematic engagement and interactions with the dataset (Braun & Clarke, 2022). The eighth assumption regarded the need for further rigorous data analysis, underpinned by theoretical assumptions, to be focused on and acknowledged (Braun & Clarke, 2022). The ninth assumption was the central tenet of reflexivity, critical to high-quality analysis; researchers must aspire to understand and 'own' their perspectives within the process (Braun & Clarke, 2022). Ultimately, the tenth assumption viewed data analysis as an art, not a science, with creativity at its core, positioned within a framework of vigour (Braun & Clarke, 2022).

Advantages and Disadvantages of Reflexive Thematic Analysis

Braun and Clarke (2017) considered reflexive thematic analysis as an approach that was often more transparent and rigorous than other qualitative methods, emphasising the researcher's reflexivity and providing a detailed analysis process. However, there were also some potential limitations to reflexive thematic analysis, such as a loose approach to qualitative analysis and an impropriety for advanced research projects (Braun & Clarke, 2017). Reflexive thematic analysis can be time-consuming, as the researcher must carefully code and analyse the data to identify patterns and themes, like grounded theory, and must compose theories to explain the data (Braun & Clarke, 2017). For this study, reflexive thematic analysis was an appropriate choice, as the objective was to understand the experience and feelings of the participant. Through analysing the core themes of experience, we can see patterns of experience and commonalities across the dataset, which can help vocalise and highlight the needs of this group.

Researcher Positionality

Given the personal nature of this research, I needed to reflect on my position within this study. Positionality is how a researcher's perspective and viewpoint integrate with the participants and process of research (Rowe, 2014). Different characteristics, such as gender, ethnicity, individual experiences, as well as values and beliefs, contribute to shaping the positionality of researchers. These elements influence presumptions, engagement with participants, questions asked, and the interpretation of data (Patton, 2015). Milligan (2016) regards positionality as that of a researcher who is neither fully an insider nor an outsider but shifts their position depending on the context of their research. For example, Katyal and King (2014) reflect on the fluidity of their positionality through cultural differences and professional similarities to the participants in the context of their research.

For this study, I reflected upon my position as a person with a lived experience similar to that of the participants and the influence this had on the chosen topic. Without my personal experience and search for answers about these experiences and camaraderie, this study may not have been initiated. For example, the chosen method reflected my need for connection, understanding, and the desire to be heard. As the sister of a neurodiverse person with high and complex needs and the daughter of parents navigating that experience, I was very much an ‘insider.’ However, I was also an 'outsider' because of my knowledge and power in the context of the research.

By recognising this position, I could hold the line between myself and the participants, focusing on their experiences through the interviews and data collection while not being afraid to reflect on my own. Additionally, I was cognizant of harnessing this position and its inherent relational power throughout the study. It also allowed me to integrate my lived experiences and knowledge throughout the data analysis, managed through engagement in journaling, ongoing supervision, and counselling to discuss any issues that arose from this process.

This reflexivity and positionality inevitably shaped the research and engagement with the data. It is reflected in the analysis, adding to the richness of the findings in this study. Consistent with Braun and Clarke’s (2021, 2022) approach, this subjectivity and reflexivity was not considered a problem to be managed but a tool and a resource for conducting analysis.

Method

This section outlines the procedures for participant recruitment and details the participant demographics, data collection, analysis processes, and researcher reflexivity. This is followed by a brief discussion of ethical considerations made through a bicultural lens.

Recruitment

Participants were recruited by sending recruitment flyers (appendix A) through the New Zealand Association of Counsellors monthly newsletter, receiving organisational support from Spectrum Care and their communities, and advertising through the *Drenched.org* online support group. Using convenience sampling, a range of five participants were selected to be part of the study. Participants interested in engaging in the study were invited to email the researcher using the information provided in the advertisement. The researcher then consulted with the participants via telephone to discuss the research project, the potential risks, and discussed how to mitigate re-traumatisation for the participants, explain the participant's requirements, and gain an understanding of the neurodiverse sibling and their presentation.

Furthermore, it was then discussed how and when participants would have liked to schedule their interview. Participants were offered the choice of an online interview or an in-person (face-to-face) interview if they were in Auckland. For safety, privacy, and confidentiality, the researcher conducted in-person interviews at the Epsom campus of the University of Auckland. If the participant preferred an online interview, this would take place using a secure Zoom link. Participants were then given a consent form (appendix B) and participation information sheet (appendix C) to review and sign before the interview. The inclusion criteria for the study were that participants must have been aged twenty-one and over and were a neurotypical sibling to a neurodiverse person or people with high and complex needs. Participants who matched all of the above criteria were invited to participate in this study. For pragmatic reasons, such as temporal limitations of a master's thesis, the study was limited to up to six participants.

Participants

Five individuals were recruited to participate in the study. Pseudonyms were allocated by the participants, as well as to named members of the participants' families, and other identifying details have been disguised.

Jane was the first participant to make contact after hearing about the study through a colleague. Jane was 22 years old, born in New Zealand, and identified as a New Zealand European, heterosexual, and female. Jane was born and raised in Waihōpai-Invercargill and moved to Auckland early in 2022. Jane had an older sister, Ella, who had no confirmed diagnosis; however, she exhibited signs of cerebral palsy and varied neurodiversity. Jane described Ella as being mentally 5 years old and having some symptoms of schizophrenia, autism, and bipolar disorder. Jane described coming from a single-parent household with a lower middle-class socio-economic background. While Jane lived in Auckland, her mother and Ella lived together in Invercargill.

Daisy found the study through the advertisement in the *Drenched.org* support group. Daisy was 22 years old and resided in Auckland. Daisy said she had lived in Auckland all her life and described herself as of European descent. Daisy came from a two-parent family and was the second youngest of five siblings, with one older brother. Daisy had a sister, Lily, who was twenty-five and had 'severe' autism and epilepsy. Daisy described Lily as needing constant care and being unable to live independently. Lily lived with Daisy, their parents, and her youngest sister at their family home. Daisy described her family and upbringing as Christian and middle-class.

Isabella also found the study through the advertisement in the *Drenched.org* support group. Isabella was a 24-year-old Pākehā female who lived in Auckland with her boyfriend. Isabella was from Ōtepoti-Dunedin and moved to Auckland in 2019. Isabella came from a two-parent family and had two younger brothers. Isabella's brother Louis had a rare neurological condition comorbid with epilepsy and was non-verbal. Isabella described Louis' neurodiversity as impacting his mental, physical, behavioural, and emotional development. Isabella also had another brother, Awatea, who was 14 years old and lived at home with Louis and their parents in Dunedin.

Rose was a 28-year-old Pākehā female born on Auckland's North Shore. Rose was a counselling student who found the study through an advertisement in the *Drenched.org* support group. She had an older brother by four years who was also neurotypical. Rose's oldest sibling, Annie, had a frontal-temporal lobe dysfunction, which impacted her affect regulation, behaviour, and communication and promoted some unpredictable and angry behaviour. Annie was in full-time care, supported by a trust set up by her parents. Rose disclosed that she experienced sexual and physical abuse by Annie. Rose described spending a long time not talking about what happened to her but having recently received a diagnosis of Complex Post Traumatic Stress Disorder (CPTSD) (American Psychiatric Association, 2013). While discussing the safety aspects of talking about traumatic events, Rose described her experience in a Dialectical Behavioural Therapy (DBT) program and that she found those strategies and tools helpful to manage anything that may have come up in the discussion (American Psychiatric Association, 2013).

Alice was a 21-year-old Pākehā female from Auckland. Alice lived with her two parents and younger brother, Dominic. Dominic was 14 years old, eight years younger than Alice, and was born with Down syndrome. Alice said she spent most of her formative years with Dominic, as she had two other sisters who are significantly older and lived abroad. Alice moved away to study in Dunedin for three years and said this space was needed to explore herself and her time apart. At the time of the study, Alice lived with her family and Dominic in Auckland.

Data Collection

The interviews took place at the University of Auckland Epsom campus and online via Zoom. The open-ended interview questions (appendix D) allowed participants to discuss and self-reflect holistically, drawing upon the experiences of being a neurotypical sibling to a neurodiverse person with high and complex needs, including personal stories and feelings.

Through conducting this research with adult participants who could reflect on their experiences with maturity, knowledge, and self-development that come with age, the research sidesteps some critical ethical issues that come with interviewing youth. To mitigate any re-traumatisation, the interview questions were constructed in a trauma-sensitive manner. However, considerations were made if there were concerns about the participants' wellbeing, such as the researcher pausing the interview to offer breaks and check-ins and empowering recruits to end the interview.

After the interview, each participant was emailed a secure link to a copy of their interview, transcribed by the researcher. Participants were advised they had two weeks upon receipt of the transcript to edit their transcripts by adding, deleting, or making changes and returning the edited transcript. Furthermore, participants could withdraw their data within two weeks of receiving the transcript without giving a reason. If participants did not reply to the email or make any changes to their original transcripts, all data from the interview was used as part of the research study. All data from the study was stored for 6 years and then securely destroyed.

Analysis

The collected data was analysed using the six phases of reflexive thematic analysis as detailed by Braun and Clarke (2022).

Step One - Familiarisation

The first step was to foster a familiarisation with the dataset, becoming profoundly and intimately familiar with the data through immersion (Braun & Clarke, 2022). This immersion involved listening back to audio files of the semi-structured interviews and making brief notes about initial thoughts and ideas. This immersion was conducted simultaneously with the transcription process, and handwritten notes were collected on initial themes such as birth order, the prevalence of violence, threats, and hypervigilance.

Step Two - Coding

Second, the data was systematically and semantically coded. This phase involved generating codes that captured and evoked critical data features relevant to addressing the research question: *What are the experiences of neurotypical siblings of neurodiverse people with high and complex needs?* For example, '*always an extreme*', '*it is what it is*' and '*it was different*'. This coding process involved coding each dataset through the web-based platform Quirkos. These codes were then entered into a Miro board colour-coded by participants for thematic analysis.

Figure 1 Example of the Quirkos coding program and the initial coding process

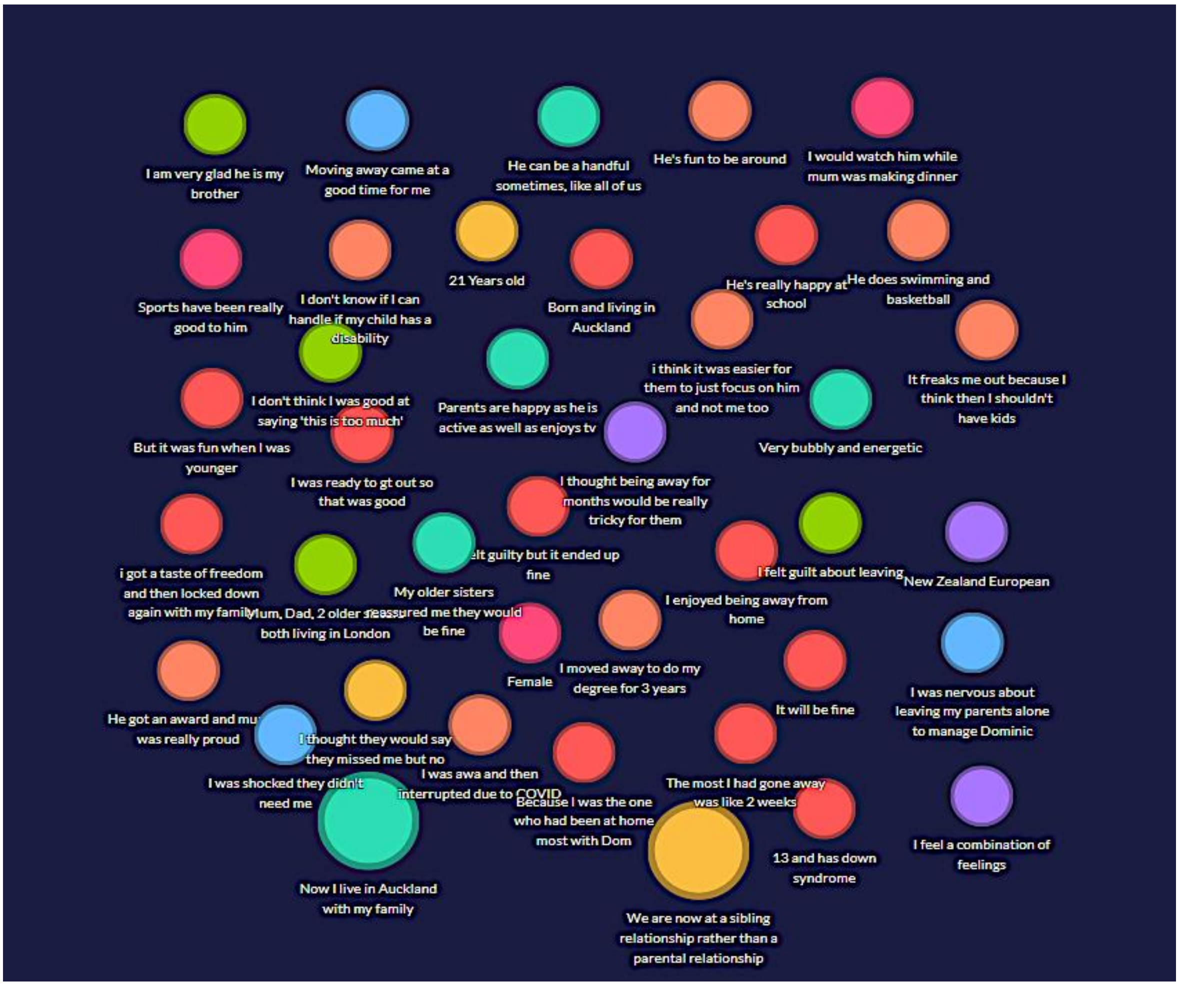
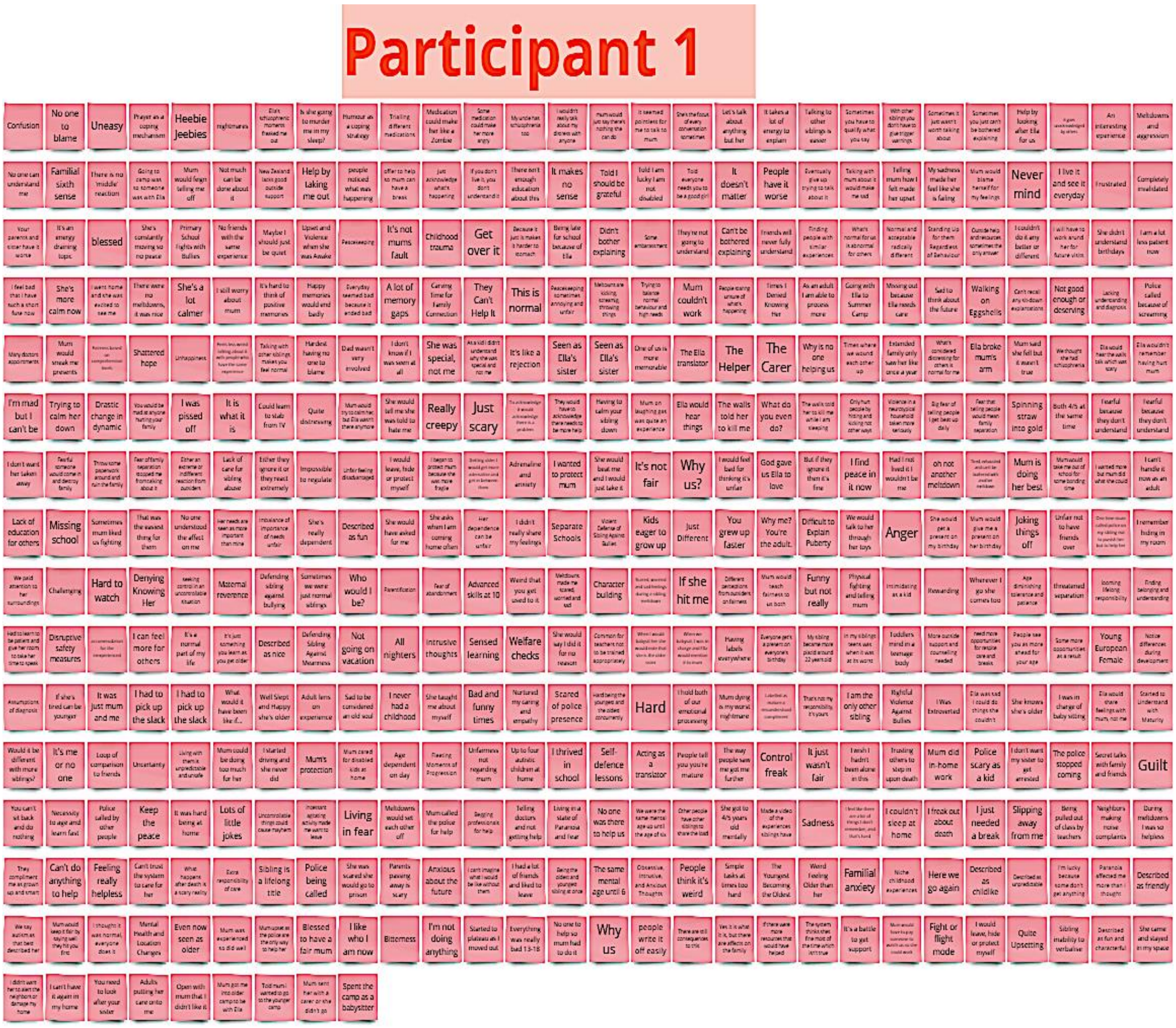


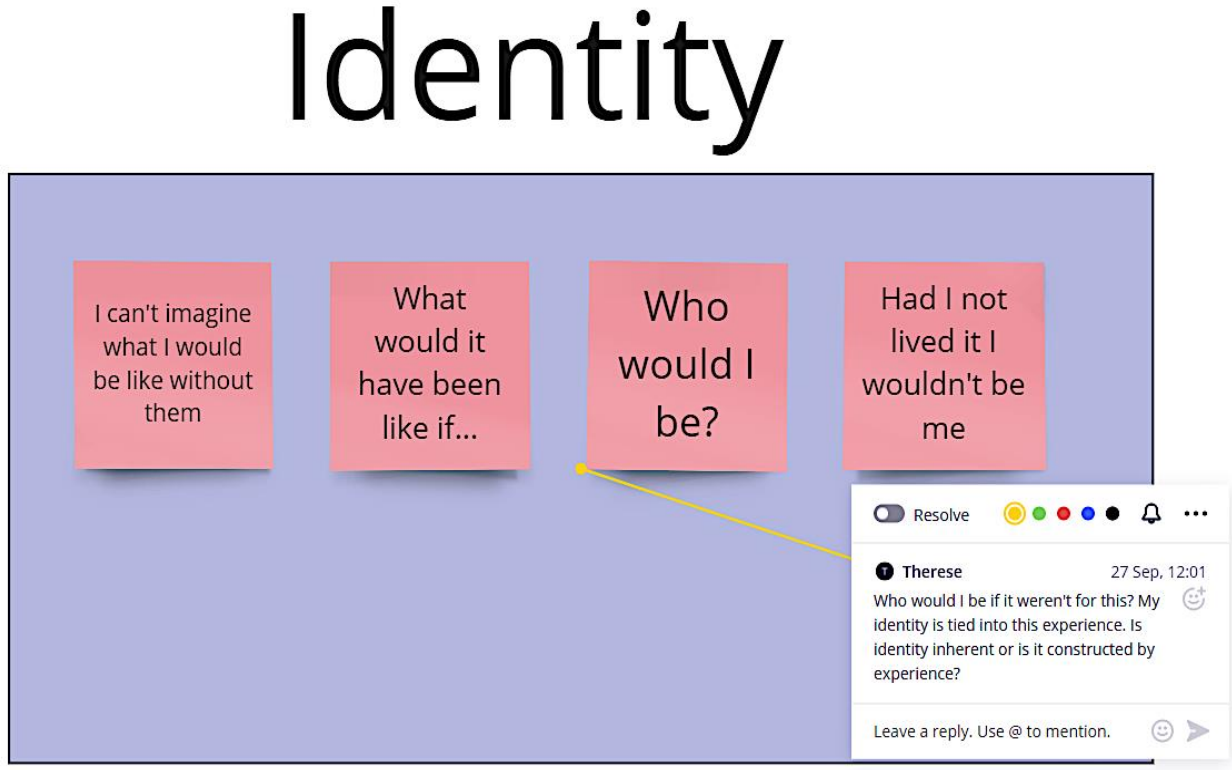
Figure 2 Example initial coding of Participant one entered into a Miro Board



Step Three - Generating Initial Themes

The third step involved generating higher-order codes from coded data. This phase involved scrutinising the codes created in Quirkos to develop significantly broader patterns or potential themes. The first participant’s data was examined and grouped into collapsing codes, and an initial theme title was assigned. Each collapsing code was analysed, and notes were taken throughout the process with reflections, potential avenues for research, and ideas for emergent themes. These ideas were then added to each collapsing code through the notes function.

Figure 3 Collapsing themes, analysis and notes



Identity

I can't imagine what I would be like without them

What would it have been like if...

Who would I be?

Had I not lived it I wouldn't be me

Therese 27 Sep, 12:01

Who would I be if it weren't for this? My identity is tied into this experience. Is identity inherent or is it constructed by experience?

Each dataset was then reviewed and collated into the existing collapsing codes, with each label and initial theme adapting to the emergent overarching ideas. This was repeated for each dataset where codes were collated into collapsing codes or added to existing collapsing codes, which provided clarity for reviewing the viability of each candidate theme.

Figure 4 Codes for dataset one added to emergent themes

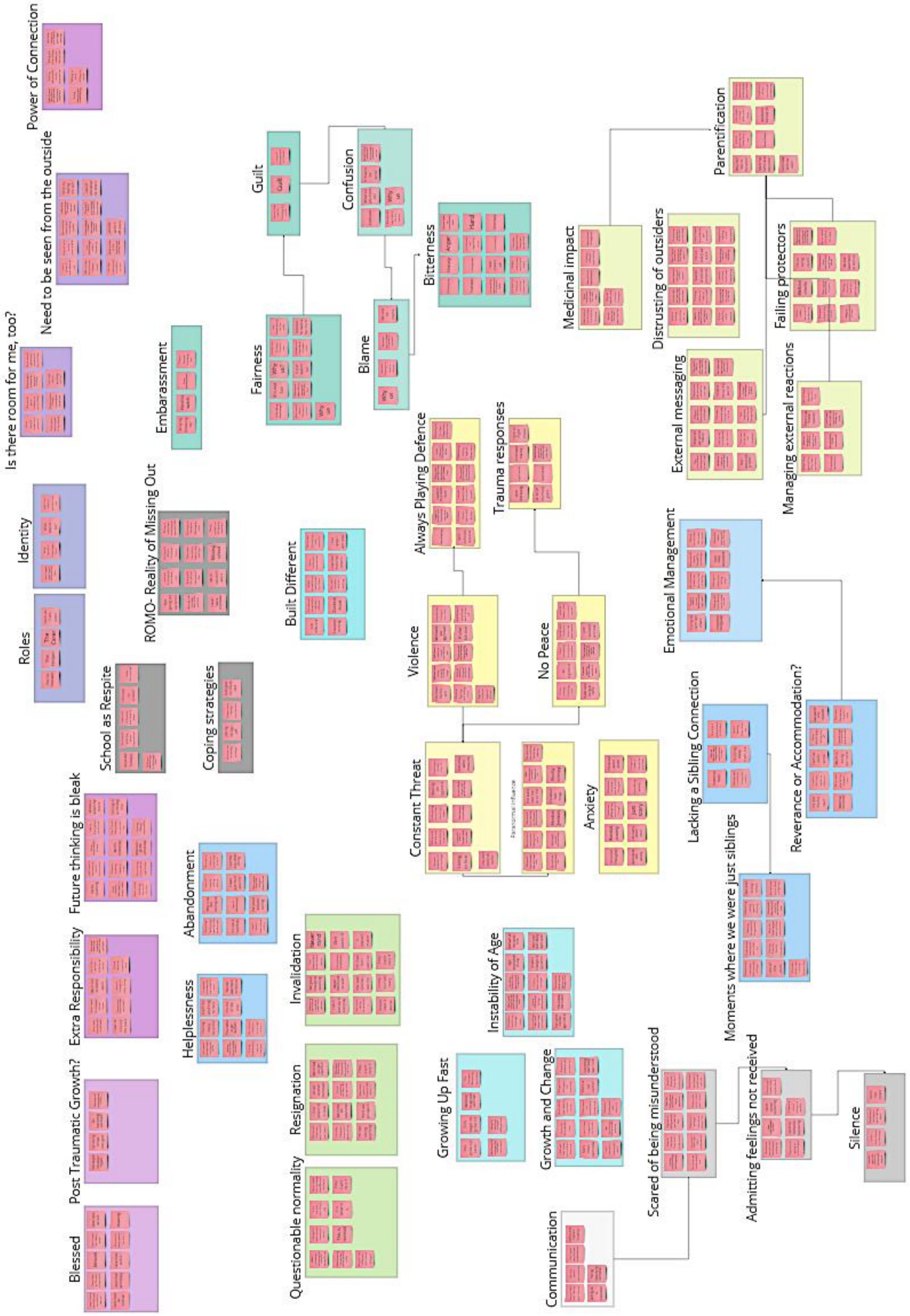
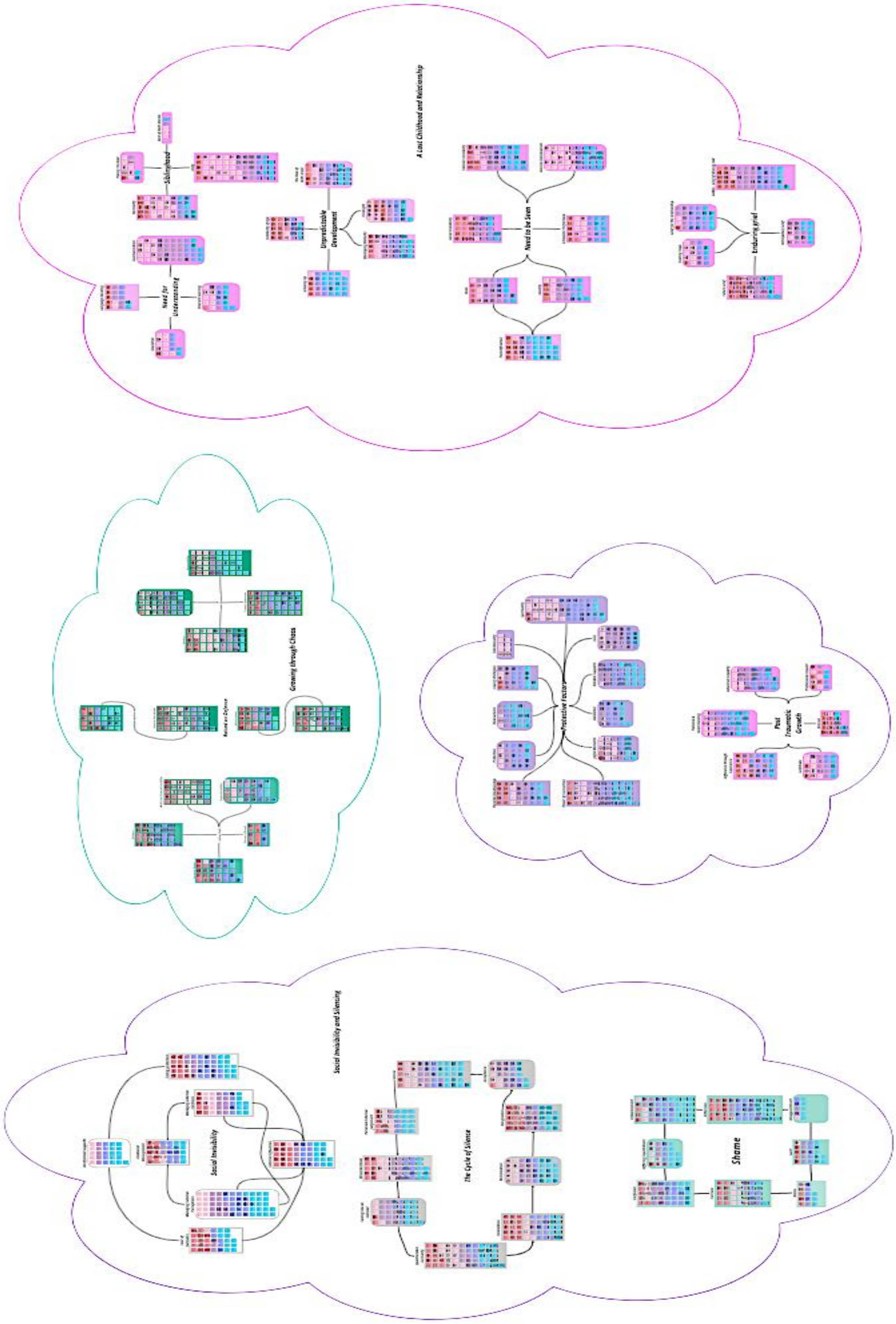


Figure 5 Dataset One, Two, Three, Four and Five and emergent themes



Step Four- Reviewing Potential Themes:

Creating and assessing themes entailed examining, analysing, and verifying them against the coded data and dataset to ensure they presented a compelling narrative of the data and addressed the research question effectively (Braun & Clarke, 2022). The themes were further developed, which involved themes and ideas being split, combined, or discarded (Braun & Clarke, 2022). For example, the subthemes of generational trauma and emotional conflicts were separated from the emerging themes due to their lack of substance and need for refinement.

Step Five - Defining and Naming Themes:

In step five, themes are defined as a pattern of shared significance supported by a central concept or idea (Braun & Clarke, 2022). During this process, the themes were refined, defined, and named. This resulted in four overarching themes, which encompassed several different subthemes (see Appendix G). Refining, delineating, and labelling themes encompassed crafting a comprehensive analysis for each theme, clarifying its scope and emphasis, and shaping the narrative within each theme (Braun & Clarke, 2022). This process also entailed selecting an apt name for each theme (Braun & Clarke, 2022). This process led to four key themes that formed a narrative to answer the question: *What are the experiences of neurotypical siblings of neurodiverse people with high and complex needs?*

Step Six - Writing the Report:

Creating the report for this research involved weaving together the analytical storyline and data excerpts, while placing the analysis within the framework of existing literature (Braun & Clarke, 2022). This process involved re-examining themes and subthemes and extracting a nuanced category to describe the experiences of these participants. This involved taking breaks from the data, reflecting in counselling and supervision, and meditating on the meaning of the emerging themes. For example, a socially nullified existence was derived from reflecting on the social isolation, rejection, and shame that grow from feeling outside of the norm. Although there were outliers and nuances to the narratives and experiences presented, such as sexual abuse, these were also validated and communicated throughout the findings. The writing process involved ongoing discussion through supervision to explore nuance and different avenues of interest. The discussion of findings was reflected upon and divided into three sections: existing literature, implications and future research, and strengths and limitations.

Ethical Considerations

During the design period of this study, ethical considerations around the participant wellbeing and effectiveness of the research were considered. These considerations focused on ethical standards such as confidentiality, informed consent, beneficence, and Te Ara Tika.

Confidentiality

This study was designed to maintain the privacy and confidentiality of the participants through several different measures. The researcher used participant chosen pseudonyms throughout the study to protect privacy and identity. The participants' identities were kept confidential and known only to the researcher. All other identifying information was disguised, such as specific diagnoses or identifying features of others mentioned in the interviews. Participants were advised that they could share their interview transcripts with their whānau if they wished.

All written data, audio recordings, and participant data were stored on the university's SharePoint drive, to which only the researcher and supervisor had access. The interview data was recorded using the Voice Notes app on the Apple iPhone and iPad, both owned by the researcher and password protected. As per university policy, all data and consent forms are retained for six years following the research; after 6 years, all data, information, and consent forms are securely destroyed.

Informed consent

Participants were informed in the consent form, participant information sheet, and at the beginning of the interview that their participation in this study was voluntary; therefore, they had the right to withdraw from the study at any given point without giving any reason. Participants were not offered compensation or koha for taking part in this research. Before initiation of the interview via Zoom, the researcher engaged the participant in a collaborative discussion to ensure the participant had used Zoom before, that the participant had access to a private space and, finally, was alone or supported through the interview. The participant was then advised before commencement of the interview that both audio and visual elements of Zoom would be used and that the interview would be recorded.

Beneficence

Considering that some participants might want some support during the interview, all participants were invited to bring a support person to their interview. The decision was made that whānau would not be directly involved in the study, as their presence in the interview space may have impeded the participant's honesty and disclosures. The chosen support person would have been given a participant information sheet to inform them of the study details.

Throughout the interviews participants were offered the opportunity to take breaks, reschedule to meet at another time, stop the interview altogether, or withdraw from the study. In addition, participants were offered the choice not to answer questions or ask to stop the recording at any time during the interview without giving a reason.

The interview design considered that participants discussing distressing situations could be triggering. The design of the interview questions, pacing, and structure were considered to mitigate any distress. However, in the consultation process, the researcher actively encouraged participants to consider how discussing these experiences may feel for them and ask questions they may have had before the interview. The researcher also encouraged participants to reflect on whether there was anything they could let the researcher know about conducting the interview that may help the participant feel comfortable and safe. The researcher was mindful that if there were concerns about the participants' wellbeing, the interview would be paused to check on the participant and to see if they wished to continue. If needed, participants were also offered a sheet with grounding exercises (Appendix F) to use should they become emotionally aroused and need some emotional regulation. Participants were offered a list of support services (Appendix E) after the interview, if required.

Te Ara Tika

The target population for this research was not explicitly Māori; however, due to the nature and locality of the research, Māori were encouraged to participate. The study's recruitment efforts, disseminated through various channels, aimed to include Māori neurotypical siblings. The research maintained cultural sensitivity through regular cultural consultation. Guidance during the research design involved meetings with cultural advisors, fostering culturally appropriate practice. The researcher attended to Te Ara Tika’s mainstream standards of Whakapapa, Tika, Manaakitanga, and Mana Tangata emphasising reciprocity, participant wellbeing, and the generation of meaningful insights that could have value within Māori communities.

Findings

The findings from this study identified four overarching categories. First, a socially nullified existence comprised themes of social invisibility, a cycle of silence, and being boxed in by shame. Second, shaky pillars of growth were made of the themes of growth through chaos, raised on defence, emotional turbulence, unpredictable development, and enduring grief. Third was yearning for connection, was represented through the themes of siblinghood, and needing to be seen. Fourth and finally were the ingredients for growth, which incorporated protective factors and post-traumatic growth themes. These categories and themes were presented in the following section, each incorporating several sub-themes and accompanied by participant quotes.

A Socially Nullified Existence

Participants reported experiences of feeling 'socially nullified'. Which included a sense of social invisibility and being overlooked as individuals. This was compounded by a cycle of silence, which seemed to lead to an internal shutdown of participants. A further dynamic was reported as feeling boxed in by shame. These themes seemed intertwined and reinforced by each other. For example, experiences of shame seemed to be an oppressive force throughout the participants' lives and perpetuated the cycle of silence. Similarly, feeling socially invisible reinforced the cycle of silence. Overall, this category portrays a powerful existential quality of being nullified by and within a society- that there is no acceptable space or place for them.

Social Invisibility

The theme of social invisibility was a common experience for participants, stemming from various subthemes of uninformed supporters, a fear of outsiders, the external messaging received by participants, managing external reactions, emotional management, and the failure of protectors to support participants. These challenges reflected the participants' unique and often overlooked struggles in such environments.

Participants expressed a lack of available resources for those navigating the complexities of living with neurodiverse individuals, with some not even realising support was an option. Other participants recounted that even when they were aware of support, existing services were ill-prepared to handle the challenges posed by hyper-aggressive neurodiverse individuals.

> *"She would try and kick the door down- she did kick it down a few times- and… all of the services that are out there to like… to support them, it's like she kept getting turned away from everything*

> *because she was violent… That's just another time I felt like I was just…yeah, looking at an adult being like help, and... nope." (Rose)*

Within this theme, there was a lack of trust in outsiders' empathy and capacity to understand the unique presentation of the participants' siblings or their relationships. The mistrust of outsiders was fuelled by the potential for social ostracization or family separation due to societal misconceptions about the participant's home life.

Participants disclosed that outsiders' perceptions of them were reduced to simplistic compliments of being *"a good girl,"* that they had advanced maturity to cope, or were *"lucky"* that they were not disabled. These messages led to internalised guilt and resentment when expressing dissatisfaction, adding to the sense of being silenced.

> *"Like, if I had, like, complained or anything, they would always tell you… You're so lucky that it wasn't you that had the disability, and, like, you should be grateful...Your mum and dad… You know, they're going through a lot, and she's going through a lot, and you just need to be a good girl." (Jane)*

These experiences contributed to participants carefully and selectively sharing information to avoid unwarranted judgements. This balancing act involved preparing friends for potential disruptive behaviour and navigating societal expectations.

> *"I guess when I am explaining it to people who don't have any understanding, I kind of start with like the funnier parts… and then you tell someone else it's like, 'Oh, that's not funny.'" (Daisy)*

The fear of judgement, both towards the neurodiverse and neurotypical siblings, highlights the complexity of participants' social dynamics. Participants recalled carrying a significant emotional burden and feeling responsible for managing both their emotions and those of others.

> *"What are you going to say to them? How are they going to react? How do you react when they react? What do I need to tell them? What do I not need to tell them?... it's a bit of a... mental burden to kind of be considering all the time if you are bringing different people over, and especially in those sorts of teen years, wondering, my God, what do other people think of me? What other people think of Louis and how we operate at home." (Isabella)*

Expressing personal feelings became challenging as participants reported balancing equipping others with the necessary information while avoiding causing overwhelm. This emotional management became omnipresent, impacting various aspects of participants' lives.

Participants also spoke of the impact of witnessing parents and guardians struggle to obtain necessary support and funding. Moreover, the failure of external protectors to secure timely help compounded participants' sense of social invisibility.

> *“My mum had called the mental health team… she's acting really off ... we're worried about ourselves, and we're worried about her… and they were like, 'Yeah, we can't take her; we don't have any space'…and I remember, like, my mum like begging on the phone… ‘it's just me and my daughter’, like ‘I don't have any help’… ‘what are you expecting us to do with her?’... And them being like, 'Oh, sorry, like, have you tried calming her down?’ … I remember my mum just being like… ‘what should I do?’ And they were like, ‘well, you could call the cops?’ And mum was like, fine if that's my only option. And I remember her calling the cops and the cops coming to get my sister.” (Jane)*

The Cycle of Silence

The central theme of the cycle of silence encapsulated the intricate web of experiences faced by the participants. This cycle, marked by sub themes such as perceived external judgment, feeling misunderstood, feeling like an outsider, questioning normality, invalidation, minimising, resignation, and ultimately reaching acceptance, revealed these participants' unique challenges.

Participants shared fearing external judgment regarding their experiences, leading to a reluctance to share their feelings. The fear of being misunderstood fostered the participants' hesitancy to disclose personal experiences to friends or supporters. For example, they avoided having friends over to the house for fear of being judged for their sibling's behaviour or presentation.

This seemed to contribute to the feeling of being an outsider, encompassing a sense of disconnect from peers and uncertainties about the universality of their experiences. There was often a feeling of being 'othered' when comparing their experiences with peers, leading to questions about their normality and reflections on their inability to reciprocate shared experiences with friends. The lack of reciprocity contributed to a growing realisation of their distinct family dynamics.

> *“Like, and I would go there, and I was like, oh, no one's fighting, there's no holes in the walls, like, you know, like, the worst argument my friends have with their sisters is like stealing each other's clothes and stuff. And, I just remember thinking like, fuck.” (Rose)*

These individual experiences seemed compounded by their families, who explicitly or implicitly told participants not to involve outsiders in their experiences or feelings towards their situation. This implied expectation of silence reinforced societal pressure within and outside the family to remain silent about aspects of their experiences, especially their emotional content.

> *“But yeah, like, my siblings, they wouldn't talk about their feelings, just don't talk about it... we didn't really...look back on it too much... I mean, even now in this family, like we'll kind of look back on different things and be like, wow, that was so interesting. And we look at it, yeah, like, we'd talked through, like…she had these types of seizures, or this, or this happened or whatever. But yeah, don't really talk about the feelings of it.” (Daisy)*

Minimising distressing events became a coping mechanism for these participants, who said that *“downplaying”* events and anecdotes about their siblings and telling people *“everything was fine”* assisted in evading excessive questioning. Parents, too, downplayed experiences to shield neurodiverse siblings from judgement, revealing the complex interplay of family dynamics in managing challenging situations.

These repeated, persistent, and generalised silencing experiences led to a sense of resignation as these siblings came to terms with their family's unique normality. Resignation extended to the role of silent witness and sometimes acted as a buffer to ease the burden on their parents.

> *"It was something where I was just like, oh, well, I definitely can't tell my parents anything because that's just like another layer of stress..." (Isabella)*

With time, these participants reached a point of acceptance of their past, their family's unconventional reality, and an acknowledgment that their lives are different. Acceptance was not without complexity, as it involved forgiveness, letting go, and embracing the changes their siblings brought to their lives. However, even here, there was a quality of 'silently' accepting things, of letting go of 'usual' societal expectations.

> *“But yeah, like, since I've...when I kind of was able to forgive her and let go of all that...I kind of describe it, and I say, like, oh like, it was just a very, like, violent childhood and yeah, it's very hard to be around her, as much as I love her sort of thing.” (Rose)*

The cycle of silence was intricately woven through the experiences discussed by participants. The silent struggle involved managing external perceptions, grappling with internal conflicts, and reaching a nuanced acceptance. This cycle was propped up by an internalised box of shame, which added to the complex experience of siblinghood for these participants.

Boxed-in by Shame

The theme of being boxed in by shame sheds light on the intricate struggles faced by participants about their neurodiverse siblings. This shame manifested through guilt, blame, inequality, confusion, differing expectations, and embarrassment.

Participants stated a sense of guilt imbued their experiences, shaped their interactions and self-expression. A sense of guilt marred the struggle to share inner thoughts and feelings, often tied to internalised invalidation and external pressures, such as the expectation to be grateful. The complexity of guilt added to internal conflicts, *"and just like, wanting, I guess, a very separate life from her. So, I was very excited when she left home." (Rose)*

Also stressed was the difficulty of living with unassigned blame. *"It's like when you can't blame your sibling, and it's not your parent's fault...you kind of just have to get over it... it is what it is...and so that almost makes it harder to stomach." (Jane)* Those involved in the study communicated a need for a clear destination for their anger and that lacking a destination for their emotions fostered bitterness.

Fairness, patience, and equality principles were reported as being learned from a young age. Feelings of unfairness pervaded the participants’ narratives, leaving them to question why they must endure unique challenges. Moreover, contributing to the confusion was the lack of clarity and feeling bad without understanding “why.” *"And a lot of… not understanding why...why do we have to, like, deal with this... why is no one helping?" (Jane)*

Shifting expectations between neurodiverse siblings and participants led to a heightened sense of unfairness. Interviewees shared that there were varying standards for siblings, which created confusion about expectations and rules in the world. Participants indicated struggling with oscillating rules, boundaries, and consequences, making comprehending and accepting these differences challenging. The unequal treatment becomes a source of conflict and frustration, shaping participants understanding of fairness.

> *"And my parents trying their best to explain to me and my brother that violence wasn't okay, but for her, it was like something she couldn't control, and so there's always like, a sense of like, there's rules for her, and then there's rules for us and yeah…" (Rose)*

Embarrassment became a significant aspect of participants' experiences, often arising from the behaviour of their neurodiverse sibling. The fear of being perceived as *"abnormal"* in front of peers added to the stress of adolescence. For example, participants felt they wanted *"to get swallowed up" (Alice)* when their sibling's behaviour would cause social embarrassment. Participants also noted some instances of pretending not to know their sibling, highlighting the complex effect of embarrassment on siblinghood.

The cumulative effect of guilt, blame, unfairness, confusion, differing expectations, and embarrassment developed some feelings of bitterness. This feeling was comprised of anger, unease, unhappiness, and frustration, resulting in resentment toward their situation, siblings, and parents. Bitterness became a potent force, and contributed to the cycle of shame that kept them silent about their experiences. *"I love him and all that, but like, I think that could have made me really resent him." (Alice)*

The silent struggles of participants were deeply entwined with the influence of shame. Participants' shame was fuelled by guilt, blame, inequality, confusion, differing expectations, embarrassment, and bitterness, constructing a formidable barrier to open dialogue. Adding strength to their shame was the instability and chaos experienced in the home.

Shaky Pillars of Growth

Participants discussed how their nullified social existence exacerbated the distressing experiences in their homes during childhood and adolescence. These experiences included growing up in chaotic environments, witnessing violence, and experiencing sensory overwhelm. Further reported were emotionally turbulent adaptations developed from these experiences that persisted into adulthood. For example, experiences of violence disrupted the safety of the participants' lives, causing emotional responses such as anxiety and fear. Furthermore, growing up in an unpredictable environment added to the turbulence of their growth journey, instability of roles and identity, and added confusion about their place in the family dynamic. As a result, participants relayed experiences of enduring grief and trauma stemming from these experiences, fostering an unstable foundation on which they lived.

Growing through Chaos

The profound theme of navigating growth amidst chaos emerged among participants, who unveiled the intricate dynamics in the households of neurodiverse siblings. This chaos unfolded through constant threat, unpredictability, medicinal unpredictability, and violence, stemming from the emotional dysregulation experienced by neurodiverse siblings due to the symptoms of their diagnoses.

Participants articulated an enduring sense of threat to safety, manifesting as an ongoing lack of protection within their homes. This fear is exemplified by reports of participants sleeping at friends' houses most of the week to escape their siblings' disruptive behaviour. The threat to safety extended to the neurodiverse siblings' diagnoses and health; for example, epileptic seizures often threatened the participants' and siblings' safety and stability.

Infrequent yet impactful threats of death from the neurodiverse sibling left lasting imprints on participants. Participants disclosed instances of their sibling's schizophrenic episodes of hearing voices in the walls, which led to unsettling moments where the neurodiverse sibling threatened to harm others. Furthermore, participants faced life-threatening situations initiated by their siblings:

> *"Like, I would sometimes, like, wake up, and she was trying to like smother me with a pillow, or chased me around the house with a hammer, and like she, like, stabbed him (my brother) with a fork one time and tried to drown us in the pool and punch the window over me when I was a kid because she saw I was playing with one of her toys." (Rose)*

Interviewees reflected that a common thread of "*walking on eggshells*" underscored the unpredictable nature of living with their siblings. Medical issues, violent outbursts, and socially disruptive behaviours contributed to the constant apprehension felt by participants. They expressed the challenge of anticipating and managing unpredictable outbursts and emphasised the toll on their sense of stability and security. The neurodiverse sibling's oscillating presentation added another layer to the unpredictability, leaving family members uncertain about who they will encounter each day. *"So, if we're aware that that's going to happen, it is easier to like, manage, you know, like mum*

> *can, like, tell him (Dominic) that something is happening the night before and give him time to think about it." (Alice)*

Medicinal interventions introduced another dimension of unpredictability for participants. Participants recounted the trials of finding suitable medications for their neurodiverse siblings, underscoring the intricate balance between managing high and complex needs and navigating the uncertainties associated with medication-induced behavioural changes. For example, participants highlighted the repercussions of missing medication, which would impact stability in family life, and, fearing the changes in medication would change their sibling's presentation, causing them to lose the progress they had made in building their sibling relationship.

The crescendo of chaos culminated in the threat and manifestation of violence, often during neurodiverse siblings' meltdowns. Participants described a spectrum of violence, from physical attacks to acts of self-harm, and reflected on the inherent challenges in managing unpredictable and potentially dangerous behaviours.

> *"Like a child's tantrum... just like a meltdown, like crying, screaming, like throwing things...letting out her frustration in any way that she can when she can't verbalise how she's feeling.... kicking, hitting, throwing things on the floor… you're scared, and you're worried, and you're sad… and I remember just like hiding in my room." (Jane)*

The rule against retaliating further complicates the dynamics, emphasising the neurotypical siblings' vulnerability. For example, participants remembered not being *"allowed"* to hit back when attacked by their sibling and *"just taking it". (Jane)*

The impact of witnessing violence became apparent, recalling examples where participants defended themselves or their siblings against external judgement. Fighting with school bullies who picked on their siblings and using violence as a righteous defence method were common among participants. However, the ripple effect of violence extends beyond the family, affecting friends brought into the home and further exacerbating feelings of embarrassment, shame, and isolation.

> *"Yeah, well, it was like she was... she had this thing of like, she always wanted to braid our hair. And so, my friend came over one time, and I think we were only, like, eight or something. And then she started like braiding her hair and just like ripping her hair out, and that was awful." (Rose)*

The participant's journey of navigating neurodiversity is marked by tumultuous growth amidst chaos. The constant threat, unpredictable nature, uncertainties, and manifestations of violence underscore the resilience required to thrive in such environments.

Raised on Defence

The theme of being "raised on defence'' emerged as participants articulated the enduring impact of their upbringing, which moulded defensive strategies that persisted into adulthood. Participants revealed the intricacies of their coping mechanisms, such as the subthemes of the need to be on guard, sensitivity to sensory overwhelm, feelings of abandonment, and powerlessness during childhood and adolescence.

Participants shared being in perpetual vigilance for potential dangers and triggers. This vigilance was described by participants as being enacted through their roles as peacekeepers in the home and their efforts to protect others from the sibling's unpredictable behaviour. Participants shared that hypervigilance was demonstrated during meltdowns and their efforts to foresee and manage tantrums. Heightened alertness as a response to the unpredictable nature of living with their siblings is labelled as always thinking *“five steps ahead”*". *(Alice)*

Participants reported that their households were marked by overwhelming sensory activity such as shouting, noise, movement, and constant activity. Participants often felt overwhelmed and overstimulated, in an environment where *“there was never a dull moment” (Isabella)*. Labelled as particularly stressful were sleeplessness, noise, and the endless activity. Participants described the constant noise and exertion of the neurodiverse sibling as a source of exhaustion and frustration, which led to an increased proficiency in emotional management as a necessity for survival.

The subtheme of abandonment resonated for participants as they expressed a sense of isolation and loneliness, questioning why they were left to navigate these challenges. Participants recalled feelings of abandonment by services, professionals, society, and the community. Instances such as professionals expressing helplessness or community members failing to check on their wellbeing contributed to the sentiment of being abandoned. For example, participants described how they were never asked how they were coping with their home life or sibling's behaviour. Participants recounted a sense of loneliness that accompanied the lack of support.

> *“Because all of our extended family just like abandoned us for that whole time...the church were the only people who were willing to be around us…all of my aunties and cousins and uncles and stuff, like, they would only come and see us if they knew that my sister wasn't going to be there.” (Rose)*

Powerlessness emerged as a central experience intertwined with experiences of helplessness, abandonment, and loneliness. Powerlessness was noted through attempts to protect their loved ones from harm or responding to medical events involving their neurodiverse siblings. Compounding this was the impact of geographical separation during crucial moments, such as hospitalisations or significant events. In particular, participants reflected on how their childhood powerlessness influenced their adult relationships, leading to a pattern of seeking safety in potentially harmful environments. *"And it also just, yeah, led to me being in abusive relationships as an adult and stuff and just feeling more comfortable around scary people." (Rose)*

The narratives of these individuals reveal the enduring impact of growing up in an environment shaped by chaos and unpredictability. Defensive strategies, honed through constant vigilance, emotional management, and a profound sense of powerlessness, persist into adulthood. Understanding the lasting effects of these experiences was considered crucial for fostering empathy, providing support, and breaking the silence surrounding the challenges faced by siblings of neurodiverse individuals with high and complex needs.

Emotional Turbulence

The theme of "emotional turbulence" reflected the emotional fallout experienced by participants due to their adverse experiences with their neurodiverse siblings. Subthemes such as anxiety, fear, heightened responsibility, and hyper-alertness emerged as core reactions and shaped the narratives around participants' traumatic experiences.

Specifically, anxiety was a prevailing response to the participant's traumatic experiences. For example, the participants constantly worried about their family's safety when left alone with their siblings and vividly expressed concerns about returning home to find their family members harmed. Similarly, participants feared the potential consequences of moving away from their families and how this would impact them. Furthermore, participants discussed how their anxiety and hypervigilance responded to others' emotions. *"I guess...just kind of constant anxiety for me, wondering if anyone's going to like to pop off and... And that's kind of been throughout the rest of my life as well." (Rose)*

Fear emerged as a frequent theme among participants, manifesting around medical events, violence, loss of control, disruptions, and potential harm to the neurodiverse siblings. Fear was multifaceted; for example, the fear of losing their sibling in a shopping mall, fears related to their siblings' health, and fears of their neurodiverse sibling's unpredictable strength were all coupled with anxiety surrounding interactions with others. Participants also relayed fears about the social perceptions of their siblings. *"It wasn't anything bad, but it just like, you know, the looks from people or just the like, I think it was just yeah, just I would always get really scared by how other people would view it." (Alice)*

The extra responsibility participants experienced through their formative years was looked at as both a benefit and a hindrance. Extra responsibility offered opportunities for growth and learning but also intensified the feeling of difference with peers. Participants reflected that their responsibilities often extended beyond typical teenage chores, centring around their siblings' care after and before school, entertainment to maintain familial harmony, diffusing tense situations, and providing support and respite for overwhelmed parents. Participants also discussed how they became caretakers early while juggling various roles during medical events like epileptic seizures.

> *"Because one of us would go and stare at the clock, and then one of us would also run and grab the like the thing that you had to put inside of their mouth...and then mum would come in and like sit her up on the floor and like, make sure she's safe and whatever." (Daisy)*

Trauma responses permeated the participants' narratives, which manifested in various forms such as anger, depression, dissociation, activation, sadness, and internalisation. Traits of Obsessive-Compulsive Disorder (OCD) emerged as a coping mechanism for some participants, which revealed the unseen struggles of intrusive thoughts (American Psychiatric Association, 2013). Also recognised was the tendency towards the "fawning" trauma response, actively trying to befriend potential threats. The profound impact of trauma is underscored by participants' acknowledgment and diagnosis of conditions such as CPTSD (American Psychiatric Association, 2013).

The participants' accounts unveil the intricate web of trauma responses woven into the fabric of their lives, emanating from the challenges posed in their upbringing. The emotional toll of anxiety, fear, heightened responsibility, and trauma responses became a poignant narrative, shedding light on the often-overlooked struggles of siblings within neurodiverse families.

Unpredictable Development

Those involved in the study communicated an intricate dance between the natural desire of children to become adults and the forced acceleration of maturity due to their circumstances. For example, participants recalled having to *"step up"* earlier than their peers regarding caregiving responsibilities for their siblings, noticing that this was not relatable for their friends. Participants described grappling with the feeling of advancing faster than their peers, as they were compelled to mature quicker than their peers due to their sibling role. *"I know a lot of people say they always like feel like they grow up really quickly, when they have like a sibling with a disability." (Alice)*

Participants recounted that the increased speed of maturity oscillated them between age brackets, sometimes making them feel older than their biological age. For example, feeling like they had to change from the youngest sibling to the oldest sibling regarding responsibility, maturity, and leadership within the home. *"I am physically the youngest, mentally the oldest." (Jane)*

The family's oscillating roles, such as shifting responsibilities and birth order, contributed to complex sibling relationships. Participants said their roles and age differences contributed to older siblings earning respect while younger ones worked for it.

> *"I am the elder sister, and I am the dominant one... I am the older one, the 'authority' sort of level. And I think he quite respects me now. Whereas I know, for Awatea, for example, it's taken him quite some time to build up that sort of level of trust and respect." (Isabella)*

Participants noted that age instability affected the siblings' capacities and altered the family dynamics. Furthermore, participants recounted being instructed to temper their expectations of their siblings, remember the differences in their sibling's abilities, and openly recognise the impact of instability on themselves.

> *"She is kind of like a toddler in a grownup's body, you know, just very like… very emotional...Yeah, it makes me so, like, so sad that I can't have a relationship with her because, yeah, when I am around her, I just immediately feel like a little kid again." (Rose)*

Early exposure to complex topics, such as medical conditions and sexual abuse, juxtaposed the participants' fleeting childhood innocence. Accelerated growth and caregiving roles created a paradoxical experience of being praised for maturity while yearning for a simple childhood.

Participants spoke of learning and understanding complex adult language and awareness regarding their sibling's condition; however, the adults around them viewed them as children. *"You feel capable to understand all these sorts of things and to be spoken to about and to have a conversation with them...and they're like, you're just a kid." (Isabella)*

Participants described hindsight as both a gift and a curse. Hindsight became a lens through which participants were able to process their experiences. *"And we're looking back at it, it's a little bit funny... I remember she went missing (in the shopping mall) to play games in a changing room, but at the time, it really was not funny." (Daisy)*

Participants admitted that hindsight allowed them to reflect with an adult lens on their experiences, which fostered a nuanced sense of resignation, acceptance, and transformative growth. Participants said they could recognise their growth and have worked to navigate acceptance as part of the hindsight journey. *"With a lot of hindsight, I can say that no, it's not the worst thing in the world…" (Alice)*

Adulthood was described as beneficial as it brought significant growth, offering better tools to rationalise and understand their experiences. Participants relayed that in their young adulthood, their anger subsided, and they could see their sibling as a vulnerable, innocent person rather than the '*monster*' who scared them as a child. As adults, participants noted they could be more involved, understanding, and advocating for their siblings. Most importantly, age catalysed improved relational capacity, with their advanced maturity emerging as a strength.

The exploration of unpredictable development revealed a tapestry woven with hurried maturity, role changes, and reflective hindsight. Participants navigated a complex journey and grappled with the paradoxes of growing up fast while remaining connected to their childhood innocence. The unstable roles and ages in the family system introduced challenges that shaped the sibling relationship. Hindsight, marked by acceptance and reflection, emerged as a transformative force. Adulthood became a crucible for growth, offering participants the tools to navigate their roles with resilience and understanding.

Enduring grief

Life for participants was entrenched in anticipatory grief, marked by the relentless thoughts of the neurodiverse sibling's potential deterioration. These anticipatory thoughts led to profound questions about the uncertain trajectory of the neurodiverse sibling's condition. Participants recalled feeling fearful at the change in their sibling's medications, asking, "*Are we going to lose her again?" (Daisy)*

A poignant issue raised by the interviewees was the overarching spectre of long-term care for the neurodiverse sibling. Participants reflected, *"I am gonna be his support person, anyway, once my mum and dad go. So, there's that I have to think about, I guess..." (Isabella)* Navigating a future overshadowed by a lifelong responsibility was a profound challenge for the participants. A recurring theme was the conflict between personal dreams and the commitment to a sibling with complex needs. For example, participants noted*, "I guess I feel limited in the sense of, like, I couldn't move overseas because I want to be close if shit hit the fan". (Isabella)*

Additionally, some participants reported that their experiences with their neurodiverse siblings had fostered some fears or anxieties around future parenting experiences. *"It definitely put me off for ages because I was like, oh my God, no, like, I don't think I could." (Alice)*

Hope was described as wavering in and out of participants' lives when thinking about their neurodiverse siblings. Participants said their levels of hope were intricately tied to the neurodiverse sibling's wellbeing and health. The interviewee's optimism was tempered by the unpredictability of their sibling's neurodiversity, marked by moments of improvement followed by setbacks. *"There's a lot of like...hope without wanting to have too much hope... A weird balance of excitement and... just that sense of oh, my goodness, we have to go through this again now."* (Daisy)

Participants said that the balance of holding onto hope despite the behavioural and health challenges of the neurodiverse sibling is poignantly captured in expressions like, *"Sometimes, it looked like we were on the up, and then the rug would be pulled out with a change to her medication". (Daisy)*

Participants treasured the few moments of 'clarity' with their neurodiverse sibling. These moments were emotional and hopeful but also a source of grief for participants. *"I think my mum used to say it to me...the real version of her was in there... the sister I could have had is in there, and we have, like, moments of where we see that a little bit." (Rose)* Participants recounted these moments as encountering the "*real*" person within, and this brevity fostered a sense of loss.

> *“When he has these funny moments, like, there's always that element like…' are you really disabled?' Like, 'you're just having me on? Right?'... he can be so cheeky that it does make you question if... he's understanding way more than we think that he's understanding.” (Isabella)*

Participants described grieving the loss of opportunities and 'missing out'. The complex interplay of grief extends to missed opportunities for care, the unique otherness experienced during childhood events like birthday parties, and the comparison with others' sibling relationships. The *Grief of Missing Out (GOMO)* encapsulated the sorrow experienced by participants due to missed opportunities throughout their childhood. *"People say you seem like an old soul... like sometimes that can make me a bit sad because I'm like, that's because I never had a childhood." (Jane)*

Enduring grief permeated participants' lives, weaving through future concerns and uncertainties, delicate moments of hope, and the multifaceted dimensions of missing out. These narratives provided a nuanced understanding of the intricate emotional landscape shaped by the enduring nature of the sibling relationship within the context of neurodiversity.

Yearning for Connection

Noting their, at times, chaotic and unpredictable home environments, participants discussed the levels of connection they strived for with their siblings, families, and the broader community as a means of fostering stability. Participants developed and curated their internal familial languages and developed specific communication strategies to meet their neurodiverse siblings' high and complex needs. Likewise, participants underscored the importance of these communications for promoting siblinghood, characterised by unity, moments of normality, and playful teasing. Concurrently, siblinghood strengthened the participants' need to be seen for their individuality, explored through schooling, roles, and identity. These connective and relational aspects of participants' lives played a crucial role in their search for uniqueness and support in their shaky world.

Need for Understanding

A need for understanding came through building language, communication, education, and inherent learning through participants' experiences. Emphasised was the paramount need for "language building." Language building went beyond conventional communication and involved the creation of unique strategies to connect with siblings. Participants shared instances where leveraging toys or puppets became a bridge for effective communication and stated that they were often regarded as "*translators*" for their siblings.

There is a different approach to the neurodiverse sibling, as they are unlike any other sibling and need to use the language and communication reflective of their ability. For example, "*it would be really frustrating because you can't just tell him to shut up as you would any other sort of sibling. You have to think of a different approach to settle him." (Isabella)*

The struggle for effective communication with neurodiverse siblings was a prevalent concern among participants. Reflections centred on the difficulty in understanding their non-verbal sibling's needs, which was compounded by the side effects of medications, such as a “*zombie-like*” demeanour.

Participants recounted instances where communication from family members, though informative, lacked emotional depth. For example, receiving a text message that their sibling has had a medical event, the abruptness of which and lack of follow up caused panic, causing them to need more information and comfort.

Participants experienced advanced education as they learned about their siblings' diagnoses and management strategies. However, a distinct absence of an explicit sit-down discussion was noted, which left participants to navigate their siblings' conditions through experiential learning. For example, participants noted that there was a lack of in-depth explanations about autism but commended their parents for educating the family on epilepsy.

> *“I don't think we ever, in terms of autism...we never really got too much explained to us...more just in terms of like what autism is... my parents did really good with educating us on what epilepsy is and looks like and how to deal with it…” (Daisy)*

Participants acknowledged the hands-on learning gained through practical experiences, with parents navigating the challenges alongside them. *"So, like, they're trying as much as they could to support us in that, but obviously, like, they were learning on the job as well." (Daisy)*

Innate understanding became a talent that shaped the participants' perceptions of their neurodiverse siblings as a natural part of their upbringing. The normalisation of neurodiversity within the family was evident, as participants highlighted that their awareness of their sibling's differences was an inherent aspect of their childhood. *"I don't think I can remember first learning about it. Because, yeah, I was just so young, so it's always been quite normal." (Isabella)*

The need for understanding was displayed through language building, the search for effective communication strategies, education, and inherent learning. Participants revealed the complexities of navigating a world where traditional communication norms may not suffice. The intrinsic learning curve and experiential education shaped a multifaceted journey as participants strived to bridge the communication gap, build unique languages, acquire nuanced knowledge, and foster empathetic and supportive familial relationships.

Siblinghood

The sibling connection was profound for participants, emphasising the excitement and shared strength of spending time as a family. This strength and excitement came through engaging in activities with their siblings, such as computer games and movies, fostering a unique sibling bond. However, it was also acknowledged that there were desired shared activities that were impossible with their siblings, such as social outings or travelling together.

Participants underscored the importance of unity not only with their neurodiverse siblings but also within the broader family, creating a network of support that transcends verbal communication. *"And I was very close with my mum…I think the only person I had was my brother...we kind of didn't feel like we needed to talk about it with each other. We just knew." (Rose)*

Capturing moments of “*normality*” emerged as a subtheme, where participants reminisced about cherished memories of simply being siblings, for example, pulling faces and teasing. These fleeting examples, described as "*dear*" and "*precious*," were marked by laughter, unity, and the joy derived from shared familial bonds.

> *“I think that's probably one of the best times where that sister-brother bond is really evident. Especially like, for example, if he's having mum and dad on, I'm like, 'okay, we're in cahoots now', like, we're on, we're on the same brainwave.” (Isabella)*

Participants acknowledged that the concept of *“normality”* is relative, with participants reflecting on the rarity and unpredictability of these moments. Participants also introduced the complex emotional experience regarding the absence of the neurodiverse sibling during joyful events or memories. These memories are marred with guilt and confusion, revealing a complex interplay between unique familial dynamics and the desire for shared, *“normal”* experiences. For example, participants noted that happier memories were derived from when their sibling was in respite care, and the family could spend time together or engage in other *“normal”* activities.

Additionally, the sibling activity of "*winding each other up"* was explored by participants. Through this playful teasing, participants unveiled a glimpse into the normalcy of sibling relationships. "W*inding each other up"* was a form of playful banter, and "*poking the bear"* became a term that encapsulated the natural, fun-loving interactions between siblings. This sibling banter was seen as a means of connection and a mechanism for learning—understanding each other's limits, boundaries, and consequences of crossing boundaries. The term *“winding up*” was a playful expression of sibling camaraderie, offering siblings a way to connect and assert their presence in a light-hearted, safe manner.

Exploring sibling dynamics revealed a multifaceted landscape where unity, moments of *“normality*,” and the best of both worlds intertwine. The profound impact of sibling connections was illuminated by participants, emphasising the joy derived from shared experiences. The nuanced nature of *“normality”* unfolded as participants navigated the unpredictability of these cherished moments. Additionally, the playful banter and *“winding up”* rituals highlighted a universal aspect of sibling relationships, and served as a means of connection, learning, and mutual understanding. Siblinghood, in all its complexity, emerged as a tapestry woven with threads of unity, shared laughter, and the enduring desire for unique and ordinary moments.

Need to be Seen

Attending school served as a sanctuary for these participants to thrive independently, where they could shed the "*sibling to*" identity often placed upon them. Participants also noted a struggle for independence and recognition of their personality traits beyond the *"sibling to*" identity. *"It wasn't until I got my job last year that I had a space where no one knew anything about my family." (Daisy)*

Participants said there was often a struggle to be seen beyond the sibling's shadow, and the desire to be treated as *“just another sibling*” emerged as a central experience. Most noted that they were often regarded as *“the sister of”* their sibling, a responsibility they carried throughout childhood and adolescence. Contrarily, some siblings reflected that being the sibling of a neurodiverse person was also, at times, a *“badge of honour.”*

The participants of this study noted that their identity was intricately tied to their experiences, which prompted contemplation on inherent versus constructed identity. For example, noting, "*Had I not, like, lived that experience, I wouldn't have been able to, like, help like the kids and stuff that I do now…*" *(Jane)*

While it offered a separate space for participants, they also noted that lacking adequate support and care in the school made them feel isolated. Contrastingly, these participants also specified that being identified as needing more could have created a sense of *'otherness'* from their peers. *"I couldn't imagine anything worse; you know, being pulled out of class to go and talk to somebody about it." (Isabella)*

Furthermore, some participants noted that school became a platform to express and process aspects of their trauma.

> *"Because I was a... small kid for my age, and so... I remember when I got there, I was thinking okay… I'm real weak here, so I need to be the scary one if I'm gonna protect myself… so I was always in the principal's office for bullying and being a violent kid." (Rose)*

Similarly, some said they often became a guide, diffuser, and stabilising force in their social, familial, and academic worlds. *"I feel like I kind of took on a role of, like, just like trying to be, like, a peacekeeper." (Alice)*

These participants acknowledged the struggle to be recognised beyond their familial context, the catch-22 of wanting to be seen as a child while seeking acknowledgment for their insight, and the invisibility surrounding their position and struggles.

Cries for attention amidst the overwhelming presence of the neurodiverse sibling reflected a genuine need for recognition for participants from their parents and wider family, and a wondering if they were ever seen at all. *"My parents were so stressed all the time, obviously… oh, well, I definitely can't tell my parents anything, because that's just like another layer of stress sort of thing" (Rose).* Furthermore, participants noted that the sacrifices made for the neurodiverse sibling impacted the participants' identity formation. Participants recalled that the needs of the neurodiverse sibling often overshadowed moments for individuality. *"No matter what, he kind of was always... even when things like, weren't necessarily about him, I guess they sort of still were." (Alice)*

Individualism was sought through school, friends, and creative expression. Participants recounted that their friends were a place to find individualism and separateness from their siblings. *"I didn't want her to come in and think that they were her friends… I wanted to keep my friends as my friends." (Daisy)*

Participants explored the need to be seen, acknowledged, and valued in various spheres of life. These needs were fulfilled through the complexities of educational environments and the overlapping and oscillating of identity, roles, and parentification.

Ingredients for Growth

While reflecting on their shaky pillars of growth and desires for connection, participants reminisced on the ingredients they were given to grow through these experiences. Several protective factors emerged as supports through these experiences: reliable supporters, internal and external validation, joyful and playful moments, connection, parental relationships, protection, reassurance, coping strategies, intentionality, spirituality, and love. These ingredients, compounded with their chaotic upbringing, culminated in post-traumatic growth. This post-traumatic growth gave the participants enhanced gratitude, patience, understanding, evolved empathy and difference through experience, leading them to various community-based career paths. This category describes the power of support and unity around the participants and the flowers that can grow from weakened soil.

Protective Factors

Participants relayed that ongoing and reliable support was a vital protective factor. Sustained support attained through family, church, or school offered care and validated their experiences. For example, participants recalled that their older siblings, who lived further afield, greatly supported them throughout these experiences. Emphasis was placed on the importance of support structures, such as respite care, for their family's wellbeing. However, participants recognised the need for enhanced support from school figures such as principals and teachers; "*I did have one teacher who sort of did...but nah no one" (Isabella)*.

Participants recalled validation as a protective factor, especially if it derives from parental care, friends' understanding, or sibling support. For example, seeing their mothers fearful or experiencing the same feelings validated them; *"my mum kind of did her best to, like, really validate us." (Daisy)*

Additionally, the power of connection emerged as a protective factor that further alleviated the sense of isolation among these siblings. Connecting with others who shared similar experiences, whether through church or other siblings, offered peace and happiness. Participants noted that engaging with other neurotypical siblings in the neurodiverse community assuaged fears and validated feelings and experiences. *"It was also good to see older siblings and realising like, well, this hasn't really taken over their lives or...this isn't their only defining thing." (Alice)* Validation was described as providing a buffer against potential adverse reactions and contributing to a sense of reliability and trust in support networks.

Participants also reflected on the significance of joyful moments and positive family memories amid challenging circumstances. For example, parents intentionally took participants out of school for bonding time, and there were funny memories of public gaffes by the neurodiverse sibling at inappropriate times. Participants described these moments of levity and togetherness as creating lasting positive impressions amidst the darkness.

> *"(At my grandmother's funeral) I'm sobbing. My parents are just...doom and gloom and stuff, and Louis just goes, "One, two, three, wake up Nana!" like, 'Wake up Jeff', and it was just like one of those moments where you're just like, the fuck what did you just say? And the funeral directors must have just been like, why are all these people pissing themselves laughing...chortling... visiting their dead grandma." (Isabella)*

According to these siblings, the parental relationship was a crucial protective factor. The participants described their parents with reverence and praise as "*always good*" and "*doing her best*". It was also reported that their parents worked hard to ensure that siblings "*never had to take on too much*".

Participants described protection as playing a multifaceted role as a protective factor. First, protection from parents shielded participants from some additional responsibilities and conversations beyond their age. For example, *"I guess because having both mum and dad, who were quite involved and... mum not working...we didn't have to be that extra parent" (Daisy).* Second was the participants' protective instincts toward their siblings *"I'd see other kids, like, laughing at her and or being scared, and I would run up and start hitting them sometimes." (Rose)*

Also highlighted for participants was their parents' reassurance that they were not solely responsible, which emerged as a protective factor against the ingrained sense of responsibility *"so you're the one* *that is calling help and doing different things, but like, they never put it on us to be like the one in charge of like if something goes wrong 'it's on you' kind of thing." (Daisy)*

Reassurance towards these siblings was displayed in various forms, mostly from peers and friends. *"I did feel like comforted. And like, I did feel kind of, like, I guess just like reassured that, like, my reaction to the situation was fine".*

Participants described different coping strategies that became a source of deflecting emotions and needs, specifically through humour or prayer. Participants described laughter and humour: "*Just like, me and mum kind of used it as a coping mechanism like oop that's a bit whacko or whatever" (Jane).* Likewise, describing their families as *"always up to shit...yeah, it's good vibes." (Isabella)*

Spirituality emerged as a source of purpose, hope, learning, and a framework for processing experiences. Some participants described spirituality as a uniting experience for families. For example, participants relayed how their parents attended church to find solace and reason in an unexplainable situation. Some said that Christianity was "*where mum and dad drew their...parallels from for, well, in terms of teaching us how to interact with her". (Daisy)*

Intentionality emerged as an essential protective factor in supporting the growth of participants. The intentional efforts of parents to bond and strengthen familial relationships emphasised the importance of deliberate actions to nurture family unity and connection. *"Mum and Dad were really intentional with just making space for us to hang out with each other." (Daisy)*

Throughout the interviews, love was interwoven throughout the narratives, manifesting in family unity, connection, gratitude, reverence, admiration, pride, and happiness. Love was portrayed as evolving through understanding, patience, trauma processing, and advanced empathy. For example, some participants became emotional and said, *"I love my family"* and *"I very much love her now" (Isabella and Rose)*. These protective factors not only provided support for the participants but also showcased the resilience and coping mechanisms that participants employed amid the complexities of growing up with a neurodiverse sibling.

Post-Traumatic Growth

The participants unveiled a significant theme of post-traumatic growth, emphasising positive transformations and insights gained from their challenging experiences. Despite the adversities faced, participants reflected a profound expression of love for their siblings, acknowledging their positive qualities and their impact on personal development. Their siblings were described as having exceeded all expectations for their health and abilities, and participants felt immense pride at how far their families had come. Feeling *“blessed”* was coupled with an undercurrent of pride, portraying the sibling as a source of inspiration and growth.

Further to feeling *“blessed,”* participants reflected on their growth through pain and highlighted gratitude for the experiences and the individuals involved; for example, *"I am so grateful for having the parents I did." (Daisy)* Further noted was the participant's gratitude for family and friends who went out of their way to support them. Participants acknowledged their experiences as precious and held awareness that their development and personality were interconnected with these transformative events *"my sibling has really taught me a lot about myself." (Jane)*

Difference through experience was a prevalent theme reflected upon by these siblings. These experiences were recognised as transformative, adding unique personal characteristics and skills that set them apart. Participants noted that "*I like who I am now*" *(Jane)* and their experiences as "*character building*", admitting that their experiences have "*shaped who I am".*

Participants understood that certain aspects of their personalities were shaped explicitly by these experiences and conveyed a positive perspective on being different. Participants recalled that *"it made life interesting..."* and noted that their family has "*our own other things that we do that are so special and unique to us.*" *(Isabella)* Despite struggling to connect with the neurodiverse sibling, the participants acknowledged the constructive impact of these experiences, fostering heightened awareness and respect for others.

An essential aspect of post-traumatic growth recognised by these siblings was the importance of time, respect, patience, and understanding in building relationships. Participants also noted that neurodiverse siblings require a distinct approach with heightened patience and care. *"A lot of the differences would probably just be, like, those traits that you have to learn a lot faster of, like, being patient with her and being understanding of the different behaviours." (Daisy)*

Participants acknowledged the acquired skills of diffusing situations and managing relationships with empathy as personal strengths that impacted their social interactions. *"I felt really proud of it, I think. And I felt like a sense of, like, control and stuff." (Jane)*

The narratives of these siblings revealed an advanced level of empathy characterised by profound reverence for parents and a strong awareness of others' emotions. Participants noted, "*It has led to...more empathy and a greater sense of patience*" and developing a heightened awareness of other emotions and feelings from their experiences. Empathy from participants extended towards their neurodiverse siblings, recognising their silent struggles, and fostering an understanding of their experiences. For example, they described their empathy for their siblings who could not communicate pain and noted how they felt strongly empathetic for siblings who had broken bones and could not verbalise their needs or pain. Evolved empathy was also reflected in a sense of control and power over emotional situations. The heightened sensitivity resulting from experiences of unpredictability enabled participants to read people and energies more quickly, empowering them to interact and maintain composure in difficult situations.

Furthermore, the participant's narratives hinted at potential triggers associated with discussing these experiences, raising questions about the psychological impact of revisiting such memories. Despite the challenges, there was a noticeable pattern of turning these experiences into opportunities for professional growth, transforming personal struggles into valuable lessons that shaped participants' futures. For example, most participants had begun working in the community to support siblings of neurodiverse people, as in-school support for neurodiverse students, or have begun counselling training to support people in a comparable situation. The impact of these experiences on future career paths and personal growth was evident, even as participants acknowledged the bittersweet nature of looking back on their journey.

The participants underscored the transformative nature of their experiences with their neurodiverse siblings, highlighting growth, gratitude, unique personal development, and advanced empathetic skills as critical outcomes of the post-traumatic growth process.

Discussion

This section begins with a discussion of the findings in relation to the existing literature examined in the literature review. Next, there is a discussion of the implications for further academic research, counselling practice, and social engagement. This section concludes with the strengths and limitations of the study such as participant diversity, positionality of an insider researcher, participant retrospectives, voice, and reflexivity.

Revisiting the Research Question

This study set out to answer the question, *what are the experiences of neurotypical siblings of neurodiverse people with high and complex needs in Aotearoa?* The findings provided a complex answer to this question. The findings identified the profound sense of a socially nullified existence but also the shaky pillars of growth, along with a sense of yearning for connection. A number of ingredients for growth were also identified, adding to the post-traumatic growth experienced by participants. The following subsections discuss how these findings relate to the existing literature reviewed earlier in this study.

Disenfranchised Grief

The socially nullified existence described by participants reflected a sense of disenfranchisement towards the participants' existence and experiences. Doka (2002) theorised that a principal component of disenfranchised grief is losses or experiences being trivialised, dismissed, or met with silence. These experiences leave individuals to navigate their grief in isolation, and the lack of acknowledgment and support can lead to feelings of isolation, shame, and guilt (Doka, 2008). The participants described their social nullification as exacerbated by the perceptions of outsiders, the unawareness of outsiders towards their experiences, and the pressure to manage the emotions of others, leaving little room for participants to express themselves or speak about their experiences. The ignorance towards this group's experience, in turn, may hinder the healing process and impede the development of adaptive coping strategies, potentially resulting in mental health disorders (Doka, 2008). These adaptive strategies and potential for mental health struggles are reflected in the findings from Becker (2022), which highlighted the potential for stress and trauma in the daily lives of young carers, leading to silence, fear of intervention by welfare systems, emotional problems, mental health issues, and educational difficulties.

Fear for the Future and the Power of Connection

Enduring grief, specifically grief for the future, emerged as a common theme in this study. These complex forms of grief reflected the guilt and fear of the future care of the neurodiverse sibling, as highlighted by Jacobs and MacMahon (2017). The sense of future or anticipatory grief is reflected in Littlejohn's (1998) findings that expectations of siblings to take on responsibilities for caregiving after their parent's pass can weigh heavily on the neurotypical sibling.

The impact of connection as a protective factor was found in McGibbon's (1994) study, which found that offering workshops with free play gave siblings more autonomy and control over their lives, which the participants noted for them was lacking due to the weight of future responsibility. The lack of autonomy and control is reflected in the powerlessness felt in the current studys participants' pessimism towards the future. Furthermore, Nel's (1987) study recommended group counselling processes and workshops that foster better feelings and hope towards their siblings' prospects, community, and connection. The need for connection is also reflected in the study by Moyson and Roeyers (2012), whose results found that participants engaging in group activities and sharing connections with others in a similar situation can assist in processing experiences, adding to their increased confidence in their future wellbeing.

Internalisation

The participants' explorations in this study signalled an ongoing feeling of grief surrounding not being seen. Similarly, Connors and Stalker (2003) found that neurotypical siblings were prone to silencing themselves, fostering a vulnerability to attacks on their psycho-emotional wellbeing, increased internalisation, self-blame, and the tendency to disregard their own needs. The internalisation of needs was similar to the grief experienced by participants, who were often left holding back their feelings, adding to their sense of invalidation.

Hanvey et al. (2022) corroborated the findings of this study by emphasising themes of internalisation, invisibility, and a need for social support from family, friends, and other community members. Hanvey et al. (2022) found that participants often disregarded their needs and feared adding a burden to their families or being rejected, reflecting the process of internalisation often highlighted in this study.

Edkins (2002) described the need for distressing events to be recognised for their impact rather than a response that hurried to forget the event or incorporate it into existing narratives, a sentiment echoed by participants in this study. For example, access to educated and well-advertised support that can hear, hold, and receive their experiences with empathy and understanding helped to reintegrate these narratives. Providing access to well-informed and adept support also mitigated any ongoing effects of internalisation of these distressing experiences. This carried profound implications for educational performance, the mitigation of behavioural problems, decreasing vulnerability to psychopathology, and even the risk of suicide (Pine et al., 1998).

Behaviour and the Impact on Sibling Relationships

The socially nullified existence facilitated the silencing of participants, which provided fertile ground for the distressing experiences to grow ongoing adaptations such as anxiety and hypervigilance. These distressing experiences risked straining the sibling relationship, as reflected in Travers et al. (2020), who found that the problematic behaviour of the neurodiverse sibling can make accessing or engaging in shared activities more difficult. The experiences of problematic behaviour, such as threats to safety, unpredictable outbursts, or medicinal effects, exacerbated senses of powerlessness, abandonment, and sensory overwhelm. This led to the formation of defences for these siblings, such as hypervigilance about others' behaviour and emotional energy.

The culmination of a socially nullified existence and its shaky pillars of growth developed adaptations with ongoing effects. Silence acted as the fertiliser that grew and intensified the impact of distressing experiences, often unspoken, unwitnessed, and unclaimed. These experiences resulted in the distressing events often expressing themselves as violence to themselves or others (Phillips, 2015). Similarly, Knapp (1998) noted that there is an increased likelihood of perpetuating violence later in life or development of post-traumatic stress disorder from exposure to violence within the home at an early age. Likewise, participants of this study engaged in bullying, acting out, and violence as a protective measure. Granat et al. (2012) found that educating the neurotypical sibling on the neurodiverse siblings' behaviour and coping strategies to regulate themselves in challenging situations provided tools to navigate the sibling relationship more effectively and reduce these violent coping strategies.

Further enriching this point, Joseph et al. (2020) found that young caregivers often grapple with elevated levels of stress, emotional strain, and heightened risks of anxiety, depression, and trauma-related symptoms. Correspondingly, this study found ongoing emotional turbulence of anxiety, fear, and stress- however, these adaptations were mitigated by protective factors such as parental protection, reassurance, and reliable supporters.

Growth

Post-traumatic growth emerged as a central component of the neurotypical sibling experience. Findler and Vardi (2009) found in their survey responses that neurotypical siblings of neurodiverse people with high and complex needs evidenced higher levels of growth, specifically surrounding self-differentiation. Self-differentiation is understood as neurotypical siblings' ability to differentiate themselves from their neurodiverse siblings, such as not suffering from guilt or recognising how their experiences have moulded them, thus fostering their growth (Findler & Vardi, 2009). This is reflected in the sub-themes of differentiation through experience and professional impact, showing how these Aotearoa-based participants have harnessed their experiences and integrated them into positive endeavours. This study indicated that participants had discovered strengths and resources not necessarily evidenced by others their age, such as higher levels of empathy, adeptness at taking on more responsibility, significant relationship-building abilities, and higher sensitivity to others.

Discoveries of higher empathy in this study match the findings in other studies, where undertaking various roles heightened perspective-taking abilities, empathy, and emotional intelligence (Findler & Vardi, 2009). In a recent study, neurotypical siblings with a sibling who had Down syndrome displayed greater empathy and engagement in childcare (Cuskelly & Gunn, 2003). Contrarily, Stoneman (2005) highlighted that siblings of people with a wide range of neurodiversity have exhibited little difference in self-concept or perceived competence, outlying the other studies performed around these groups.

Attitudes

Overall, despite the challenges, relationships with neurodiverse siblings were regarded positively and lovingly. Prevalent attitudes from participants towards their neurodiverse sibling were love, protection, gratitude, and understanding. These discoveries align with those of Travers et al. (2020), who surveyed participants about their connection with their neurodiverse sibling. 86.9% of neurotypical siblings indicated their relationship was predominantly positive, showing a high level of agreement with previous research demonstrating optimistic perceptions of sibling relationships. Contrastingly, Petalas et al. (2009) found that neurotypical siblings of neurodiverse people with high and complex needs were more likely to score within the high abnormal range for emotional distress and prosocial behaviour issues. These conflicting findings open a dialogue for further studies to identify what factors contributed to the differences in responses. Additionally, Sommantico et al. (2020a) found varying levels of intimacy with respondents depending on the familial structure, noting that some first-born siblings reported greater feelings of marginalisation. However, this study's parameters and questionnaire format left this unclear.

Similarly to the findings in the present study, Hastings and Taunt (2002) agree that many siblings thrive and benefit from having a sibling with neurodiversity while remaining mindful that some children experience harm in various forms, such as psychological, emotional, or physical. Stoneman (2005) also reported that the positive effects of the roles that siblings of children with neurodiversity engage in might bring developmental benefits such as advanced empathy and responsibility-taking.

Protection of Connection

Protective factors highlighted the importance of parental intentionality, characterised as carving out time for connection, specific interventions from parents to cater to the needs of neurotypical siblings, and shared activities to promote familial connection. Participants noted intentionality as family time, shared meals, shared entertainment, or being prioritised for time shared with parents. This finding matches one of the protective factors characterised as 'practical approaches' by Hallahan and Kauffman (2011). Practical approaches included daily adaptations to accommodate the neurodiverse siblings' needs (Hallahan & Kauffman, 2011). Families might choose to go to social events ahead of time so that their neurodiverse child can adjust, or they might request specific seating arrangements in cafes or cinemas (Hallahan & Kauffman, 2011). Alternatively, they might pack favourite snacks for an excursion to help calm their neurodiverse sibling's distress (Hallahan & Kauffman, 2011). These practical approaches not only act to destress social situations for parents but are intentional in their effort to create memories, experiences, and connections for the neurotypical sibling as a result.

The findings of the current study reflected many positives of the neurotypical sibling experience: protective factors extended by caregivers, friends, family, and external supporters all of which are vital in precipitating growth. These results also align with Burke's (2004) recommendations for practitioners to consider the feelings and needs of neurotypical siblings equally within the family. This provides further support for Burke’s (2004) recommendation that practitioners give the neurotypical siblings a chance to control and engage in discussions, which could extend to the intentionality of parents and extended supporters to cater to and engage with the neurotypical siblings.

An Unfocused Lens on the Sibling's Experience

The existing literature reflected several core needs for neurotypical siblings of neurodiverse people with high and complex needs, which mirror the after-effects of distressing experiences. Neurotypical siblings who assume major caregiving roles have been found to have a higher chance of developing behavioural problems and psychological issues such as anxiety and increased conflict (Cuskelly & Gunn, 2003). Additionally, Shaw (1998) found that the main concerns for neurotypical siblings were anger, worry, tension, and embarrassment. These emotions were found to be further exacerbated by stress, conflict in the home, and extra caregiving responsibilities, reinforcing the cyclical nature of silence and chaos experienced by these participants. Goode (1960) described the pressure from these extra responsibilities as *role strain*, or the stress of trying to fulfil multiple role obligations.

Gender and Sibling Care

Leane (2019) highlighted gender as a factor in determining caregiving later in life for neurodiverse people with high and complex needs. Leane's (2019) study showed that female siblings were more likely to become 'key carers' for their neurodiverse siblings. Gendered socialisation, in combination with the close emotional bonds made in childhood between siblings, fostered a higher sensitivity to other's feelings and emotions or advanced empathy. This higher cognisance of emotion impacted decisions and familial expectations regarding caregiving, how the neurotypical sibling makes sense of their role, and how they manage and negotiate care.

Similar to this study, Seltzer et al. (2005) found that the family's most involved sibling was more likely a female sibling than a male, adding to Leane's (2019) findings of needing support services that are representative of the responsibilities and ambitions of female-identifying siblings. This ties into the results of this study, which found that support services and professionals need to tailor their work with neurotypical siblings to a whānau-centred approach and could consider the gendered issues that present for caregivers.

This gender-sensitive approach should consider the gendered socialisation combined with expectations of neurotypical caregivers, tailoring supports and responses appropriately. Due to the high proportion of female presenting caregivers for neurotypical siblings both in Leane’s (2019) study and the present study, opportunities to voice emotions, conflicts and dilemmas regarding caregiving could be beneficial to break down barriers to finding support. These opportunities could be beneficial to changing the gendered expectations of caregiving through a sensitivity towards the experiences and feelings of this group, who are often unseen, under-appreciated, and under-researched. Further research regarding how this could be facilitated safely and sensitively would be beneficial.

Implications and Future Research

The findings of the study have several implications for service provision, education, and practice, as well as for further research. The following section identifies key areas for growth, including the evolution of whānau-centric models, strengthening of communities, recognition of disenfranchised trauma, unity between siblings, and opportunities for academic exploration.

A Whānau Centric Model

Findings suggest that, in Aotearoa, the accessibility of support services or specific programs to cater to neurotypical siblings of neurotypical people with high and complex needs were lacking. Moreover, education was deficient for support services staff to manage the intricacies of the unique familial or sibling dynamics, thus providing inadequate support for families. Participants felt untrusting and sceptical of support, adding to their social nullification. Participants spoke about the lack of support and the need for better accessibility, stressing that there was often a lack of education, support, or advertising for support services that were available for families with a neurodiverse person with high and complex needs, noting that they often "*didn't know it was an option*". Increasing community visibility is imperative to mitigate ongoing social nullification for siblings and families. Constructing a whānau-centric method of learning about the specific intricacies of each family, integrating all whānau members, and spending time within the home to learn about how specific daily issues present could be beneficial for support services to meet the needs of this group.

Unity of Community

The findings of this study supported the need for and power in connection, community, and relationships with fellow members of the neurodiversity community. The yearning for connection to see, understand, and process complicated experiences and feelings reflected the nullification of experience being internalised for siblings, hindering their access to meeting, or knowing others and finding solace. There was a need, desire, and opportunity for the construction of support groups, specifically for neurotypical siblings in their adolescence. These groups and the connections formed could assist in mitigating the development of ongoing mental health struggles, such as anxiety, which arise during their shaky pillars of growth. Further, neurotypical siblings could have benefitted from emotional holding, advice sharing, and learning more adaptive coping strategies through their peers. This approach could have mitigated the social silencing experienced by this group, foster trust in their future and their supporters, and minimise the felt sense of invalidation from this social pacification. In part, findings from the present study highlighted that support services should have been working with whānau and schools to educate neurotypical siblings about services or supports that were available to help them navigate these experiences, ultimately assisting in mitigating the shame that grows from feeling socially nullified.

Disenfranchised Trauma and Care

A common thread throughout the data was the experience of feeling invalidated. The implications of this study suggest that it was vital to tend to the person as a culmination of complicated experiences and silencing, offering a holding for needs, experiences, and feelings often disenfranchised by their support networks.

Disenfranchised trauma refers to distressing experiences that are not recognised or validated by society, communities, or peers and, as such, are not incorporated into the individual's narrative of their life experiences (Henshaw, 2019). For participants in this study, their experiences, needs, feelings, and existence were often disregarded or ignored by society, leading to the sense of disenfranchisement of their distressing experiences. To engage safely, sensitively, and appropriately with this group, a careful and trauma-informed approach would work to restructure the narratives around these distressing experiences for this group.

Trauma-informed care recognises the influence of distressing experiences on behavioural and psychological functioning, effectively supporting those impacted (Ridgard et al., 2015). The three pillars of trauma-informed care were safety, connection, and emotional regulation, which construct a resilient and empowering culture (Ridgard et al., 2015). These three pillars reflect the core needs of stability and unity that participants have recognised as central themes of experience throughout childhood and adolescence. Trauma-informed care could be an effective method to engage safely, authentically, and sensitively with neurotypical siblings of neurodiverse people with high and complex needs.

Trauma-informed care is not a universal solution to trauma-related care; it requires ongoing attention, awareness, and cultural sensitivity (Centre for Disease Control, 2020). Trauma-informed care involves three persistent components: first, continuous data gathering, such as ongoing collaboration with the neurotypical sibling to ascertain their needs and symptoms of trauma (Ridgard et al., 2015). Second, collaboration with stakeholders, such as the siblings' support network, ensuring a circle of support for the neurotypical sibling to thrive (Ridgard et al., 2015). Third, the counsellors' engagement in assessments to monitor outcomes, such as the Survey for Trauma-Informed Systems Change (STISC), which evaluates the effectiveness of trauma-informed counselling by measuring emotional and behavioural functioning, social skills, and ongoing management of trauma for clients (Dunn et al., 2005; Ridgard et al., 2015).

Trauma-informed care means that employing a person-centred approach when working with clients who have experienced distressing events. This approach, characterised by Carl Rogers's (2004) three core conditions of empathy, unconditional positive regard, and freedom from judgement, engages a human connection between counsellor and client. This connection reduces fear and promotes emotional integration through relational and moment-by-moment contact (Rogers, 2004). The therapeutic process is co-created through attuning and responding to clients' physiological and linguistic cues, emphasising self and relational experiences (Mearns et al., 2013). Increasing knowledge contributes to a diverse understanding of the therapeutic process, broadening the connection between client and counsellor (Mearns et al., 2013). Subsequently, broader self-awareness helps counsellors attend sensitively to their presence within the therapeutic relationship, enhancing the overall effectiveness of trauma-focused counselling (Rogers, 2004). Murphy et al. (2019) pinpointed four trauma-focused principles that embraced a person-centred philosophy for therapists working with clients who have undergone trauma. Initially, early relationship building and alliance formation; secondly, aiding client identification and acknowledgment of past events as traumatic experiences; thirdly, aiding work on traumatic sources of current experiential and interpersonal challenges; and lastly, providing self-agency-focused empathy (Murphy et al., 2019).

Holding and engaging with this group, counsellors should expect the ongoing adaptations from the shaky pillars of growth, such as turbulence, defensiveness, and self-protection, to emerge in the client's presentation. These adaptations have grown out of a feeling of invisibility and a fledging tolerance for being seen. This can lead to the psychological and emotional defences and protections they have learned from an early age to present when their experiences, feelings, and authenticity are witnessed and held respectfully. Most important is to recognise that these reactions are inherent growth factors for this group, and a trauma-informed approach may be appropriate to support the process of reintegrating these experiences authentically and sensitively into ingredients for growth.

Sibling Unity and Connection

Future studies may explore the desire for connection and unity between neurotypical and neurodiverse siblings with high and complex needs. Yearning for connection and siblinghood implies that further exploration is needed regarding the desire to be a sibling and how this might be possible when high and complex needs are added to the dynamic. One possibility is to foster engagement in shared activities to grow the unity these siblings value and desire.

The sibling relationship has significant life course variation, reflected in the findings of this study, with participants noting that they had more robust communications and relationships with their neurodiverse siblings fostered by hindsight, maturity, and post-traumatic growth. Future studies could further explore the shared activities of siblings to see if the Aotearoa context varies in type, frequency, or activity. It could also be examined through a bi-cultural lens to see if siblings found their relationships strengthened through culturally specific activities.

An Academically Nullified Existence

Future research should endeavour to expand academic discourse on neurotypical siblings of neurodiverse people with high and complex needs in the Aotearoa context. Research projects such as the current study that could further highlight, promote, and focus on the experiences of neurotypical siblings, finding new and culturally appropriate approaches to care. Studies such as these work to validate these existences, elevate discourse, and promote understanding of the core needs identified by this group. Academic discussions of sibling experiences are rare, reflecting academia's complicity in silencing this group.

Therefore, future studies may aim to refocus the study on a holistic view of the relationship between neurotypical siblings and their neurodiverse siblings. For example, this study focused on distressing experiences rather than asking participants how they perceived these experiences. To illustrate, "Could you tell me about any distressing experiences you remember that affected you?" emphasises distressing experiences rather than capturing a holistic view of any experience that springs to mind. Instead, using more open ended and expansive questions would provide a wider scope.

Additionally, participants were primed to focus on distressing experiences through the recruitment process. Advertisements mentioned the study aims as "*to explore the experience of any distressing or disturbing experiences encountered by siblings of neurodiverse people, especially experiences that may not have been openly, publicly, or socially acknowledged as distressing or disturbing.*" Focusing on the experiences of distress imposes a negative lens on the study rather than allowing a fully universal exploration of the participants' experiences. Future studies could engage participants in holistic reflections on their experiences, which encompassed all aspects of the relationship in the findings, adding to the robustness of academic discourse for this group and lessening the academic silencing of their lives.

Strengths and Limitations

There were several challenges during the process of completing the study, which imposed limitations on the findings. These include limited participant diversity, the complexity of being an insider researcher, and the reliance on participant retrospective recall. However, these limitations also incorporated aspects that strengthened the study. Following is a discussion of these areas, along with a key strength of the study: offering participants an opportunity to reflect and give voice to their experiences.

Participant Diversity

Participant diversity in this study was limited due to recruitment methods, time constraints, and the number of respondents. Recruitment for this study was limited to two months due to pragmatics around the researcher's availability and university deadlines. However, this two-month window gave participants the drive and desire to engage and share their experiences. Recruitment was facilitated through the New Zealand Association of Counsellors newsletter, Spectrum Care specialists who work directly with whānau of neurodiverse people with high and complex needs, and the *Drenched.org* online support group for neurotypical siblings of neurodiverse people with high and complex needs. These platforms for recruitment posed their own benefits and challenges.

The board members of *Drenched.Org* and Spectrum Care were presented with the study parameters and measures for confidentiality, fostering trust with the organisations and highlighting the sensitive approach to their members. The participants recruited through *Drenched.org* had trust in the study due to the board members' advocacy of the study and had increased confidence in sharing their experiences from their involvement in the group. These participants emphasised their drive to engage in the study and share their stories to help broaden the conversation around their experiences in society and academia.

All five participants were female-identifying, Pākehā and in the Auckland region. This sample size did not explicitly exemplify the nuance of a bi-cultural context of Aotearoa and gave rise to potential gendered issues as raised by Leane (2019), such as lack of male representation. Furthermore, as all participants were from middle-class families, they did not adequately highlight the impact of socio-economic issues in Aotearoa. Despite the homogeneity of these participants, they reflected the diversity of experiences found in this under-researched group. The diversity reflected that neurotypical siblings of neurodiverse people with high and complex needs have many different understandings, experiences, and relationships. This showed the uniqueness of the life, learning, and processing of these experiences for each neurotypical sibling of a neurodiverse person with high and complex needs.

An Insider Researcher

The methodology of reflexive thematic analysis was chosen as the researcher aligned with the participants as a fellow neurotypical sibling of a neurodiverse person with high and complex needs (Braun & Clarke, 2022). Through reflexive thematic analysis, the researcher examined, analysed, and reflected upon their personal experience while uncovering other unique aspects of the experiences presented by participants (Braun & Clarke, 2022). There were several complexities to maintaining adequate boundaries with the data and using lived experience to enhance the study. The researcher engaged in journaling, ongoing supervision, and counselling to discuss any conflicts arising from their involvement in the data.

Furthermore, the researcher's proximity to the participants' experiences provided a rich understanding and sensitivity to the data and participants; however, it could have also biased the methods or findings for this study. For example, a biased perspective could have been integrated into the study through specific questioning or the integration of personal views on the findings. Alternatively, having a researcher who is well-acquainted with the subject matter and has lived experience adds to the complexity, sensitivity of approach, and understanding of the participant experience. The researcher managed this by maintaining a critical lens throughout the analysis period, to maintain distance from the data, and to separate personal experience from that of participants. However, the researcher's subjective experiences and views could have been processed through and with the findings and thematic construction as a fellow participant, adding to the findings' richness.

Participant Retrospectives

Engaging participants in retrospective analysis and reflection on their childhood and adolescent experiences can mitigate ethical dilemmas when interviewing youth (Moyson & Roeyers, 2012). Participants reflecting on their experiences can often notice or remember experiences at a distance when their involvement at the time may have blighted their understanding or processing. However, engaging participants in a retrospective analysis can also challenge their recall abilities. Memory recall can be problematic, referenced to by one participant: "*I definitely feel like I have gaps in my memory… I don't remember a lot…you have to sit and think really hard*" (Jane).

Participant retrospectives could also prove to be an issue in the findings. Participants may have agendas or aims for what they want to focus on in telling their story, which could skew the results or theme construction. Overall, the strength of a participant retrospective was the maturity and understanding with which participants discussed their experiences, adding to the richness of the findings of this study.

Voice and Reflexivity

Participants were vocal in their appreciation for a study highlighting the lives and experiences of neurotypical siblings of neurodiverse people with high and complex needs. The benefit of this study was that participants feel heard and valued and that their experience was acknowledged and validated. Participants mentioned feeling the catharsis of exploring their childhood and adolescent experiences, vocalising that exploring these experiences was helpful, and recognising that aspects of their adaptations or coping strategies may need further analysis or reflection through counselling.

Reflexive thematic analysis opened discourse of this study to engage in reflections on the participants' and researchers' experiences of being a neurotypical sibling to a neurodiverse sibling with high and complex needs. This method was vital for the aim of this study: to engage in a contemporary exploration of the experiences of this under-researched group, to give voice to neurotypical siblings of neurodiverse people with high and complex needs, and to represent this group in academic discourse. Through reflexive thematic analysis, the voices of neurotypical siblings of neurodiverse people with high and complex needs were central to understanding the themes of experience. They were the central focus of implications for practice, bringing them to the forefront of the discussion while validating their feelings and experiences.

Conclusion

In conclusion, this study spotlights an under-researched and under-acknowledged group in our society. This study aimed to serve as a cathartic experience for neurotypical siblings by giving them a voice, adding to the academic discourse around supporting families with neurodiverse members, and highlighting common themes of experience for neurotypical siblings of neurodiverse people with high and complex needs.

Overall, participants were explicit, emphatic, and celebratory of their parents and efforts to manage an unmanageable situation. The overarching message to families with neurodiverse people with high and complex needs was that their efforts and difficulties were not unnoticed or unappreciated. Their tireless work to meet the needs of all family members fostered their growth and love for their life and family. *"I think because I just have so much love for all four of my family…we just have such a cool, somewhat weird, kind of family…I guess it sets us apart. That's really cool. Yeah… just love" (Isabella)*.

Practical recommendations include specific counselling modalities such as trauma-informed care and person-centred philosophies to safely and sensitively mitigate the silencing encountered by this group. There is a call for structuring social supports to cater to families of neurodiverse individuals with high and complex needs and to integrate a whānau approach to service delivery. Future studies could delve into gender implications, explore cultural differences in New Zealand, and focus on Māori neurotypical siblings of neurodiverse individuals with high and complex needs through a culturally specific lens. These avenues for future research would contribute to a more comprehensive understanding of the experiences of neurotypical siblings in different contexts and diversify the academic discourse.

In contrast, the outcry from the participants of this study was towards society; siblings of neurodiverse individuals do not experience a family-nullified existence; it is a socially nullified existence. Society must do better to acknowledge and engage the ingredients for growth from these experiences: love, protection, intentionality, and reliability; embrace all the diverse members of our tribe, bringing these people into the spotlight; and ultimately, caring.

References

Aldridge, J., & Becker, S. (1993). Children who care: inside the world of young carers (Version 1). Loughborough University. https://hdl.handle.net/2134/619

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (Fifth Edition). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Anthony, E. J., & Bene, E. (1957). A Technique for the Objective Assessment of the Child's Family Relationships. *Journal of Mental Science*, *103*(432), 541–555. https://doi.org/10.1192/bjp.103.432.541

Becker, S. (2022). *Putting young carers on the map | Dr. Saul Becker at the 2022 Low-Beer Event* [Video]. YouTube. https://www.youtube.com/watch?v=NqRuOo61T-g

Berry, D. (2022). *Navigating neurodiversity: The experiences of neurodiverse people and the people who support them*. https://doi.org/10.7488/ERA/2746

Bevan-Brown, J., Berryman, M., Hickey, H., Macfarlane, S., Smiler, K., & Walker, T. (2015). *Working with Māori children with special education needs: He mahi whakahirahira*. NZCER Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, *12*(3), 297–298. https://doi.org/10.1080/17439760.2016.1262613

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I *not* use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37–47. https://doi.org/10.1002/capr.12360

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

Burke, P. (2004). *Brothers and sisters of disabled children*. Jessica Kingsley.

Centre for Disease Control (CDC). (2020). *Infographic: 6 guiding principles to a trauma-informed approach*. Centre for Disease Control and Prevention. https://www.cdc.gov/orr/infographics/6_principles_trauma_info.htm

Chellappa, S. L. (2023). Language matters for neuro-inclusivity. *Nature Mental Health*, *1*(3), 146–146. https://doi.org/10.1038/s44220-023-00028-w

Cloitre, M., Stolbach, B. C., Herman, J. L., van der Kolk, B., Pynoos, R., Wang, J., & Petkova, E. (2009). A developmental approach to complex PTSD: Childhood and adult cumulative trauma as predictors of symptom complexity. *Journal of Traumatic Stress*, 22(5), 399-408. https://doi.org/10.1002/jts.20444

Cocks, J. (2013). *The oppositional imagination: Feminism, critique, and political theory*. Routledge.

Collins, A., & Wilson, G. (2008). Māori and informal caregiving: A background paper prepared for the National Health Committee. http://nhc.health.govt.nz/system/files/documents/publications/maori-informal-caregiving-apr08.pdf

Connors, C., & Stalker, K. (2003). *The views and experiences of disabled children and their siblings: A positive outlook*. Jessica Kingsley Publishers.

Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with down syndrome: Perspectives of mothers, fathers, and siblings. *American Journal on Mental Retardation*, *108*(4), 234. https://doi.org/10.1352/0895-8017(2003)

Delve, H. L., & Limpaecher, A. (2020). *What is narrative analysis? Essential guide to coding qualitative data.* Delve. https://delvetool.com/blog/narrativeanalysis

Den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, *23*(2), 271–273. https://doi.org/10.1177/1362361318820762

Doka, K. J. (Ed.). (2002). *Disenfranchised grief: New directions, challenges, and strategies for practice*. Research Press.

Doka, K. J. (2008). Disenfranchised grief in historical and cultural perspective. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention.* (pp. 223–240). American Psychological Association. https://doi.org/10.1037/14498-011

Dunn, T. W., Burlingame, G. M., Walbridge, M., Smith, J., & Crum, M. J. (2005). Outcome assessment for children and adolescents: Psychometric validation of the Youth Outcome Questionnaire 30.1 (Y-OQ®-30.1). *Clinical Psychology & Psychotherapy*, *12*(5), 388–401. https://doi.org/10.1002/cpp.461

Durie, M. H. (1977). Māori attitudes to sickness, doctors and hospitals. *The New Zealand Medical Journal*, *86*(600), 483–485. https://pubmed.ncbi.nlm.nih.gov/272561/

Dyke, P., Mulroy, S., & Leonard, H. (2009). Siblings of children with disabilities: Challenges and opportunities. *Acta Paediatrica*, *98*(1), 23–24. https://doi.org/10.1111/j.1651-2227.2008.01168.x

Edkins, J. (2002). Forget trauma? Responses to September 11. *International Relations*, *16*(2), 243–256. https://doi.org/10.1177/0047117802016002005

Findler, L., & Vardi, A. (2009). Psychological growth among siblings of children with and without intellectual disabilities. *Intellectual and Developmental Disabilities*, *47*(1), 1–12. https://doi.org/10.1352/2009.47:1–12

Flick, U. (2009). *An introduction to qualitative research* (4th ed). Sage Publications.

Flick, U. (2017). *Designing qualitative research* (2nd edition). SAGE Publications.

Flick, U. (2018). *The Sage handbook of qualitative data collection*. SAGE Publications Ltd.

Goode, W. J. (1960). A theory of role strain. *American Sociological Review*, *25*(4), 483. https://doi.org/10.2307/2092933

Granat, T., Nordgren, I., Rein, G., & Sonnander, K. (2012). Group intervention for siblings of children with disabilities: A pilot study in a clinical setting. *Disability and Rehabilitation*, *34*(1), 69–75. https://doi.org/10.3109/09638288.2011.587087

Grant, B. M., & Giddings, L. S. (2002). Making sense of methodologies: A paradigm framework for the novice researcher. *Contemporary Nurse*, *13*(1), 10–28. https://doi.org/10.5172/conu.13.1.10

Hallahan, D. P., & Kauffman, J. M. (Eds.). (2011). *Handbook of special education*. Routledge.

Hanna, S., & Chisnell, C. (2019). An invisible population—Young carers in Aotearoa, New Zealand. *Aotearoa New Zealand Social Work*, *31*(2). https://link.gale.com/apps/doc/A673083026/AONE?u=learn&sid=bookmark-AONE&xid=e96b6f4c

Hanvey, I., Malovic, A., & Ntontis, E. (2022). Glass children: The lived experiences of siblings of people with a disability or chronic illness. *Journal of Community & Applied Social Psychology*, *32*(5), 936–948. https://doi.org/10.1002/casp.2602

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation*, *107*(2), 116. https://doi.org/10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2

Henshaw, L. A. (2019). *The complexity of unrecognized trauma: Survivors' narratives* [ProQuest Dissertations Publishing]. https://search.proquest.com/docview/2240049314?pq-origsite=primo

Jacobs, P., & MacMahon, K. (2017). 'It's different, but it's the same': Perspectives of young adults with siblings with intellectual disabilities in residential care. *British Journal of Learning Disabilities*, *45*(1), 12–20. https://doi.org/10.1111/bld.12169

Joseph, S., Sempik, J., Leu, A., & Becker, S. (2020). Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolescent Research Review*, *5*(1), 77–89. https://doi.org/10.1007/s40894-019-00119-9

Katyal, K. R., & King, M. E. (2014). Non-Chinese researchers conducting research in Chinese cultures: Critical reflections. *International Journal of Research & Method in Education*, *37*(1), 44–62. https://doi.org/10.1080/1743727X.2012.736484

King, P. (2019). *Māori with lived experience of disability part I* [Computer software]. Ministry of Justice.

Knapp, J. F. (1998). The impact of children witnessing violence. *Pediatric Clinics of North America*, *45*(2), 355–364. https://doi.org/10.1016/S0031-3955(05)70011-0

Kovacs, M. (2015). Children's Depression Inventory (CDI and CDI 2). In R. L. Cautin & S. O. Lilienfeld (Eds.), *The Encyclopedia of Clinical Psychology* (1st ed., pp. 1–5). Wiley. https://doi.org/10.1002/9781118625392.wbecp419

Leane, M. (2019). Siblings caring for siblings with intellectual disabilities: Naming and negotiating emotional tensions. *Social Science & Medicine*, *230*, 264–270. https://doi.org/10.1016/j.socscimed.2019.04.022

Leidenhag, J., & King, P. E. (2023). Neurodiversity and thriving: A case study in theology-informed psychology. *Studies in Christian Ethics*, *36*(4), 827–843. https://doi.org/10.1177/09539468231187784

Littlejohn, M. (1998). *Grown-up: Adult siblings reflect on the impact of disability during their lives*. Thesis B. Soc.Sci--Auckland College of Education.

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, *37*(6), 1060–1067. https://doi.org/10.1007/s10803-006-0249-0

Mair, D. (1997). *Out of focus: “Siblings and parents share their stories.”* Thesis Dip.EI -- Auckland College of Education.

Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors that may affect the health of siblings of children who have an intellectual/developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(4), 273–286. https://doi.org/10.1111/jppi.12309

McGibbon, A. (1994). *Sibling workshops: For young children who have siblings with special needs*. Thesis DipEI--Auckland College of Education.

McGuire, D. E., & Chicoine, B. (2006). *Mental wellness in adults with Down syndrome: A guide to emotional and behavioural strengths and challenges* (1st ed). Woodbine House.

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioural adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *22*(1), 83–100. https://doi.org/10.1007/s10882-009-9171-7

Mearns, D., Thorne, B., & McLeod, J. (2013). *Person-centred counselling in action* (4th ed). SAGE.

Milligan, L. (2016). Insider-outsider-inbetweener? Researcher positioning, participative methods and cross-cultural educational research. *Compare: A Journal of Comparative and International Education*, *46*(2), 235–250. https://doi.org/10.1080/03057925.2014.928510

Morrow, S. L. (2007). Qualitative Research in Counselling Psychology: Conceptual Foundations. *The Counselling Psychologist*, *35*(2), 209–235. https://doi.org/10.1177/0011000006286990

Moyson, T., & Roeyers, H. (2012). ‘The overall quality of my life as a sibling is all right, but of course, it could always be better’. Quality of life of siblings of children with intellectual disability: The siblings’ perspectives: Quality of life of siblings of children with ID. *Journal of Intellectual Disability Research*, *56*(1), 87–101. https://doi.org/10.1111/j.1365-2788.2011.01393.x

Murphy, D., Elliott, R., & Carrick, L. (2019). Identifying and developing therapeutic principles for trauma-focused work in person-centred and emotion-focused therapies. *Counselling and Psychotherapy Research*, *19*(4), 497–507. https://doi.org/10.1002/capr.12235

Nel, L. (1987). *Brothers and sisters of people with special needs: Their needs and concerns*. Dissertation Dip.EHC--Auckland College of Education.

O'Dowd, G. (2003). Recognising the 'living' grief and loss experience of people with a mental illness and their carers: personal reflections from a former mental health worker. *Grief Matters: The Australian Journal of Grief and Bereavement*, *6*(2), 26–30. doi/abs/10.3316/INFORMIT.811806384714896

Opai, K., & Severne, E. (2020). *Te Reo Hāpai - The Language of Enrichment*. https://www.tereohapai.nz/

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research*, *51*(9), 682–696. https://doi.org/10.1111/j.1365-2788.2007.00954.x

Pantazakos, T. (2023). Neurodiversity and psychotherapy—Connections and ways forward. *Counselling and Psychotherapy Research*, *1*(1) 1-7. https://doi.org/10.1002/capr.12675

Parent2Parent. (2018). *20. Parenting siblings with and without special needs* (1020). Retrieved May 14, 2023, from https://podcast.parent2parent.org.nz/1802293/8743154

Park, C. L., Cohen, L. H., & Murch, R. L. (2013). Stress Related Growth Scale. American Psychological Association. https://doi.org/10.1037/t17236-000

Patton, M. Q. (2015). *Qualitative research & evaluation methods: integrating theory and practice* (Fourth edition). SAGE Publications, Inc.

Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism*, *13*(5), 471–483. https://doi.org/10.1177/1362361309335721

Phillips, S. B. (2015). The dangerous role of silence in the relationship between trauma and violence: A group response. *International Journal of Group Psychotherapy*, *65*(1), 64–87. https://doi.org/10.1521/ijgp.2015.65.1.64

Piers, E. V. (1984). Piers-Harris children's self-concept scale. Los Angeles: Western Psychological Services.

Pine, D. S., Cohen, P., Gurley, D., Brook, J., & Ma, Y. (1998). The risk for early-adulthood anxiety and depressive disorders in adolescents with anxiety and depressive disorders. *Archives of General Psychiatry*, *55*(1), 56. https://doi.org/10.1001/archpsyc.55.1.56

Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., & Ghosh Dastidar, M. (2014). *Hidden heroes: America's military caregivers*. RAND Corporation. https://doi.org/10.7249/RR499

Ridgard, T. J., Laracy, S. D., Dupaul, G. J., Shapiro, E. S., & Power, T. J. (2015). *Trauma-informed care in schools: A social justice imperative*. National Association of School Psychologists. *44*(2), 1. https://www.nasponline.org/publications/periodicals/communique/issues/volume-44-issue-2/trauma-informed-care-in-schools-a-social-justice-imperative

Riessman, C. K. (1993). *Narrative analysis*. Sage Publications.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage Publications.

Rogers, C. R. (2004). *On becoming a person: a therapist's view of psychotherapy*. Constable.

Rowe, W. E. (2014). Positionality. In D. Coghlan & M. Brydon-Miller (Eds.), *The SAGE Encyclopedia of Action Research* (pp. 628–628). SAGE.

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation (Washington)*, *43*(5), 354–359. https://www-proquest-com /docview/1293498757?pq-origsite=primo&sourcetype=Scholarly%20Journals&imgSeq=1

Shaw, D. (1998). *What about me? The effects on siblings who have brothers and sisters with special needs*. Thesis Dip. ESSTN -- Auckland College of Education.

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: theory, method and research* (2nd edition). SAGE.

Smyth, C., & Michail, S. (2010). Exploring young carers' agency. *Qualitative research journal*, *10*(2), 36–50. https://doi.org/10.3316/QRJ1002036

Sommantico, M., Parrello, S., & De Rosa, B. (2020a). Adult siblings of people with and without intellectual and developmental disabilities: Sibling relationship attitudes and psychosocial outcomes. *Research in Developmental Disabilities*, *99*, 103594. https://doi.org/10.1016/j.ridd.2020.103594

Sommantico, M., Parrello, S., & De Rosa, B. (2020b). Sibling relationships, disability, chronic, and mental illness: Development of the siblings' experience quality scale (SEQS). *Journal of Developmental and Physical Disabilities*, *32*(6), 943–961. https://doi.org/10.1007/s10882-020-09730-4

Spiers, J., & Smith, J. A. (2019). Interpretative phenomenological analysis, In P. Atkinson, S. Delamont, A. Cernat, J.W. Sakshaug, & R.A. Williams (Eds.), SAGE Research Methods Foundations. https://doi.org/10.4135/9781526421036813346

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, *43*(5), 339–350. https://doi.org/10.1352/0047-6765(2005)43[339:SOCWDR]2.0.CO;2

Travers, H. E., Carlton, M. E., & Carter, E. W. (2020). Social connections among siblings with and without intellectual disability or autism. *Intellectual and Developmental Disabilities*, *58*(1), 19–33. https://doi.org/10.1352/1934-9556-58.1.19

Weiss, C. R., Baker, C., Gillespie, A., & Jones, J. (2022). Ambiguous loss in family caregivers of loved ones with cancer, a synthesis of qualitative studies. *Journal of Cancer Survivorship*, *17*(2), 484–498. https://doi.org/10.1007/s11764-022-01286-w

Welch, H. T. (2021). *Te kura tapa whā: Embedding an indigenous model of wellbeing into the learning environment*. NZCER Press.

Yang, C., Hsieh, M., Lee, L., & Chen, S. (2017). Experiences of caring for a sibling with schizophrenia in a Chinese context: A neglected issue. *International Journal of Mental Health Nursing*, *26*(4), 409–417. https://doi.org/10.1111/inm.12269

Zetlin, A. G. (1986). Mentally retarded adults and their siblings. *American Journal of Mental Deficiency*, *91*(3), 217–225. https://pubmed.ncbi.nlm.nih.gov/3799727/

Appendices

Appendix A – Advertisement for Participants

UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

SEARCHING FOR RESEARCH PARTICIPANTS

Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.

Hello, Kia ora, Tālofa lava, Mālō e lelei, Bula, Fakalofa Atu, Kia Orana, Ni Hao, Konnichiwa, Xin Chào, Annyeong Haseyo, Bonjour, Ola, Hola, Hallo, Ciao, Namaste, As-Salamu Alaikum, Privyet, Ahoj, Guten Tag, Sawubona, Kumusta, Yassou.

I am Therese Murdoch, a master's student in the School of Counselling, Human Services and Social Work - Te Kura Tauwhiro Tangata. Under the guidance of my supervisor, Dr Brian Rodgers, I am searching for participants for my research project: *experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand*.

For this study, I am recruiting adult-aged (21+) neurotypical siblings of neurodiverse people with high and complex needs from across Aotearoa to participate in my dissertation study. The term neurodiverse refers to individuals who may have a diagnosis of foetal alcohol spectrum disorder, autism, down syndrome, or other severe neurological conditions. This may also include conditions that do not fit a specific diagnosis, including profound and severe intellectual conditions. This means that the neurodiverse person cannot live independently and requires close supervision and daily assistance with self-care activities. They could also have limited ability to communicate and/or physical limitations. The term "high" or "complex" needs refers to neurodiverse individuals who require a higher level of ongoing support or accommodations due to the severity or complexity of their cognitive differences. To be eligible to take part in this study, participants must also identify as "neurotypical," i.e., not having a severe or complex condition as indicated above.

This study aims to explore the experience of any distressing or disturbing experiences encountered by siblings of neurodiverse people, especially experiences that may not have been openly, publicly, or socially acknowledged as distressing or disturbing. Specifically, we are interested in people's childhood and adolescence experiences regarding meeting the needs of their neurodiverse siblings. Participation in the research is entirely voluntary.

Are you or is someone you know…

- **A neurotypical sibling to a neurodiverse person with high and complex needs?**
- **Over 21?**
- **Interested in participating in one 60–90-minute semi-structured interview in person or via a secure Zoom link online?**

If you or someone you know is interested in participating in my research, please contact me at tmur036@aucklanduni.ac.nz .

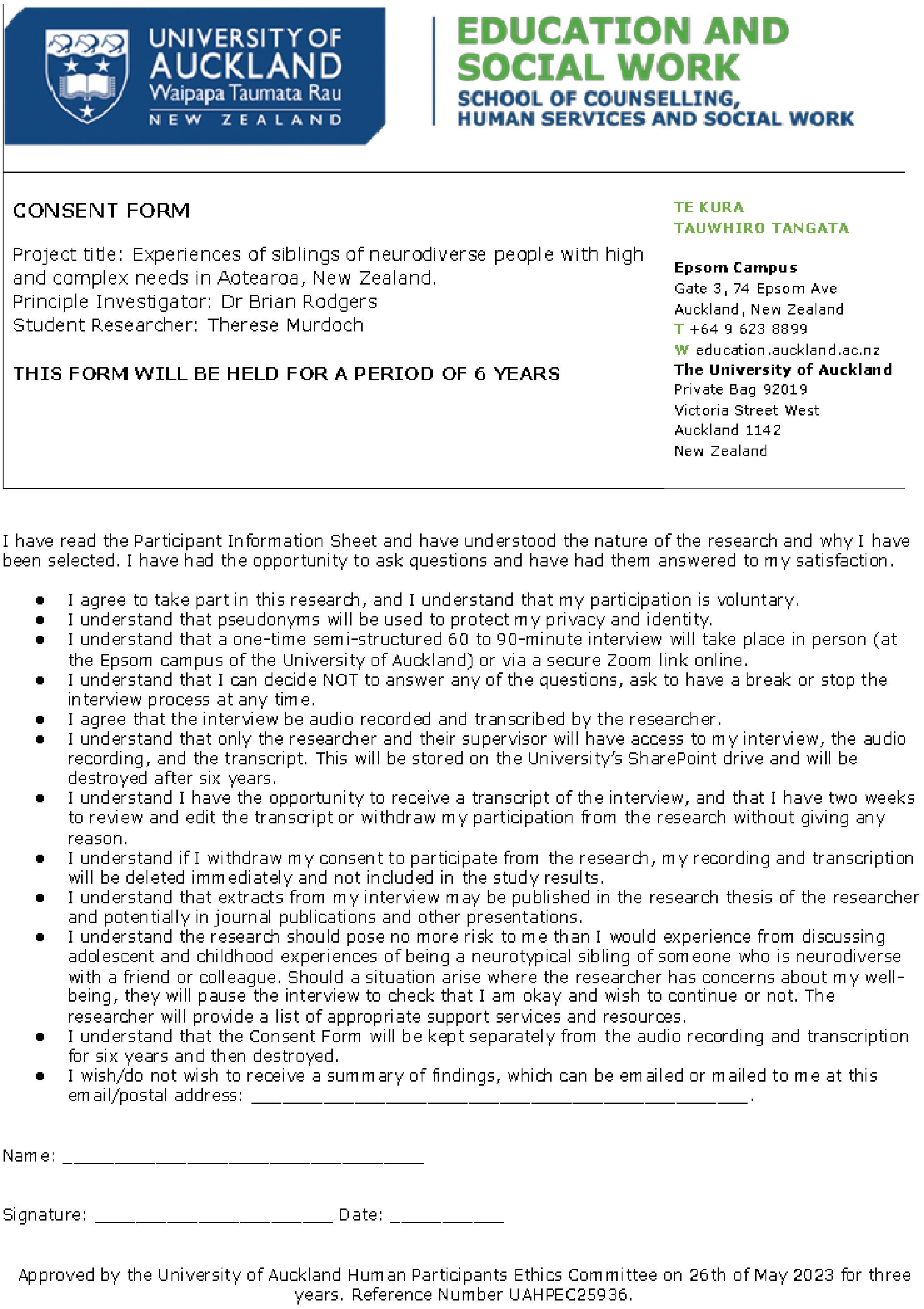
I will be more than happy to share the Participant Information Sheet and Consent Form, which will provide you with more information about my research. Please note in person (face-to-face) interviews will take place at the University of Auckland, Epsom campus. Online interviews will take place using a secure zoom link. If you have any further questions, please do not hesitate to contact me via email tmur036@aucklanduni.ac.nz.

Thank you for showing interest in my research.

Ngā mihi nui,
Therese Murdoch
tmur036@aucklanduni.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 26th of May 2023 for three years. Reference Number UAHPEC25936.

Appendix B – Consent Form



UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

CONSENT FORM

Project title: Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.
Principle Investigator: Dr Brian Rodgers
Student Researcher: Therese Murdoch

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS

TE KURA
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New Zealand

I have read the Participant Information Sheet and have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have had them answered to my satisfaction.

- I agree to take part in this research, and I understand that my participation is voluntary.
- I understand that pseudonyms will be used to protect my privacy and identity.
- I understand that a one-time semi-structured 60 to 90-minute interview will take place in person (at the Epsom campus of the University of Auckland) or via a secure Zoom link online.
- I understand that I can decide NOT to answer any of the questions, ask to have a break or stop the interview process at any time.
- I agree that the interview be audio recorded and transcribed by the researcher.
- I understand that only the researcher and their supervisor will have access to my interview, the audio recording, and the transcript. This will be stored on the University's SharePoint drive and will be destroyed after six years.
- I understand I have the opportunity to receive a transcript of the interview, and that I have two weeks to review and edit the transcript or withdraw my participation from the research without giving any reason.
- I understand if I withdraw my consent to participate from the research, my recording and transcription will be deleted immediately and not included in the study results.
- I understand that extracts from my interview may be published in the research thesis of the researcher and potentially in journal publications and other presentations.
- I understand the research should pose no more risk to me than I would experience from discussing adolescent and childhood experiences of being a neurotypical sibling of someone who is neurodiverse with a friend or colleague. Should a situation arise where the researcher has concerns about my well-being, they will pause the interview to check that I am okay and wish to continue or not. The researcher will provide a list of appropriate support services and resources.
- I understand that the Consent Form will be kept separately from the audio recording and transcription for six years and then destroyed.
- I wish/do not wish to receive a summary of findings, which can be emailed or mailed to me at this email/postal address: ____.

Name: _______________________________

Signature: ____________________ Date: _________

Approved by the University of Auckland Human Participants Ethics Committee on 26th of May 2023 for three years. Reference Number UAHPEC25936.

Appendix C – Participant Information Sheet

UNIVERSITY OF AUCKLAND
Waipapa Taumata Rau
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EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

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PARTICIPANT INFORMATION SHEET

Project title: Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.
Principle Investigator: Dr Brian Rodgers
Student Researcher: Therese Murdoch

Researcher introduction

My name is Therese Murdoch. I am a Master of Counselling student at The University of Auckland Faculty of Education and Social Work under the guidance of my supervisor, Dr Brian Rodgers. I have been studying in the field of counselling and psychotherapy for four years and working as a counsellor for two years at HELP Auckland. I decided to study the experiences of siblings of neurodiverse people with high and complex needs. I too have a sibling who has been diagnosed with a 'profound intellectual disability' and am interested in the potential links of experience for neurotypical siblings in Aotearoa New Zealand.

Project description and invitation

For this study, I am recruiting adult-aged (21+) siblings of neurodiverse people with high and complex needs across Aotearoa. The term neurodiverse refers to individuals who may have a diagnosis of fetal alcohol spectrum disorder, autism, down syndrome, or any other severe neurological conditions. This may also include conditions that do not fit a specific diagnosis, which may include profound and severe intellectual conditions, which mean that the person cannot live independently and requires close supervision and daily assistance with self-care activities. They could also have limited ability to communicate and/or physical limitations. The term "high" or "complex" needs refers to individuals who require a higher level of ongoing support or accommodations due to the severity or complexity of their cognitive differences. They could also have limited ability to communicate and/or physical limitations.

To be eligible to participate, you will also need to identify as "neurotypical," i.e., not having a severe or complex condition as indicated above. This study aims to explore the experience of any distressing or disturbing experiences encountered by siblings of neurodiverse people, especially experiences that may not have been openly, publicly, or socially acknowledged as distressing or disturbing.
Participation in the research is entirely voluntary.

Project Procedures

If you consent to be part of the study, we will invite you to participate in one 60 to 90-minute interview either at the Epsom campus of the University of Auckland or via a secure Zoom link online.

During the interview, you will be asked about your distressing or disturbing experiences during childhood and adolescence due to the needs of your neurodiverse sibling. We may also ask specific questions about what was distressing or disturbing about these experiences and the impact these experiences have had on your later life.

The interview should pose no more risk to you than you would experience from discussing adolescent and childhood experiences of being a sibling of someone who is neurodiverse with a peer or colleague. However, I would encourage you to consider how discussing these experiences may feel for you and to let me know what I can do to help you feel comfortable and safe.

You are also welcome to bring a support person to the interview if you choose; we would suggest a friend or person who is not in your immediate family. I will share the Participation Information Sheet with the support person to ensure they understand the details of the research project.

However, should a situation arise where I have concerns about your well-being, I will pause the interview to check that you are okay and to see if you wish to continue or not.

A list of emotional support resources is listed below and will also be provided for you at the interview should you require any ongoing support:

- 1737 Need to talk? – 1737 SMS and phone line
- Samaritans - 0800 72 66 66 https://www.samaritans.org.nz/
- Yellow Brick Road – https://yellowbrickroad.org.nz/
- IHC - https://www.ihc.org.nz/how-we-can-help/family-whanau-liaisons
- Family Services 211 Helpline – 0800 211 211 - https://www.familyservices.govt.nz/directory/ - for help finding (and direct transfer to) community-based health and social support services.
- Skylight – 0800 299 100 - https://www.skylight.org.nz/ - for support through trauma, loss and grief; 9 am–5 pm weekdays.

Please be aware there is an option on the consent form for you to opt-in to have a summary of the findings sent to you via email or postal address.

Data storage/retention/destruction/future use

All materials related to this study, for example, audio recordings and transcripts, will be digitally stored on a password-protected computer and on the University's SharePoint drive to which only my supervisor, Dr Brian Rodgers, and I have access. The consent form will be stored separately from the research data collected in the password-protected SharePoint Drive. After six years, all your data will be destroyed or deleted, including any online consent forms that you may have submitted.

Right to Withdraw from Participation

During the interview, you have the right to ask for the audio recording to be stopped at any time, to take a break, not to answer a question or to end the interview without needing to provide any reason at all.

After the interview, you will be given an opportunity to review and edit the transcript to clarify any miscommunications or errors. You may withdraw at any point up until two weeks after receiving your interview transcript, again, without giving a reason. Please note that after these two weeks, you will no longer be able to withdraw from the study.

Anonymity and Confidentiality

To protect your privacy and identity, pseudonyms will be used for yourself and any other people you discuss. You will be offered the opportunity to decide what pseudonyms will be used. The information you provide will be used in completing a qualitative thematic analysis, which will be written up as part of the research thesis and potentially in journal publications and presented at conferences.

Contact Details

Thank you for showing interest in my research. If you have any questions or concerns, please contact any of the following:

Researcher: Therese Murdoch (Masters student)
Email: tmur036@aucklanduni.ac.nz

Supervisor: Dr Brian Rodgers
Email: brian.rodgers@auckland.ac.nz
Phone: +64 9 6238811

Head of School
(School of Counselling, Human Services and Social Work): Dr Allen Bartley
Email: a.bartley@auckland.ac.nz
Phone: +64 9 373 7999, extn. 48140.
Location: N - BLOCK. EPSOM - Bldg. 6EN, EPSOM CAMPUS, 74 EPSOM AVE, EPSOM, AUCKLAND, 1023, New Zealand.

UAHPEC Chair contact details: For any queries regarding ethical concerns, you may contact the Chair, The University of Auckland Human Participants Ethics Committee, Office of Research Strategy and Integrity, The University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 26th of May 2023 for three years. Reference Number UAHPEC25936.

Appendix D – Interview Questions

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EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.

Interview Questions:

- Demographics: age, ethnicity, place of birth, choice of pseudonym
- How would you describe your neurodiverse sibling?
- How would you describe growing up with your neurodiverse sibling?
- What do you recall about first learning about your sibling's neurodiversity?
- What thoughts and feelings did this evoke?
- What was it like for you as a sibling to someone with high and complex needs?
- How would you describe your home life to someone who has never experienced living with someone with neurodiversity and high and complex needs?
- Reflecting on your childhood and adolescence, what experiences do you recall involving your neurodiverse sibling that differentiated you from your peers?
- What thoughts or feelings do these experiences evoke?
- How would other people respond to you discussing your feelings about these experiences?
- How do you feel your community or peers received your experiences and feelings?
- What did you notice about how you were seen as a sibling to someone with high and complex needs?
- Could you tell me about any distressing experiences you remember that affected you?
- Do you feel that your distress was allowed?
- Do you feel that distress was acknowledged? How?
- Could you talk to anybody about these distressing experiences?
- Looking back, how could people have supported you through these experiences?
- What other words would you use to describe growing up with a neurodiverse sibling and your experiences?
- How would you describe the presence of spirituality in your family growing up? How did this help?
- If the Participant has a brother: How would you describe the differences in experience between you and your brother from your perspective?

Appendix E – Support Services

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EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

INFORMATION FOR RESEARCH PARTICIPANTS

Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.

Support Services:

- **1737 Need to talk?** – 1737 SMS and phone line
- **Samaritans** - 0800 72 66 66
  - https://www.samaritans.org.nz/
- **Yellow Brick Road** – https://yellowbrickroad.org.nz/
- **IHC** - https://www.ihc.org.nz/how-we-can-help/family-whanau-liaisons
- **Family Services 211 Helpline** – 0800 211 211
  - https://www.familyservices.govt.nz/directory/
  - For help finding (and direct transfer to) community-based health and social support services.
- **Skylight** – 0800 299 100 – https://www.skylight.org.nz/
  - For support through trauma, loss and grief, 9 am–5 pm on weekdays.

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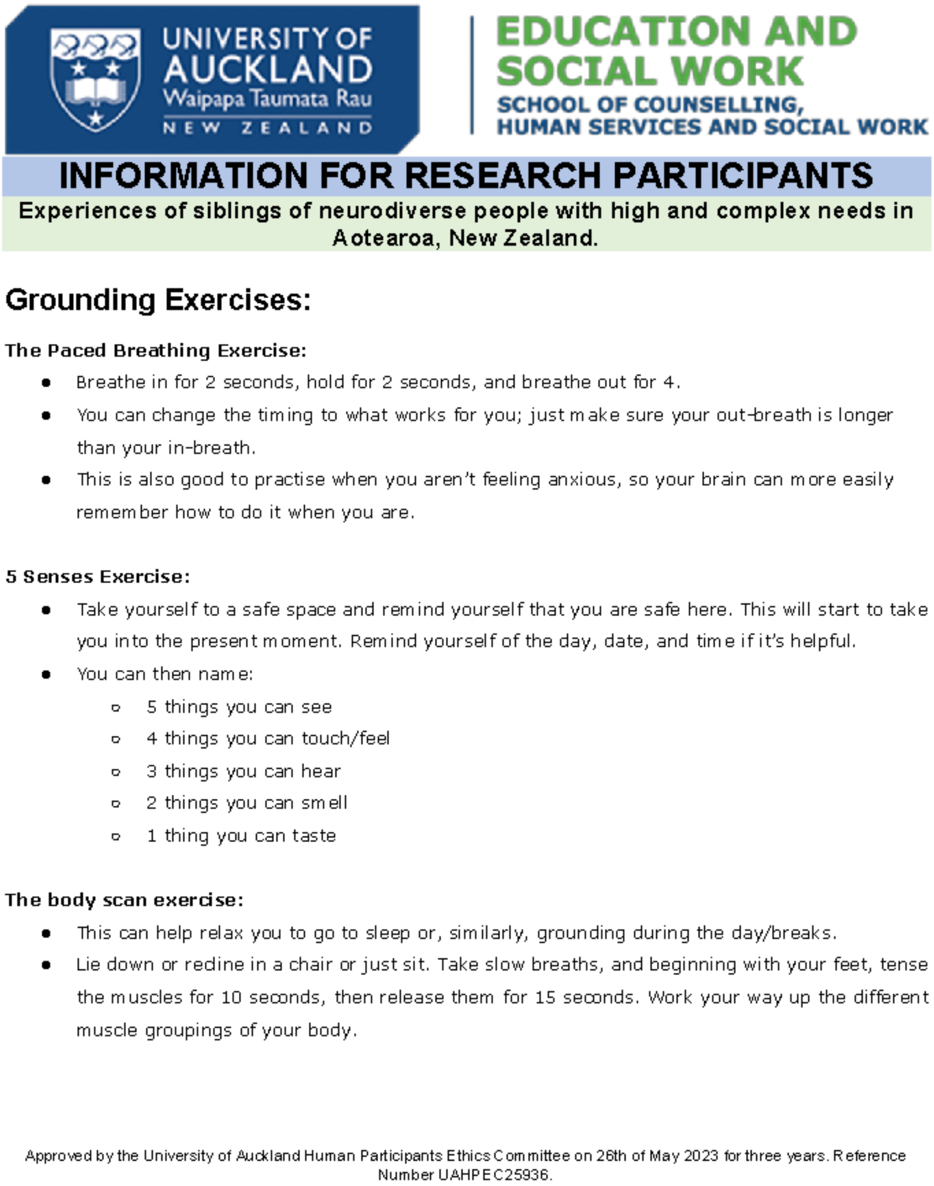
Appendix F – Grounding Exercises



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EDUCATION AND SOCIAL WORK
SCHOOL OF COUNSELLING, HUMAN SERVICES AND SOCIAL WORK

INFORMATION FOR RESEARCH PARTICIPANTS

Experiences of siblings of neurodiverse people with high and complex needs in Aotearoa, New Zealand.

Grounding Exercises:

The Paced Breathing Exercise:

- Breathe in for 2 seconds, hold for 2 seconds, and breathe out for 4.
- You can change the timing to what works for you; just make sure your out-breath is longer than your in-breath.
- This is also good to practise when you aren't feeling anxious, so your brain can more easily remember how to do it when you are.

5 Senses Exercise:

- Take yourself to a safe space and remind yourself that you are safe here. This will start to take you into the present moment. Remind yourself of the day, date, and time if it's helpful.
- You can then name:
  - 5 things you can see
  - 4 things you can touch/feel
  - 3 things you can hear
  - 2 things you can smell
  - 1 thing you can taste

The body scan exercise:

- This can help relax you to go to sleep or, similarly, grounding during the day/breaks.
- Lie down or recline in a chair or just sit. Take slow breaths, and beginning with your feet, tense the muscles for 10 seconds, then release them for 15 seconds. Work your way up the different muscle groupings of your body.

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Appendix G – Code Table

Category	Theme	Subthemes
A Socially Nullified Existence	Social Invisibility	Uninformed Supports Fear of Outsiders External Messaging Managing External Reactions and Perceptions Failing Protectors
	The Cycle of Silence	Perceived External Judgement Misunderstood Feeling like an Outsider Questionable normality Invalidation Minimisation Resignation Acceptance
	Boxed-in by Shame	Guilt Blame Inequality and fairness Confusion Differing Expectations Embarrassment Bitterness
Shaky Pillars of Growth	Growing through Chaos	Constant Threat Threats of Death Unpredictability Medicinal Unpredictability Violence
	Raised on Defence	Constantly on Guard Sensory Overwhelm Abandonment Powerlessness
	Emotional Turbulence	Anxiety Fear Responsibility Survival Strategies

	Unpredictable Development	Growing Up Instability of Age The Role of Birth Order Hindsight Developing Maturity
	Enduring grief	Anticipatory Grief Future Grief Fleeting Hope Grief for the relationship GOMO - Grief of Missing Out
Yearning for Connection	Siblinghood	Unity Normality Best of Both Worlds
	Need to be Seen	Scholastic Performance Identity Roles Parentification Familial Invisibility Desired Individualism
	Need for Understanding	Language Building Communication Education Inherent Learning
Ingredients for Growth	Protective Factors	Reliable Supports Validation Joyful Moments Power of Connection Parental Relationship Protection Reassurance Coping strategies Intentionality Spirituality Love
	Post Traumatic Growth	Blessed Gratitude Difference through Experience Patience & Understanding Advanced Empathy Professional Impact