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Traumatic Stress Symptoms in Family Caregivers of Adults with Neurodevelopmental Disorders: A Mixed-Methods Inquiry from Singapore

Submitted by

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Thesis submitted under the supervision of

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In fulfilment of the requirements for the degree of

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Psychology

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Statement of the Contribution of Others

The contributions outlined in the table below were crucial to the successful completion of this thesis.

Nature of Assistance	Contributions	Details of Contributions
Supervision	• Support • Guidance • Intellectual input	• Dr. Joanna Barlas • Dr. Divjyot Kaur
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Abstract

This thesis explored the complex and multifaceted experiences of family caregivers of individuals with neurodevelopmental disorders, with a particular focus on posttraumatic stress symptoms (PTSS). Caregiving within this context was often fraught with significant emotional, psychological, and physical challenges, including exposure to aggressive behaviours and other traumatic events. This research, underpinned by a mixed-methods approach, illuminated the intricate dynamics of caregiving, the cultural and societal influences on caregivers, and the coping mechanisms employed to manage the stressors associated with their roles.

The study began with a scoping review (Lim et al., 2024) that synthesized existing literature on PTSS in caregivers of individuals diagnosed with neurodevelopmental, psychiatric and neurocognitive disorders. Although the subsequent research focused on primary family caregivers of adults with neurodevelopmental disorders, the broader scope of the scoping review was necessary and to explore this emerging area and informed the design of the mixed-methods study, highlighting the prevalence of trauma and the subsequent impact on caregiver well-being. Building on these findings, the quantitative component of the research investigated the occurrence of PTSS among primary family caregivers of adults with neurodevelopmental disorders (NDD), the nature of traumatic caregiving events, and the psychological and cognitive processes that influenced the development of trauma symptoms.

The quantitative component of the study found that 11.1% of 45 primary family caregivers of adults with neurodevelopmental disorders met DSM-5 criteria for PTSD. Physical aggression by care recipients was identified as the most significant caregiving event, correlating positively with trauma symptoms. Regression analyses indicated that event rumination and disengagement coping strategies were significant predictors of trauma symptoms. Mediation analysis showed that intrusive cognitions mediated the relationship

between aggressive behaviours and trauma symptoms, while moderation analysis demonstrated that caregiver burden moderated this relationship. Cultural beliefs, however, did not significantly influence the relationship between aggressive behaviours and trauma symptoms. The findings highlight the complex interplay between caregiver experiences, stress responses, and mental well-being in the context of caregiving for adults with NDD.

The qualitative component of the study explored in depth the lived experiences of primary family caregivers who are parents, offering a richer, more nuanced understanding of the challenges faced. Through in-depth interviews with 10 primary family caregivers of adults with neurodevelopmental disorders, the research explored their personal caregiving narratives. These narratives revealed a complex interplay between cultural beliefs, family dynamics, and individual coping strategies. The study emphasized the role of cultural context in shaping caregiving practices, with Singapore's multicultural environment providing a unique backdrop for understanding the diverse experiences of caregivers.

The findings indicated that cultural values and religious beliefs influenced primary family caregivers' perceptions of their roles and their responses to trauma. Cultural norms—such as the emphasis on filial piety in Chinese culture, the belief in karma and fate in Indian culture, and the view of caregiving as a divine test in Islamic teachings—instilled a strong sense of duty and acceptance, which fostered emotional resilience and commitment amidst adversity. Religious practices such as prayer, spiritual reflection, and viewing suffering through a faith-based lens served as coping mechanisms that buffered the emotional toll of caregiving-related trauma. The study also highlighted the cultural stigma surrounding mental illness, particularly in Asian communities, sometimes hindered caregivers from seeking timely professional support, thereby amplifying their psychological burden.

Family dynamics and community support emerged as critical factors in the caregiving experience. The study found that strong family bonds and active community networks

provided essential emotional and practical resources, helping caregivers manage the demands of their roles. Spousal support, in particular, was identified as a pivotal element in sustaining caregivers' mental health and enabling them to balance caregiving with personal well-being.

The analysis of the data specific to PTSS generated several key themes, including the emotional turmoil experienced by caregivers, the constant vigilance and anxiety associated with managing aggressive behaviours, and the coping mechanisms employed to navigate these challenges. The study through participants' qualitative self-reports, uncovered the significant emotional toll of caregiving, with many participants reporting feelings of acute stress reactions, such as intense fear, persistent helplessness, anxiety in response to aggressive behaviours, and frustration. These emotional experiences were compounded by the unpredictability and uncontrollability of aggressive behaviours, which created a pervasive sense of fear and insecurity.

In response to these challenges, caregivers employed a range of coping strategies, including immediate crisis management, communication and negotiation, and adaptation through learning and experience. The study highlighted the importance of these coping mechanisms in helping caregivers maintain their resilience and continue providing care despite the overwhelming demands of their roles.

This research makes a novel contribution to the understanding of PTSS among primary family caregivers of adults with NDD, a topic that remains underexplored, particularly in Asian contexts. By integrating quantitative and qualitative methods, this study offers the first mixed-methods investigation in Singapore examining both the psychological mechanisms (e.g., rumination, disengagement coping, caregiver burden) and lived experiences underlying trauma symptoms in this group. The research revealed that trauma in caregiving is not only a product of individual psychological processes but also deeply shaped by cultural values, familial expectations, and the relational nature of caregiving roles. These

insights advance current trauma theories by demonstrating how socio-cultural dynamics intersect with cognitive processes to shape trauma outcomes in caregivers.

Furthermore, this study proposes an expanded conceptual framework for understanding caregiver trauma by bridging Ehlers and Clark's cognitive model with Carlson and Dalenberg's relational-situational framework. This integrated model captures both the internal and external factors contributing to trauma, offering a more nuanced, culturally attuned perspective of caregiver distress. By identifying specific risk and resilience factors unique to family caregivers of adults with NDD—such as persistent exposure to aggression, culturally driven coping strategies, and the impact of sustained vigilance—this research lays the groundwork for developing tailored, trauma-informed, and culturally sensitive interventions. In doing so, it addresses a significant gap in the literature and informs practice, policy, and future research aimed at supporting this often-overlooked caregiver population.

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Chapter 1

Navigating the Complexities of Caregiving for Individuals with Neurodevelopmental Disorders

Caregiving represents the compassionate act of tending to the needs of those requiring assistance, encompassing a universal role entailing both physical and mental health support (Talley & Montgomery, 2013). This encompassing role extends to the regular care of an ailing child, an elderly individual, or someone with disabilities. Within this context, an informal caregiver refers to an unpaid individual who takes on the responsibility of aiding others with daily activities and/or medical tasks (American Association of Retired Person [AARP], 2015). The bedrock of health and social care often rests upon this informal caregiving, predominantly carried out by family members. As acute and chronic illnesses, injuries, and the process of aging unfold, caregiving assumes a pronounced presence in the lives of caregivers, shaping their experiences profoundly.

The immense influence of caregiving on the lives of caregivers cannot be overstated. Given that these informal caregivers are often family members of the care recipients, it becomes evident that certain facets of their lives are bound to undergo transformation. For instance, family caregivers who are employed may face difficulties balancing their dual roles, which can result in work-related challenges. Alternatively, family caregivers might ultimately decide to step away from their employment, a choice that brings about an income loss (AARP, 2015). The consequences of these scenarios reverberate across healthcare and social domains, imposing additional burdens on an already weighed down system (Family Caregiver Alliance, n.d.). This ripple effect extends to the economic landscape of the nation, with the repercussions of caregiving-induced impacts prompting escalated requirements for health, social, and financial support from governmental entities.

In Singapore, Caregiver Alliance, a recently established non-profit organization supporting family caregivers, recorded 13608 family caregivers in 2019 (Caregiver Alliance, 2019). This record unveiled the predominant caregiver clusters, with the three most prominent groups encompassing those who provide care for individuals grappling with mental health issues. Particularly noteworthy among these groups were family caregivers of individuals diagnosed with conditions like schizophrenia, major depressive disorder, and major anxiety disorder. Notably, within these family caregiver demographics caring for individuals with mental health issues, a subset of 1.7 percent represented family caregivers supporting individuals with neurodevelopmental disorders (NDD).

Neurodevelopmental disorders (NDD) encompass a range of disorders, including Autism Spectrum Disorders (ASD), Down's Syndrome (DS), Prader-Willi Syndrome, and Intellectual Disability (ID). Those bearing the diagnosis of these conditions navigate a landscape of intricate health and psychosocial needs, with a heightened vulnerability to mental health challenges (Allen et al., 2008; Dagnan & Lindsay, 2012; Langstrom et al., 2009; Newman & Ghaziuddin, 2008). This group of individuals grapple with an elevated occurrence of psychiatric and physical comorbidities compared to the general populace (Cawthorpe, 2017; Cooper et al., 2015; Joshi et al., 2010). Adding to the complexity, the challenging behaviours that frequently emerge during childhood often endure well into adulthood (Murphy et al., 2005). Coupled with this, the prevalence of cognitive deficits and linguistic challenges (Underwood et al., 2017) further compounds the negative impact on the adaptive psychosocial functioning of these individuals.

While there is no existing framework specifically tailored to intellectual disability caregiving, the four dimensions of elderly caregiving proposed by Horowitz (1985) may be relevant and adaptable to this context. Caregiving for individuals with neurodevelopmental disorders (NDD) shares similarities with elderly caregiving in terms of care provision, as both

populations require support due to cognitive and adaptive functioning deficits, such as difficulties in understanding and processing information, decision-making, problem-solving abilities, and assistance in daily living activities. These dimensions encompass direct care, involving tasks like dressing assistance and medication management; emotional care, signifying the provision of social bolstering and encouragement; medication care, denoting the negotiation on the care receiver's behalf; and financial care, entailing fiscal resource management. These dimensions may be relevant to the caregiving of individuals with NDD as these individuals present with complex needs that require direct support and engagement. Moreover, both elderly and NDD caregiving involve managing chronic conditions, navigating healthcare systems, and providing ongoing support. The cognitive and adaptive functioning deficits inherent to NDD necessitate similar levels of support and accommodation as those required by older adults with cognitive decline or chronic illnesses.

It is pertinent to note that the responsibilities borne by family caregivers of NDD individuals do not wane with the transition of their care recipients into adulthood (Harrington et al., 2005; Mulvany et al., 2007; Orsmond et al., 2007). This continuous obligation, spanning the lifespan, may often culminate in a sense of being overwhelmed and emotionally drained as family caregivers grapple with the daily hurdles. The realization of the unrelenting nature of caregiving for NDD individuals contributes to this sentiment, where family caregivers are acutely cognizant of the ceaseless care imperative that underscores their role (Mulvany et al., 2007; Orsmond et al., 2007).

Given the intricate nature of the requirements posed by individuals with NDD, family caregivers find themselves contending with a myriad of challenges in the provision of care. The subsequent sections delve into an in-depth exploration of this intricate matrix of needs.

1.1 Complex Caregiving Needs of Individuals with NDD

1.1.1 *Adaptive Functioning*

The amount of support required is contingent upon the individual's unique intellectual and adaptive strengths and challenges, reflecting the diverse needs across the spectrum of adaptive functioning abilities for individuals with NDD, as described by the American Psychiatric Association (2013). For instance, someone with mild intellectual functioning, capable of age-appropriate personal care, might necessitate intermittent aid for complex tasks such as financial matters, healthcare decisions, and legal choices. Conversely, individuals with moderate intellectual functioning may require - extended support to achieve independence in personal care skills, while still necessitating reminders.

For family caregivers, the spectrum of responsibilities can range from providing ongoing daily support to enabling them to complete conceptual tasks of day-to-day life, with some family caregivers fully assuming these responsibilities. Family caregivers aiding those with severe and profound intellectual functioning often find themselves engaged in extensive support, spanning all aspects of daily living, including meals, dressing, and bathing. This comprehensive assistance is necessary due to the limited skill attainment of these individuals. They necessitate constant supervision and are unable to make informed decisions concerning their well-being. Consequently, family caregivers in these scenarios often struggle with stress and fatigue (Orsmond et al., 2007), as the perpetual provision of support across multiple facets of an individual's life – encompassing daily activities, education, work, emotional, and communication realms – becomes a ceaseless obligation.

1.1.2 *Medical and Psychiatric Co-Morbidities*

Navigating caregiving demands stemming from comorbid conditions in NDD presents family caregivers with formidable challenges. These challenges emerge as a result of the intricate interplay between various health concerns and the NDD itself. For instance, common gastrointestinal problems observed in individuals with cerebral palsy, spina bifida, and autism pose multifaceted challenges (Gentile & Bien, 2019). In addition, seizure disorders represent a significant neurological comorbidity within autism spectrum disorders (Tuchman & Cuccaro, 2011; Tuchman et al., 2013). The emergence of such health issues can catalyze or exacerbate behavioral problems, thereby amplifying the complexities faced by family caregivers (Matthews et al., 2008). These comorbid conditions invariably necessitate intricate caregiving responsibilities, ranging from facilitating regular medical appointments to undertaking fundamental nursing and personal care duties. Ensuring adherence to prescribed treatments, as well as maintaining vigilant supervision for individuals at risk of falls, forms another integral part of these caregiving demands.

Furthermore, NDD individuals are susceptible to a spectrum of psychiatric disorders (Matson & Williams, 2014; Pandolfi & Magyar, 2016). The prevalence of mental health issues within this population ranges between 40 percent and 50 percent (Cooper et al., 2007). Notably, psychiatric crises often translate into emergency department visits for these individuals (Lunsky et al., 2012), further underscoring the pressing need for specialist mental health services as advocated by professional bodies like the Royal College of Psychiatrists in the UK (Royal College of Psychiatrists, 1996, 2003).

Singapore's population was estimated to be 5.7 million in 2009 (Ministry of Health, 2020). While local data is not available, insights from other nations suggest an approximate prevalence of 1 percent of the general population with intellectual disabilities, with countries like China reporting a prevalence of 6.68 percent (Jeevanandam, 2009). Extrapolating this, it

can be inferred that around 22,800 to 28,500 individuals in Singapore with NDD might encounter comorbid psychiatric and behavioral issues, thereby potentially requiring access to mental health services at various points in their lives. Mood disorders and anxiety disorders are particularly prevalent among adults with ASD. Depression rates in this population range between 20 percent to 33 percent, while the prevalence of general anxiety disorder stands at 30 percent (Howlin, 2000; Shtayermman, 2007). When coupled with cognitive deficits, individuals with NDD often encounter difficulties in acquiring and employing appropriate skills and strategies to navigate emotional and psychological challenges (Lim, 2020). In this context, caregiver support is not just beneficial, but crucial, as individuals embark on the journey of treatment and recovery.

1.1.3 *Challenging Behaviours*

Alongside the caregiving demands contingent upon varying levels of adaptive functioning in individuals with NDD, family caregivers often find themselves grappling with the complex challenge of managing challenging behaviors. These behaviors are characterized by their intensity, frequency, and duration, to the extent that they significantly impede the individual's safety and social interactions, extending their impact to those around them (Emerson & Einfeld, 2011). The ramifications of challenging behaviors on family caregivers have been extensively studied (Maes et al., 2003; Huang et al., 2014; Griffith et al., 2014), with a reciprocal relationship between caregiver stress levels and challenging behaviors being noted, wherein behavior issues and caregiver stress mutually amplify one another (Lecavalier et al. 2006).

Among the array of challenging behaviors, some common ones include stereotyped behaviors, self-injurious behaviors, and aggression (Sturmey, 2014). Stereotyped behaviors, with their consistent, rigid, and repetitive nature devoid of immediate practical significance,

can be perplexing for caregivers to manage (Vollmer et al., 2014). Conversely, self-injurious behaviors can evoke substantial distress in caregivers (Hastings & Remington, 1994; Oliver & Petty, 2002). The prevalence of such self-injurious behavior is directly correlated with the severity of the individual's intellectual and adaptive impairments (Didden et al., 2012). Recognized as one of the most challenging behaviours to navigate due to its detrimental effects on the well-being and quality of life of individuals with NDD, it's been linked to higher burnout levels, the development of learned helplessness, and emotional exhaustion among caregivers (Snow et al., 2007). Aggressive behaviors encompass both physical acts (targeting people or property) and verbal aggression. In efforts to understand the impact of aggressive behaviors, studies have highlighted the severity and chronicity of behaviour problems in adults with NDD in various community settings. One study revealed a 9.8 percent prevalence of aggressive behaviors, including verbal and physical manifestations directed at individuals and property, among 1023 adults with intellectual disabilities (Cooper et al., 2009). These individuals with NDD had different accommodation and support arrangements, such as living within a family home, with a paid carer, within a group home or living independently. Moreover, high levels of aggressive behaviours were observed in adults with NDD residing in residential settings (Matson & Rivet, 2008), suggesting that some individuals with NDD exhibiting aggressive behaviors within the community context might eventually transition to residential care arrangements.

These aggressive behaviours exact stress upon both caregivers and family members (Benderix & Sivberg, 2007). The toll of aggressive behaviors can be formidable, encompassing disruption, emotional turmoil, and occasionally physical harm (Healy et al., 2014). Research indicates that aggressive behaviors in individuals with NDD correlate with adverse outcomes for family caregivers, such as caregiver burden and compromised mental well-being (Sabapathy et al., 2016; Turnbull & Ruef, 1996; Tyrer et al., 2006; Unwin & Deb,

2011). Owing to the gravity of the situation, challenging behaviors often emerge as primary targets for psychiatric intervention or reasons for moving to residential care when they become overwhelming and distressing for caregivers (Cowley et al., 2005; Grey et al., 2018).

1.1.4 *Aging, Compound Caregiving and Future Planning*

The confluence of aging and the responsibility of familial care for adults with NDD gives rise to multifaceted challenges that pose considerable difficulties for family caregivers who are parents. The aging process can bring about diminishing physical health and overall well-being for these parents. Consequently, they might find themselves unable to provide the level of care required by their adult child with NDD. Instances might arise where physical frailties and the vulnerabilities associated with old age hinder their capacity to offer extensive personal care. Financial support might also become strained due to factors such as loss of employment or retirement (Bowey & McGlaughlin, 2007; Dillenburger & McKerr, 2009; Weeks et al., 2009).

Moreover, the concept of compound caregiving can unexpectedly emerge for certain aging family caregivers, as they become responsible for caring not only for their adult-child with NDD but also for another aging or ill family member. This layering of caregiving responsibilities adds an extra dimension to their existing caregiving duties (Perkins, 2010). In the face of compound caregiving, these individuals may encounter challenges concerning both the additional caregiving role and anxieties about the future well-being of their loved ones. The demand to juggle multiple caregiving roles with limited resources available for support can engender feelings of being overwhelmed, leading to burnout and exhaustion (Perkins & Haley, 2010).

Compounding these challenges are the realities of diminished independence resulting from cognitive and adaptive functioning deficits. Aging family caregivers are acutely

concerned about the dearth of opportunities and services that would enable further education, employment, and financial and physical independence for individuals with NDD (Blacher et al., 2010; Dillenburger & McKerr, 2011). The intricate relationship between cognitive and adaptive impairments often means that individuals with NDD face difficulties in attaining autonomy. For instance, Howlin and colleagues (2004) conducted a follow-up study involving 68 individuals meeting autism criteria and possessing a performance IQ of 50 or above. Their findings showed that many of these individuals remained highly reliant on their families or formal support services. This dependence was correlated with communication challenges, limited reading and writing abilities, and persistent stereotyped behaviors into adulthood. These skill deficits in adulthood for these individuals will in turn perpetuate the dependence they have on their aging family caregivers.

Baumbusch and colleagues (2017) illuminate the unique experience of aging in tandem with caring for an adult-child with NDD. This experience leads to changes in the way family members care for each other and interact with one another, resulting in new patterns of support and relationships within the family. Some aging family caregivers perceive few viable options or solutions, while others bear the conviction that only they can provide the precise care required by their adult-child with NDD. The establishment of a sustainable, long-term care plan for these adults with NDD can suddenly emerge as a pressing concern, given that many family caregivers of adult children with disabilities often lacked such a plan (Herrema et al., 2017). Formulating these future care plans is anything but straightforward, as the advanced care-planning process is enmeshed with the limited understanding of death and dying among adults with NDD (Baumbusch et al., 2017). Additionally, the family's inclination to shield adults with NDD from confronting their caregivers' mortality adds another layer of complexity to the equation (Bigby, 2002; Bowey & McGlaughlin, 2007; Hole et al., 2013).

1.1.5 *Summary of Caregiving Needs*

Individuals with NDD often require varying levels of support due to their unique adaptive functioning abilities. Family caregivers play a crucial role in providing assistance, which can range from intermittent aid for complex tasks to extensive support for daily living activities. The extent of support needed depends on the individual's intellectual and adaptive functioning, with some requiring constant supervision and others needing help with specific tasks.

Family caregivers face numerous challenges, including navigating comorbid medical and psychiatric conditions, managing challenging behaviors, and planning for the future. Aging family caregivers may experience compound caregiving responsibilities, added stress, and concerns about their adult child's independence and well-being. The establishment of sustainable, long-term care plans is essential but often complicated by the limited understanding of death and dying among adults with NDD and the family's inclination to shield them from confronting their caregivers' mortality.

The enduring impact of these challenges underscores the caregiver burden experienced by this specific group of family caregivers. While advocating for appropriate treatment and services for individuals with NDD is crucial, it's equally vital to adopt a comprehensive approach that addresses the mental health and well-being of these family caregivers. It is natural and commendable for family caregivers to prioritize and respond to the needs of adults with NDD to enhance their quality of life. Nonetheless, this journey often spans a lifetime, and caregivers require effective and appropriate support themselves to sustain their commitment and role in the caregiving process. The insights gleaned from the aforementioned literature underscore that family caregivers' experiences are shaped by the unique profiles and needs of the individuals with NDD they support, common themes such as persistent caregiving demands, emotional strain, and long-term commitment are consistently reported

across the literature. Recognising both the diversity and shared aspects of caregiving is essential to developing meaningful, targeted supports. While adopting a person-centered approach is vital for delivering care to individuals with NDD (Horner et al., 1990), the key to ensuring continuous and comprehensive care lies in addressing the gap in targeted support for caregivers' mental health and well-being.

1.2 General Caregiving Impact

The profound influence of the intricate needs of individuals with NDD underscores the substantial challenges inherent in caregiving for this population. Before expanding on how these challenges can lead to negative outcomes for family caregivers, it is worth noting caregiving can also lead to positive outcomes. Research reveals that caregiving can serve as a catalyst for personal growth and resilience among caregivers. In the process of caring for individuals with NDD, family caregivers frequently cultivate novel skills, deepen their understanding of the condition, and gain a sense of fulfillment (Bayat, 2007; Bekhet et al., 2012; Iacob et al., 2020). This journey also tends to foster emotional fortitude, granting family caregivers increased emotional strength as they navigate obstacles and surmount the complexities inherent in caregiving (Bekhet et al., 2012; Iacob et al., 2020). Notably, families with children with autism have been shown to display resilience, citing a sense of increased strength arising from their experiences (Iacob et al., 2020).

Furthermore, caregiving kindles empathy and compassion within family caregivers. For instance, by providing care and support to their children with autism, parents have been reported to develop a heightened sensitivity to their child's unique needs, experiences, and perspectives (Kayfitz et al., 2010). This heightened empathy extends beyond the realm of caregiving, positively impacting their interactions with others. A study conducted by Corman (2009) sheds light on the positive aspects of caregiving experienced by mothers. Many

mothers expressed that caregiving enhanced their empathy and patience, serving as a profound learning and growth opportunity. This journey thus appears to broaden family caregivers' perspectives and deepens their appreciation for the small joys and accomplishments in life (Corman, 2009). The daily struggles and victories witnessed in their children's lives foster a profound sense of fulfillment, driving their commitment to nurturing their children's growth, progress, and overall well-being.

Whilst there is the potential for these positive outcomes to occur when caregiving, family caregivers typically also experience substantial challenges and adverse effects, as caregiving also comes with a set of challenges that can take a toll on the caregiver's physical, emotional, and mental well-being. Family caregivers of adults with NDDs often experience high levels of emotional exhaustion due to the constant demands of caregiving. They may feel overwhelmed, stressed, and emotionally drained from managing their loved one's needs and behaviours (Seymour et al., 2013). The extended duration of care family caregivers provides places significant emotional, physical, and financial demands on caregivers. For example, providing continuous assistance with basic activities of daily living such as bathing, dressing, feeding, and toileting can take a toll on caregivers' physical health. This strain is often linked to increased rates of chronic health conditions, sleep disturbances, fatigue, and compromised immune function (Lovell et al., 2021; Miodrag & Hodapp, 2011; Herrema et al., 2017).

In the study on parenting stress in mothers of adults with intellectual disabilities, the researchers found that parental cognitive variables, such as parenting self-esteem and parental locus of control, significantly predicted parenting stress (Hill & Ross, 2009). Specifically, the study highlighted the impact of emotional exhaustion, physical stress, and psychological stress experienced by mothers of adults with intellectual disabilities. The results indicated that these factors contribute to the overall parenting stress experienced by mothers in this population. Furthermore, behavioural challenges, including aggression and repetitive

behaviours, pose significant hurdles for caregivers, adding to their stress and emotional strain. The perpetual vigilance required by family caregivers to manage such behaviours, coupled with meeting the intricate needs of individuals with NDD, can lead to physical, emotional, and mental exhaustion, ultimately culminating in caregiver burnout (Phelps et al., 2009).

Providing care for an adult with an NDD can be financially demanding, particularly if the family caregiver needs to reduce or quit their job to provide full-time care. Consequently, maintaining full-time employment can be compromised, exacerbating the financial strain resulting from caregiving responsibilities. This financial pressure further contributes to stress and detrimentally affects caregivers' overall financial well-being and quality of life (Hogg et al., 2000; Oti-Boadi, 2017). Financial strain adds another layer of stress and worry for family caregivers, impacting their overall well-being. Additionally, as family caregivers age, planning for the future of their loved ones with NDD presents yet another challenge, necessitating continuous effort and consideration (Nelson Goff et al., 2016).

While advocating for the treatment and services required by individuals with NDD is crucial, an equally imperative approach is to address the mental health and well-being of their family caregivers holistically. While family caregivers endeavor to respond to the needs of adults with NDD for an enhanced quality of life, it is imperative to recognize that this journey is often lifelong. Unlike other caregiving roles that might come to an end as children grow into adults, the responsibility of family caregivers for individuals with NDD often extends throughout the individual's life. Family caregivers must receive appropriate and effective support to ensure their resilience and ability to fulfill their caregiving role. This is particularly critical since the life span of individuals with NDD can extend well into their later years, ushering in a host of challenges related to independence, transition, and long-term care planning (Nelson Goff et al., 2016).

In the trajectory of caregiving, caregivers encounter and grapple with a multitude of challenges. This is compounded by the gradually increasing lifespan of individuals with NDD over recent decades (Coppus, 2013), many of whom continue to reside with their families (Trip et al., 2019). Caregiving for adults with NDD often serves as an extension of parents' previous child-rearing role. Family caregivers, in particular, find themselves in a situation where they are relied upon to maintain this role in whatever capacity they can (Dillenburger & McKerr, 2009). In the United States, for instance, over 75 percent of adults with NDD live at home with their parents, with over 25 percent of these caregivers aged 60 years or older (Braddock et al., 2008).

Comparatively, families of children with NDD experience higher levels of stress and poorer coping mechanisms than families of typically developing children (Hodapp et al., 2001; Sanders & Morgan, 1997). Furthermore, family caregivers of children with ASD tend to experience higher stress levels compared to family caregivers of children with intellectual disability (Dabrowska & Pisula, 2010; Eisenhower et al., 2005; Hodapp et al., 2001). Variations have also emerged between family caregivers of individuals with Down Syndrome (DS) and other NDDs, with parents of children with DS reporting slightly lower stress levels and better coping scores than parents of individuals with other NDDs, such as ASD and Cerebral Palsy (Eisenhower et al., 2005). Collectively, these findings underscore the significant impact of caregiving challenges on family caregivers and the weight of caregiver burden they must shoulder.

1.2.1 *Impact on Mental Health*

The weight of caregiving has profound implications on the caregiving journey, impacting both the family caregivers and the individuals with NDD under their care, and could lead to caregiver burden and stress (Tint & Weiss, 2016). The repercussions of this

burden and stress extend to the realm of mental health, highlighting the critical role of mental well-being in caregiving dynamics (Tint & Weiss, 2016). Notably, mental health challenges appear to be a prevalent issue among family caregivers of individuals with NDD, transcending age groups of the NDD individuals. Commonly reported symptoms include depression and anxiety, which tend to manifest regardless of the NDD individual's age. For instance, studies involving family caregivers of children with NDD highlighted that caregiver burden is a significant predictor of mental health problems where high scores on depression and anxiety were endorsed (Gallagher et al., 2008; Hamlyn-Wright et al., 2007; Scherer et al., 2019), elevating the risk of clinical depression (Bailey et al., 2007). Furthermore, a study investigating the impact of caregiver burden on mental health found that poor mental health among family caregivers of individuals diagnosed with intellectual disability or severe mental illness was associated with greater caregiving challenges and burdens (Sit et al., 2020). Specifically, caregiver burden scores were significantly associated with depression, anxiety and stress among family caregivers. This indicates that the higher the caregiver burden, the greater the likelihood of experiencing mental health issues in this population.

Delving deeper, Falk and colleagues (2014) expanded on these findings, identifying that anxiety correlated with family caregivers' perceived ability to set behavioral limits for their NDD child, whereas depression was linked to the child's aggression towards others. While these observations were framed within the broader context of parenting experiences, the common thread underlying these symptoms appeared to be the perception of limited control. Caregivers often found themselves grappling with the sense of having limited direct influence over their child's well-being and behavior.

In family caregivers of adults with NDD, mental health challenges are similarly prevalent. Family caregivers of adults with NDD have reported experiences of depression, stress, and caregiver burden as direct consequences of their caregiving responsibilities

(Bianco et al., 2009; Neece et al., 2009; Rawson, 2010). Prior investigations into service utilization further revealed a correlation between higher service utilization and elevated levels of maternal burden and stress (McConkey, 2005; Pruchno & McMullen, 2004). The chronic stress associated with caregiving and the ensuing burden have been identified as risk factors for the development of depressive disorders in family caregivers (Lecavalier et al., 2006; Lin, 2011; Tint & Weiss, 2016; Tomeny, 2017). To further elucidate the distinctions between the impact of caregiving on family caregivers of adults with NDD and family caregivers of adults with general mental health disorders, Grootscholten and colleagues (2018) conducted a comparative analysis. Their study examined family caregivers of adults with ASD in contrast to family caregivers of adults diagnosed with depression and schizophrenia. The findings showed that family caregivers of adults with ASD experienced heightened tension and emotional distress. Consequently, these mental health challenges and associated struggles exacerbate the strain on family caregivers' well-being and their capacity to provide effective care.

Caregiver mental health and burden are deeply intertwined, forming a vicious cycle that can have devastating consequences. When family caregivers experience poor mental health, it can exacerbate their burden, making it even more challenging to navigate the complexities of caregiving for individuals with NDD. The emotional toll of caregiving, combined with the stress of managing complex care needs, can lead to anxiety, depression, and other mental health issues. As a result, the burden becomes overwhelming, impeding their ability to effectively manage caregiving responsibilities and provide optimal care. This, in turn, leads to a decline in the quality of life for both the family caregiver and the individual with NDD, further intensifying the caregiver's burden. As family caregivers struggle to meet the diverse needs of individuals with NDD, they may provide suboptimal care, perpetuating a cycle of increasing burden and poor mental health.

Collectively, these studies underscore several significant implications related to the impact of mental health challenges on family caregivers of individuals with NDD. Firstly, they unequivocally establish that heightened levels of parenting stress are intimately intertwined with an increased susceptibility to mental health issues within this family caregiver group. Secondly, a noteworthy observation is the pervasive nature of mental health problems within this caregiving demographic, spanning across diverse age brackets of family caregivers for individuals with NDD. Family caregivers of individuals with NDD face a multitude of challenges that can vary depending on the specific neurodevelopmental condition of the person they are caring for. However, one universal concern that frequently emerges among these family caregivers is the occurrence of challenging behaviours in individuals with NDD. These behaviours come in diverse forms and can range from aggression, self-injury, disruptive conduct, and non-compliance (Mudford et al., 2008). The manifestation of such behaviours can be particularly distressing for family caregivers, prompting them to seek treatment and support. Studies have consistently shown that the burden of caring for someone with NDD can be substantial, and the presence of challenging behaviours exacerbates this burden (Vogan et al, 2014; Yıldız et al., 2021). The repercussions are far-reaching, affecting not only the individual with NDD but also those responsible for their care. These challenging behaviors manifest in various forms and have been correlated with significant impacts on caregivers' mental health and overall well-being (Barker et al., 2011).

Given that aggressive behaviours include violence towards others and destruction to property, psychiatric or medical services are often sought for by family caregivers of individuals with NDD. For instance, Lunsky and colleagues (2011) investigated the experiences of individuals with NDD and their families in emergency departments, found that thirty-nine percent of these visits involved crises characterized by physical aggression. One of the significant findings of their study was the higher likelihood of aggressive behaviours

among individuals with NDD leading to hospitalization. The decision to admit a patient with intellectual disabilities following an episode of physical aggression may be influenced by various factors, including the severity of the aggression, patient characteristics, caregiver burnout, and hospital-based variables (Lunsky et al., 2011). This discovery illuminated a critical aspect of caregiving for individuals with NDD. It indicated that, in some cases, family caregivers may not possess the necessary tools, resources, or support to effectively manage and address aggressive behaviours within the home environment. Aggressive behaviours can manifest in various forms, posing risks to both the individual with NDD and those around them. This finding carries important implications, particularly for adults with NDD who exhibit aggression.

Thirdly, it is imperative to acknowledge that the trials faced by family caregivers of individuals with NDD are distinct from those encountered by caregivers in other contexts. The mounting evidence in the field of caregiving for individuals with challenging behaviours especially those with NDD, unequivocally establishes that these challenging behaviors intersect with caregiver burden, caregiver stress, and caregiver mental health concerns. While existing literature has predominantly focused on stress, depression, and anxiety as outcomes, the possible implications of traumatic experiences due to aggressive behaviors warrant exploration. As a consequence, the prospect of caregiver traumatization emerges as an additional and critical mental health concern. The general PTSD literature identifies being a victim of aggression as a risk factor for development PTSD (Gillikin et al., 2016). Just as victims of aggression in other contexts can experience lasting psychological trauma, family caregivers who are frequently exposed to aggressive behaviours may also face similar risks. Family caregivers of individuals with NDD who display aggressive behaviours may find themselves in situations that are not only emotionally taxing but also be potentially traumatic.

There is a possibility that prolonged exposure to these challenging behaviours can lead to the development of posttraumatic stress symptoms (PTSS).

While the connection between caregiving stress, burden, and conditions like depression and anxiety is well-established, the potential also exists for these stressors to contribute to a broader spectrum of mental health challenges. This holds particularly true for family caregivers of adults with NDD who grapple with multiple and complex needs in adulthood. Given that the manifestation of depression and anxiety symptoms aligns with other psychiatric disorders, such as trauma and stressor-related disorders—where psychological distress follows exposure to traumatic or stressful events (APA, 2013)—the door opens to the possibility of family caregivers experiencing posttraumatic stress symptoms (PTSS). Consequently, there remains room for further exploration into the extent of mental health problems among family caregivers, as some avenues within this intricate landscape may have yet to be fully investigated.

1.3 Cultural Influences on Caregiving

In many societies, cultural beliefs and values play a crucial role in shaping family caregivers' experiences, influencing their roles, responsibilities, and their perceptions of and approaches to caregiving. Understanding these cultural factors is essential to fully grasp their impact on caregiving for individuals with NDD. Caregiving within a cultural context goes beyond providing practical support; it embodies deeply rooted expectations, values, and social structures. For instance, some cultures emphasize caregiving as a shared family responsibility that strengthens family cohesion, while others view it as an individual obligation, potentially increasing isolation and stress (Scharlach et al., 2006).

Cultural beliefs can significantly influence family caregivers' decisions to seek mental health support for the behavioural and mental health needs of the individuals they care for,

particularly in collectivist societies. In these communities, caregiving is often seen as a familial or communal duty, and managing mental health challenges within the family is preferred over seeking support from external services. Perceptions of caregiving differ across cultures, with individuals from more collectivist societies often endorsing family care as a natural and essential duty (Fenton & Sadiq, 1993; Willis, 2012). In these collectivist contexts, family is central to daily life, and the community is frequently regarded as an extension of the family unit (Choudhry, 2001; Ibrahim et al., 1997). Cultural norms and expectations place high value on family honour and duty, and accepting outside help may be seen as a failure to fulfill these responsibilities, particularly in South Asian cultures (Dilworth-Anderson, 2002). In these communities, caregiving is often perceived as both a social and religious obligation (Adamson & Donovan, 2005; Lawrence et al., 2008; Steiner & Bansil, 1989; Willis, 2012). Seeking professional assistance, however, may be viewed as falling short of one's responsibilities (Lawrence et al., 2008), adding complexity to caregiving in these cultural settings.

Cultural norms and gender roles significantly influence caregiving responsibilities across different ethnic groups. In many cultures, caregiving is seen as a primarily female role, with women often expected to take on the main tasks of direct, personal care (Dilworth-Anderson, 2002). Furthermore, it was found that cultural values such as filial piety in Asian families emphasize familial responsibility, shaping expectations around who should provide care and often reinforcing traditional gender roles (Dilworth-Anderson, 2002). These insights underscore that cultural values and gender expectations not only determine who provides care but also influence the emotional and social dimensions of caregiving. This dynamic can affect family caregivers' well-being differently based on gender and the cultural support systems available to them, adding another layer to the complex experience of caregiving in a cultural context.

Family caregivers' beliefs and attitudes toward disability, their caregiving practices, and the emotional toll of caregiving are shaped by cultural frameworks that dictate what is expected of family members in times of need. Culture provides a lens through which family caregivers interpret the challenges they face, assign meaning to caregiving tasks, and develop strategies to cope with the demands of caregiving. For example, perceptions of NDD vary significantly across cultures; some view developmental differences as part of the natural human spectrum, while others regard them as deviations that require intervention (Norbury & Sparks, 2013). These beliefs influence whether families seek a diagnosis or support services. In societies where NDD is stigmatized, often attributed to parental faults or supernatural causes, families may avoid seeking help due to fear of shame, social isolation, or damage to family reputation (Norbury & Sparks, 2013). Such stigmatization can have profound psychological effects on both individuals with NDD and their family caregivers, often leading to social withdrawal and reluctance to access support services, thereby increasing the emotional strain on families. Additionally, cultural norms around behaviours—such as eye contact—may affect how symptoms of NDD are perceived; in some societies, these behaviours are seen not as symptoms but as natural variations, which can further influence caregivers' approaches to seeking or providing care (Norbury & Sparks, 2013).

Examining specific cultural contexts further illustrates these dynamics. In South Korea, for instance, a diagnosis of autism is often accompanied by societal stigma that extends beyond the individual to the entire family. Autism is not only seen as a cognitive impairment but is also viewed as a reflection on the family's reputation, leading to feelings of shame and embarrassment (Ecker, 2010). This perception reinforces social stigma, leading to judgment and discrimination against families, as autism is often seen as a defect that diminishes the family's reputation (Ecker, 2010). Such cultural pressures can intensify family caregivers' emotional burdens and limit their willingness to seek community support.

Similarly, in traditional Chinese culture, Confucian and Buddhist beliefs around fate, karma, and family honour influence how disabilities are viewed. Disabilities may be interpreted as a consequence of ancestral transgressions or as a failure to honour family traditions (Chan & Lee, 2004; Deng et al., 2001; McCabe, 2007). Some may view disabilities as a reflection of past wrongdoings or as a source of shame for the family, leading to social isolation and marginalization of individuals with disabilities (Lu, 2008). Families may view the presence of disability as a family secret that must be concealed to avoid dishonour. Consequently, family caregivers may find themselves isolated from their communities, coping with the dual burden of caregiving and cultural stigma. Research shows that some families, driven by beliefs in fate or karma, may even attribute a disability to divine punishment, leading to profound feelings of guilt and responsibility (Huang et al., 2010).

In Malaysia, family caregivers of children with autism reported that cultural beliefs and societal prejudice have detrimental effects on their well-being. A qualitative study found that some family caregivers were accused of causing their child's condition due to perceived past transgressions, such as spirit possession (Ilias et al., 2019). This type of cultural stigma reinforces isolation and places additional emotional stress on family caregivers, as they may feel judged and unsupported within their communities.

These examples illustrate that cultural beliefs do not merely inform family caregivers' attitudes but actively shape their experiences of caregiving, impacting how they cope with stress and how they are perceived and supported by others. In some cultures, caregiving is seen as an honourable family duty, fostering a collective approach to care. In others, family caregivers face considerable stigma and isolation, which can exacerbate the challenges of caregiving. Cultural beliefs about illness and disability also influence family caregivers' emotional responses and coping strategies, with some families finding strength in their

cultural values, while others may experience heightened distress due to cultural stigmatization.

Understanding cultural context is therefore essential for developing effective, culturally sensitive interventions and support systems that address the unique challenges faced by family caregivers in multicultural settings. By recognizing how cultural norms, values, and expectations shape the caregiving experience, practitioners and policymakers can create support structures that are both empathetic and relevant, helping family caregivers feel understood and supported within their cultural frameworks. This approach promotes holistic care by addressing not only the practical needs of family caregivers but also their emotional and social well-being in a culturally informed manner.

1.4 Chapter Conclusion

Navigating the intricate landscape of caregiving for individuals with NDD presents caregivers with persistent and often overwhelming challenges that are distinct from typical parenting experiences. The demands of caregiving can exact a toll on the physical, emotional, and financial well-being of family caregivers. However, research highlights that caregiving can also be a crucible for developing novel skills, deepening understanding, and fostering emotional resilience among caregivers. Moreover, caregiving kindles empathy and compassion, enhancing family caregivers' capacity to connect not only with their loved ones but also with others. These positive outcomes illustrate caregiving as a transformative experience, enriching the lives of family caregivers in profound ways.

The increasing life expectancy of individuals with NDD (Coppus, 2013) and their continued residence with family members (Trip et al., 2019) underscore the urgent need for a deeper understanding of caregiving's impact, particularly within diverse racial and ethnic groups. This understanding must encompass the coping mechanisms employed by family

caregivers as they navigate challenging caregiving events. The role of culture in caregiving for individuals with neurodevelopmental disabilities cannot be overstated. Cultural beliefs and practices profoundly shape family caregivers' experiences, influencing their perceptions, emotional responses, and the level of support they receive from their communities. Examples from South Korea, traditional Chinese culture, and Malaysia demonstrate how cultural stigma and societal prejudices can significantly impact family caregivers, often leading to isolation and increased stress. Therefore, understanding these cultural dimensions is essential for developing effective support systems and interventions.

Despite the positive aspects of caregiving, addressing the substantial challenges and adverse effects that caregivers inevitably encounter is imperative. The burden of caregiving, compounded by the perpetual vigilance required to manage the complex needs of individuals with NDD, can exact a heavy toll on family caregivers' mental health and well-being. Depression, anxiety, and caregiver burden are prevalent, forming a vicious cycle that exacerbates the challenges of caregiving and diminishes the quality of life for both family caregivers and their loved ones. Recognizing the distinct nature of caregiving stressors and their implications for mental health underscores the urgent need for holistic support systems tailored to the unique needs of family caregivers in this population. Addressing the mental health and well-being of family caregivers is essential not only for their resilience but also for ensuring optimal care and quality of life for individuals with NDD.

Studies reviewed highlight several significant implications related to the mental health challenges faced by caregivers of individuals with NDD. Firstly, they establish a clear link between heightened levels of caregiving stress and increased susceptibility to mental health issues within this group. Secondly, they reveal the pervasive nature of mental health problems among family caregivers, affecting individuals across various age brackets. A common concern is the occurrence of challenging behaviours in individuals with NDD, such as

aggression, self-injury, and non-compliance, which can exacerbate the burden on caregivers. These behaviours often lead family caregivers to seek psychiatric or medical services, as managing aggressive behaviours within the home can be particularly difficult. The impact of these challenging behaviours extends beyond the individual with NDD, significantly affecting family caregivers' mental health and overall well-being. The literature also suggests that the traumatic experiences associated with aggressive behaviours can lead to the development of posttraumatic stress symptoms (PTSS) in family caregivers. While the connection between caregiving stress, burden, and mental health issues like depression and anxiety is well-documented, there is a need for further exploration into the broader spectrum of mental health challenges faced by family caregivers, particularly in relation to trauma and stressor-related disorders. This underscores the importance of developing holistic support systems tailored to the unique needs of caregivers of individuals with NDD.

Consequently, a scoping review approach becomes evident as an effective means to gain insight into the existing research landscape of PTSS in family caregivers. The next chapter, consisting of a scoping review, aims to holistically survey and illuminate the extant landscape of investigation. The primary goal of this scoping review is to systematically map out the present state of evidence, clarify key themes, and identify notable gaps in research pertaining to PTSS experienced by family caregivers responsible for individuals with neurodevelopmental, neurocognitive, and psychiatric disorders, regardless of whether these individuals are children or adults. This broader scope is intentional and necessary, as PTSS in family caregivers remains a relatively underexplored area. By capturing a wider range of caregiving contexts, the review will help establish a more comprehensive understanding of the field, which in turn to help the design and focus of the subsequent mixed-methods study. This research however will narrow its scope to family caregivers of individuals with NDD to allow for a more targeted investigation of trauma-related experiences within a specific

population. This approach will help pave the way for a deeper understanding of the challenges faced by family caregivers of individuals with NDD and the potential avenues for future research in this important area.

Chapter 2

A Scoping Review Exploring Post-Traumatic Stress Symptoms in Caregivers of Individuals with Neurodevelopmental, Psychiatric and Neurocognitive Disorders

This scoping review aims to explore post-traumatic stress symptoms (PTSS) experienced by caregivers of individuals with neurodevelopmental, psychiatric, and neurocognitive disorders. While the impact of caregiving on mental health has often been examined through the lens of caregiver stress and burden, less attention has been given to trauma-related responses in caregivers. This review seeks to address this gap by mapping the existing literature on PTSS among caregivers, identifying the key factors contributing to trauma, and highlighting areas for future research and intervention. By synthesizing evidence from studies conducted between 2005 and 2022, this review provides an in-depth understanding of how caregiving for these populations may lead to significant psychological distress, including PTSS. The findings aim to inform both clinical practice and policy, offering insights into the complexities of caregiver trauma and the need for targeted support.

2.1 Publication Status

This Scoping review was published in the journal of Trauma, Violence, and Abuse in April 2024 (DOI:10.1177/15248380241241018). This chapter includes the published version of the scoping review, with formatting adjustments made to ensure consistency with the rest of the thesis.

2.2 Manuscript

2.2.1 *Abstract*

The impact of caregiving on caregivers' mental health is typically considered within the caregiver stress and burden literature, however more recently research has investigated the experience of post-traumatic stress symptoms (PTSS) in caregivers. As an emerging area of research, it is timely to conduct to a scoping review to map the existing literature in relation to PTSS amongst adult caregivers of children and adults with neurodevelopmental (NDD), neurocognitive, and psychiatric disorders. The scoping review was conducted using PRISMA-ScR guidelines and Arksey & O'Malley's (2005) five-stage methodology framework. Published and unpublished grey literature between 2005 and 2022 was included in the scoping review. 9125 studies were originally identified for screening and 22 studies were selected for inclusion in the final review. Trauma and PTSS experienced by NDD caregivers were related to news breaking, NDD diagnosis, and behavioral issues, whereas caregivers of individuals with psychosis reported aggression and violence as traumatic events. Studies showed that up to half of caregivers reported PTSS, although no conclusions could be drawn about prevalence rates. A wide variety of tools measuring PTSS were used across the 22 studies. Many symptoms of PTSS were reported by caregivers and cognitive appraisals were associated with PTSS in caregivers. The findings highlight the importance of recognizing the impact of trauma in caregiver mental health and the potential value of using traumatic stress frameworks with these populations. Research should be expanded to establish prevalence rates and to examine the long-term impact of trauma on caregiving as caregivers and care recipients age.

2.3 Introduction

2.3.1 *Posttraumatic Stress Symptoms and Caregiving*

Post-traumatic stress disorder (PTSD), as outlined in the DSM-5, emerges following exposure to a traumatic event. Essential criteria encompass exposure to a traumatic event, intrusive thoughts or memories, avoidance of trauma-related stimuli, negative shifts in mood and beliefs, heightened arousal and reactivity, along with functional impairment persisting for at least one month. Post-traumatic stress symptoms (PTSS) refer to a cluster of trauma-related symptoms that can arise following exposure to a distressing or life-threatening event. While they do not necessarily meet the full diagnostic criteria for Post-Traumatic Stress Disorder (PTSD) as defined in DSM-5, PTSS typically include intrusive re-experiencing (e.g., flashbacks, nightmares), avoidance of trauma-related stimuli, emotional numbing, and heightened arousal (APA, 2013). These symptoms significantly affect daily activities, relationships, and overall functioning. The key distinction between PTSS and PTSD lies in the severity, duration, and functional impairment of symptoms—PTSD requires symptoms to persist for more than one month and to cause significant distress or impairment (APA, 2013).

Research on post-traumatic stress has primarily focused on military veterans (Conard & Sauls, 2014; Kitchiner et al., 2012) and victims of interpersonal violence (Dutton et al., 2006; Lagdon et al., 2014), but medical illnesses have also been examined. For example, one study expanded the conceptualization of traumatic events in the context of caregiving by utilizing a post-traumatic stress model to investigate the psychological effects on parents who care for children with cancer (Stuber et al., 1998). Findings indicated that parents experienced more severe post-trauma symptoms than the children with cancer, revealing the significant toll of caregiving-related stress. By employing a post-traumatic stress model, such studies recognize and highlight the profound impact of ongoing stressors, such as repeatedly witnessing a child's suffering and fearing their loss, on caregivers. This nuanced approach

broadens the lens of traumatic events beyond traditional PTSD criteria and, arguably, provides a valuable framework for understanding the complexities of ongoing distress experienced by caregivers. Furthermore, the post-traumatic stress model employed in this study not only facilitated the comprehension of ongoing distress but also presented practical implications for supporting these parents (Ehlers & Clark, 2000).

The current scoping review focused on understanding whether post-traumatic stress symptoms exist in other groups of caregivers. Caregivers of individuals with mental health disorders (i.e. neurodevelopmental, psychiatric, and neurocognitive disorders) have typically been studied within a caregiver burden framework (Cadman et al., 2012; Koujalgi et al., 2021; Lethin et al., 2020; Marsack-Topolewski et al., 2019; Murphy et al., 2018; Zoladl et al., 2020). However, given that caregiving for this population can often include being exposed to distressing events (Ferriter & Huband, 2003; Giffin, 2008) and challenging (Ekdahl et al., 2011; Lecavalier et al. 2006; Reichhart & Kissling, 2010) or aggressive behaviour (Cooper et al., 2009; Healy et al., 2014; Lauber et al., 2003; Steadman et al., 1998), it is suggested that a post-traumatic stress model may be useful in expanding our understanding of the needs of these caregivers given that PTSS arise from exposure to traumatic events Whether or not these distressing experiences within caregiving would meet the DSM-5 definition of Criterion A is an ongoing debate in the literature (e.g. Hyland et al., 2021; Marx et al., 2023) and is not addressed by the current review. Similarly, whilst there are threshold differences between PTSD and PTSS, the aim of this scoping review was to consider post-traumatic stress using as broad a lens as possible rather than delineate by severity.

2.4 Health and Well-being of Caregivers

Extensive research has focused on caregiver experience and burden across various care recipient populations. Caregivers' general health tends to decline, especially for those providing care over extended periods (American Association of Retired Person, 2015; Northouse et al., 2000; Raveis et al., 1998). Studies consistently show that caregiver distress increases as responsibilities grow or change, with high levels of burden, distress, and role strain (Berg-Weger et al., 2000; Seltzer & Li, 2000). Comparisons with the general population indicate elevated self-reported stress, psychological distress, and various negative emotions among caregivers (Li & Loke, 2013a; Nijboer et al., 2001; Weitzner et al., 1997).

The profound influence of caregiving on the lives of caregivers cannot be overstated. Given that these informal caregivers are often family members of the care recipients, it becomes evident that certain facets of their lives are bound to undergo transformation. For instance, scenarios may unfold wherein family caregivers who are also engaged in paid employment grapple with challenges linked to their dual roles, potentially leading to work-related complexities. Alternatively, caregivers might ultimately decide to step away from their employment, a choice that brings about income loss (American Association of Retired Person, [AARP], 2015). Caring for individuals with specific needs or health conditions often entails significant costs, including medical expenses, specialized care, and alterations to living arrangements. These financial burdens can lead to diminished economic stability, impacting the caregiver's quality of life and restricting access to resources essential for both the caregiver and the recipient of care (Ten Hoopen et al., 2020). The consequences of these scenarios reverberate across healthcare and social domains, inflicting additional burdens on an already burdened system (Family Caregiver Alliance, n.d.). Beyond the financial aspect, the burden on caregivers deeply influences social dynamics. Caregivers often encounter challenges in maintaining personal relationships, pursuing careers, and engaging in social

activities (AARP, 2015; Robison et al., 2009). This burden can result in social isolation, mental health issues, and a decline in overall well-being, affecting not only the caregiver but also the broader community (Robison et al., 2009).

Extensive research has also examined caregiver burden in various caregiving groups, including dementia (Alltag et al., 2019; Chiao et al., 2015;), psychiatric conditions (Beentjes et al., 2012; Möller-Leimkühler & Wiesheu, 2012), and neurodevelopmental disorders (NDD) (Grootscholten et al., 2018; Marsack-Topolewski & Church, 2019). Caregivers in these groups face mental health challenges such as stress, anxiety (Kuusikko-Gauffin et al., 2013;), depression (Falk et al., 2014; Grootscholten et al., 2018), and poor physical health (Herrema et al. 2017; Smith et al. 2010). Recognizing this broad impact is crucial, emphasizing the need for supporting caregivers to safeguard their health and well-being.

Furthermore, caregiving may involve exposure to distressing events, including violence or hostility from the care recipient (Beentjes et al., 2012; Grootscholten et al., 2018; Kuusikko-Gauffin et al., 2013). Understanding the impact of these events is crucial, as it may lead to PTSS in caregivers, which can negatively affect caregivers' mental health, overall well-being, and the quality of care they provide. However, literature on post-traumatic stress in caregiving is limited. Understanding and addressing the challenges faced by caregivers are crucial for several reasons. Firstly, it impacts a significant segment of the population, potentially affecting anyone who may assume a caregiver role. Secondly, the well-being of caregivers directly correlates with the quality of care provided to those they care for (Litzelman, 2019; Ten Hoopen et al., 2020). Neglecting the challenges faced by caregivers can create a cascading impact, compromising the care received by vulnerable individuals.

2.4.1 *PTSS in Caregivers*

In recent years, research has started exploring impact of trauma on caregivers and the occurrence of PTSS among them. An initial literature search yielded three studies on PTSS among caregivers of individuals with psychosis (Boye & Malt, 2002; Kingston et al., 2016; Loughland et al., 2009), one study on caregivers of individuals with NDD (Casey et al., 2012) and one study on mothers of individuals with NDD (Stewart et al., 2020).

Given the psychological distress faced by caregivers of individuals with neurodevelopmental, psychiatric and neurocognitive disorders, coupled with exposure to stressful events, PTSS is likely to be relevant to many caregivers (Boye & Malt, 2002; Casey et al., 2012; Kingston et al., 2016; Loughland et al., 2009; Stewart et al., 2020). As this is a relatively new area of investigation, a scoping review was conducted. The purpose of this scoping review was to map the existing research and uncover gaps in our understanding of PTSS in caregivers of individuals with these disorders. By mapping out the experience of PTSS in caregivers, this scoping review aims to shed light on the urgency of addressing the multifaceted challenges and consequences faced by caregivers experiencing trauma. PTSS, stemming from various traumatic experiences, manifests not only as psychological distress but may also engender a cascade of repercussions across personal, societal, and healthcare domains. Understanding the implications of PTSS becomes imperative for several reasons.

Primarily, PTSS significantly impact an individual's mental and emotional well-being, often leading to severe distress, disrupted daily functioning, and diminished quality of life. Beyond the personal sphere, untreated PTSS can permeate into social dynamics, straining relationships, hindering social integration, and contributing to heightened stress within communities (Howgego et al., 2005). It is hypothesized that caregivers supporting individuals with neurodevelopmental, psychiatric, and neurocognitive disorders may exhibit a noteworthy presence of PTSS. The hypothesis posits that the unique challenges associated with caring for

individuals with these disorders may contribute to heightened stress levels, resulting in the manifestation of PTSS. The aim of this scoping review is to map out the breadth and depth of PTSS implications across various facets of life. This comprehensive understanding can serve as a catalyst for prioritizing interventions, policies, and support systems aimed at early identification, intervention, and holistic care for individuals grappling with PTSS. Addressing PTSS not only improves individual outcomes but also fosters a more resilient and supportive societal framework, emphasizing the critical importance of a proactive and inclusive approach toward mental health care.

2.5 Methods

2.5.1 *Current Review*

Scoping reviews aim to synthesize research by reviewing, assessing, and reporting evidence in less extensively reviewed research areas (Khalil, et al., 2016) to clarify complex concepts, identify gaps in the existing literature, inform practice, and refine future research (Arksey & O'Malley, 2005).

Following the Preferred Reporting Items of Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guideline, the purpose of the current scoping review was to (a) summarize current conceptualizations of post-traumatic stress symptoms amongst the caregivers in the literature, (b) synthesize key findings, and (c) highlight gaps and limitations in the extant literature. A scoping review protocol based on Arksey & O'Malley's five-stage methodology framework was developed by the authors and published in the British Medical Journal (Lim et al., 2022). The stages of the scoping review as outlined in the protocol are presented below.

2.5.2 *Stage 1: Identifying the Research Question*

Through consultation with the research team, an iterative process was followed in refining the research question, as the scope of the literature was unknown. The scoping review question and search terms were refined as familiarity with the literature was gained. The scoping review question was then formulated using the population, interest, and context (PICo) framework (Table 1). This framework helps to create a logical search strategy by identifying key elements of the research question, and translating them into search concepts that can be applied in a structured search strategy (Stern et al., 2014).

The population was identified as the informal caregivers who provide care to individuals with neurodevelopmental, psychiatric, or neurocognitive disorders. The interest in

the PICo was to identify articles that conducted quantitative or qualitative research exploring, investigating, and examining post-traumatic stress symptoms (PTSS), trauma symptoms, or post-traumatic stress disorder (PTSD), among these caregivers.

The scoping review encompassed various study designs, both experimental (e.g., randomized controlled trials, before and after studies) and observational (e.g., cohort studies, case-control studies, cross-sectional studies). Qualitative studies (phenomenology, grounded theory, ethnography, etc.) and descriptive studies (case series, individual case reports, cross-sectional) were also included in the review. Lastly, the main focus of the review was on caregivers providing care to individuals with specific disorders: neurodevelopmental, psychiatric, or neurocognitive. Based on these considerations, the overall main scoping review question was formulated as: “What is known about the occurrence, causes, and other factors associated with traumatic stress symptoms among caregivers of individuals with neurodevelopmental, psychiatric, or neurocognitive disorders?”

Table 1

PICo Framework for Eligibility of Study

Criteria	Determinants
P – Population	- Participants of the study involve informal caregivers who provide care to individuals with neurodevelopmental, psychiatric, or neurocognitive disorders.
I – Interest / Concept	- The article explores/investigates/examines post-traumatic stress symptoms, trauma symptoms, or PTSD, in these caregivers. - The article reports qualitative or quantitative primary data about post-traumatic stress symptoms (PTSS), trauma symptoms, and PTSD in these caregivers
Co – Context	- Caregivers must be providing caregiving to individuals with neurodevelopmental, psychiatric, or neurocognitive disorders.

2.5.3 *Stage 2: Identifying Relevant Studies*

A comprehensive search was conducted in various electronic databases, such as CINAHL, SCOPUS, PsychInfo, OVID PubMed, ProQuest Dissertation, and Thesis Global, for both published and unpublished grey literature. The search strategy was customized for each database, utilizing specific keywords and index terms. Additionally, reference lists from the included studies were manually reviewed to identify any additional relevant research. The original search was conducted in September 2020 and an updated search, using the same search terms in the same databases, was conducted in May 2023. Four articles were then added into the review after going through the same screening stages.

Search terms were determined with input from the research team. An experienced research librarian contributed to the development of the search strategy, which was refined based on the research team's feedback. The search strategy is shown in Appendix A. The search utilized terms as both keywords in the title/abstract and subject headings, following the requirements of each database. Studies published between 2005 and May 20223 were considered due to the scoping review's emphasis on recent research in this emerging caregiver

area. Moreover, to the best of the research team's knowledge, very few studies have been conducted before this period. The search results were managed using Endnote 20 software, which helped identify and eliminate duplicates. Subsequently, Abstrackr (Wallace et al., 2012) was employed in the review screening process during Stage 3.

2.5.4 *Stage 3: Study Selection*

The PRISMA-ScR checklist was used to guide the selection process of eligible studies (Moher et al., 2009). As presented in Figure 1, the literature search yielded 9125 potential studies. The review process consisted of two stages of screening: (1) a title and abstract review and (2) a full-text review. During the first stage, two experienced reviewers (a clinical psychologist with 13 years of experience and a psychiatrist with six years of experience) independently screened the title and abstract of the first 100 search results using the abstract screening tool (Appendix B) in Abstrackr (Wallace et al., 2012). No conflicting ratings were identified, leading to no changes in the abstract screening tool.

In the full-text review, studies relevant to the research met the following criteria: they were written in English; focused on informal/unpaid primary caregivers responsible for the majority of care for individuals with neurodevelopmental, psychiatric, or neurocognitive disorders; investigated post-traumatic stress symptoms (PTSS), trauma symptoms, or PTSD in these caregivers; and reported qualitative or quantitative primary data about PTSS, trauma symptoms, or PTSD in these caregivers. As this was a scoping review the aim was to be as inclusive as possible and hence, we did not have strict criteria for what constituted PTSD/PTSS; i.e., we included self-reported symptoms of PTSS/PTSD.

Studies excluded from consideration had the following characteristics: they were not written in English, involved professional/paid caregivers, reviewed secondary data on PTSS, trauma symptoms, or PTSD in caregivers, exclusively focused on post-traumatic growth in

caregivers, or pertained to caregiving for individuals with medical illnesses or premature infants. At the conclusion of the first stage of screening, 128 studies were deemed eligible for further full-text screening (refer to Figure 1 for details). In the second stage of the screening, each of the two reviewers independently assessed the full-text articles to determine whether the inclusion/exclusion criteria were met. No full-text articles with conflicting ratings were identified, and 22 full-text articles were included in the final review.

2.5.5 *Stage 4: Extracting and Charting the Data*

The research question guided the data extraction and charting process. As this is a scoping review, no quality appraisal was conducted. The term "charting" refers to the process of sorting and analyzing qualitative data by sifting and sorting it according to key topics and themes (Ritchie & Spencer, 1994). To ensure rigor in the search, screening, inclusion, and data charting, two reviewers participated in Stages 3 and 4. As reported in Table 2, 22 studies were included and each study was independently charted based on the following key information:

1. Author(s)
2. Years of publication
3. Title of study
4. Aim(s) / purpose
5. Study population and sample size
6. Country
7. Study design

The reviewers used the research question to develop a matrix that included selected studies' characteristics, and the relevant content of the research findings. The reviewers

independently charted the data for the included studies according to the matrix before discussion and consensus.

Table 2

Overview of Included Studies in Reverse Chronological Order (n = 22)

Neurodevelopmental Disorders						
Author(s)	**Year of publication**	**Title of study**	**Aim(s) / purpose**	**Study population and sample size**	**Country**	**Study design**
Baker et al.	2021	A survey of complex trauma in families who have children and adults who have a learning disability and/or autism	To explore the experiences of and support needs of the families of children and adults who have a learning disability and/or are autistic from a trauma-informed perspective	214 caregivers Mothers = 186 Fathers = 7 Sibling = 15 Relatives = 7 Others = 9 Age not specified	UK	Quantitative survey study
Stewart et al.	2020	Challenging child behaviours positively predict symptoms of posttraumatic stress disorder in parents of children with autism spectrum disorder (ASD) and rare diseases	To investigate whether a traumatic stress framework can be utilised to understand the elevated stress in parents of children who exhibit challenging behaviours, and in parents of children with ASD and rare diseases.	395 caregivers 226 caregivers of ASD children Females = 219 Males = 7 Mean age = 42.2 years old (SD = 6.3) 139 caregivers of children with rare disease Females = 131 Males = 8 Mean age =42.3 years old (SD = 6.7) 30 caregivers of neurotypical children Females = 29 Males = 1 Mean age =39.9 years old (SD = 5)	Australia	Quantitative survey study

Schnabel et al.	2020	An Initial Examination of Post-Traumatic Stress Disorder in Mothers of Children with Autism Spectrum Disorder: Challenging Child Behaviors as Criterion A Traumatic Stressors	To explore the relevance of a trauma-based diagnostic framework to a sample of 30 mothers of children with ASD.	30 female caregivers Mean age = 42.97 years old (SD = 5.82)	Australia	Qualitative interview study
Kielb et al.	2019	Posttraumatic Stress Symptoms and Posttraumatic Growth in Mothers of Children with Intellectual Disability – The Role of Intrusive and Deliberate Ruminations: A Preliminary Report	To find out if mothers of children with intellectual disability (ID) demonstrate symptoms of posttraumatic stress and posttraumatic growth (PTG). To define the role of intrusive and deliberate ruminations in this area.	85 female caregivers Mean age = 41 years old (SD = 10)	Poland	Quantitative survey study
Stewart et al.	2017	Through a trauma-based lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder	To investigate the validity of conceptualising parenting stress within a traumatic stress framework. To investigate whether trauma-related symptomatology was prevalent in a subpopulation of mothers of children with ASD.	12 female caregivers Age not specified	Australia	Qualitative IPA study
Nguyen et al.	2016	Problem-solving skills training for mothers of children recently diagnosed with autism spectrum disorder: A pilot feasibility study	To assess whether mothers of children recently diagnosed with autism spectrum disorder would be receptive to receiving problem-solving skills training (feasibility trial).	24 female caregivers Age not specified	USA	Feasibility intervention study
Roberts et al.	2014	Women's posttraumatic stress symptoms and autism spectrum disorder in their children	To examine the relationship between PTSD symptoms in women and ASD in their children. To elucidate whether PTSD in the mother may increase risk for ASD in her child and whether the child's ASD may increase risk of PTSD in the mother. To examine the association of women's PTSD and child's ASD both in women whose PTSD onset before the birth of the child and in women whose PTSD onset after the birth of the child.	413 female caregivers Age range = 24–44 years	USA	Mixed method study
Mazaheri et al.	2013	The impact of Prader–Willi syndrome (PWS) on the family's	To examine the effects of caring for a child diagnosed with PWS on the mothers and unaffected siblings.	11 female caregivers	USA	Mixed method study

		quality of life and caregiving, and the unaffected siblings' psychosocial adjustment	To assess overall family functioning, the mothers' psychological health, the psychosocial and behavioural functioning of siblings, and the quality of life of siblings.	3 caregivers = 30-40 years old 6 caregivers = 51-50 years old 2 caregivers = 51-55 years old		
Casey et al.	2012	Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder	To investigate PTSS in parents experiencing their child's diagnosis of autism.	265 caregivers Females = 244 Males = 21 29 caregivers = < 30 years old 93 caregivers = 31-40 years old 143 caregivers = > 40 years old	USA	Quantitative survey study
O' Neil	2004	Investigation of the prevalence and predictors of posttraumatic stress symptomology in parents of children with disabilities	To investigate whether news-breaking event qualifies as a traumatic stress event, resulting in PTSS and depression in caregivers. To examine the impact of social support, parental age, family income, and a history of positive relationships with PWD on PTSD and depression.	148 caregivers Females = 143 Males = 5 Mean age = 43.3 years old (SD = 8.06)	USA	Quantitative survey study
Psychiatric Disorders						
Author(s)	**Years of publication**	**Title of study**	**Aim(s) / purpose**	**Study population and sample size**	**Country**	**Study design**
Daoud et al.	2021	Factors associated with post-traumatic stress disorder in family caregivers of psychotic patients	To identify the factors associated with PTSD in family caregivers of psychotic patients following exposure to aggression.	95 caregivers Age and gender not specified	Tunisia	Cross-sectional Quantitative survey study
Daoud et al.	2021	Exposure to violence and risk of post-traumatic stress disorder in family caregivers of psychotic patients	To clarify the relationship between violence directed towards caregivers of patients with psychosis and developing PTSD.	95 caregivers Age and gender not specified	Tunisia	Cross-sectional Quantitative survey study
Charfi et al.	2021	Evaluation of psycho-trauma related to aggressions committed by psychotic patients on their family caregivers: cross-sectional survey in the region of Sfax, Tunisia	To identify the prevalence of aggression perpetrated by psychotic patients towards their family caregivers, to assess the psycho-traumatic impact on them and to identify the factors associated with it.	95 caregivers Females = 46 Males = 49 Spouse = 40 Parent = 25 Child = 5 Sibling = 25	Tunisia	Cross-sectional Quantitative survey study

				Mean age = 47.71 years old (SD = 12.96)		
Kageyama & Solomon	2018	Post-traumatic stress disorder in parents of patients with schizophrenia following familial violence	To clarify the relationship between violence directed towards parents by patients with schizophrenia and parents' risk of PTSD.	353 parents Females = 240 Males = 113 Mean age = 69 years old (SD = 7.3)	Japan	Quantitative survey study
Lowenstein	2018	A Knock on the Door	To explore and make sense of the embodied experience son's mental illness through journaling.	1 mother Age not specified	USA	Single case study
Kingston et al.	2016	Posttraumatic stress symptoms (PTSS) in caregivers of people with psychosis and associations with caregiving experiences	To assess PTSS in a sample of caregivers of people with psychosis and to examine the relationship between PTSS and caregiving experiences.	32 caregivers Females = 27 Males = 5 Parents = 19 Spouse = 7 Child = 4 Sibling = 1 Friend = 1 Mean age = 49 years old (SD = 14.9)	United Kingdom	Mixed method study
Bailey et al.	2014	Supporting a person with personality disorder: a study of carer burden and wellbeing	To compare the experience of caring for or supporting a person with any personality disorder with published comparison groups using empirically validated measures of carer burden and well-being.	287 caregivers Females = 194 Males = 93 Mother = 90 Father = 16 Child = 39 Sibling = 14 Partner/spouse = 106 Significant other = 22 Mean age = 47.2 years old	Australia	Quantitative survey study

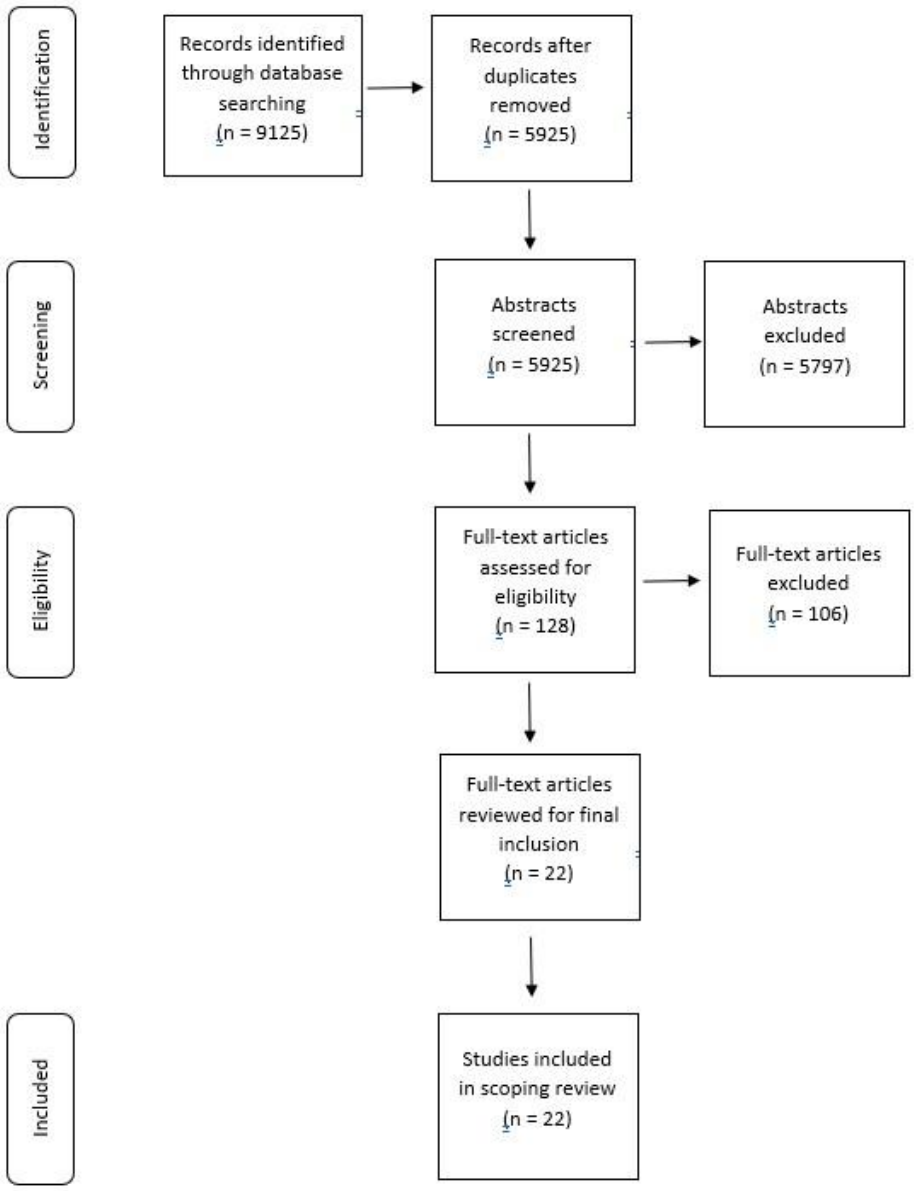
Hanzawa et al.	2013	Psychological impact on caregivers traumatized by the violent behavior of a family member with schizophrenia	To investigate the psychological impact of trauma experienced by family caregivers of individuals with schizophrenia who exhibited violent behavior as the result of acute psychosis.	116 caregivers Females = 64 Males = 43 Unknown = 9 Father = 18 Mother = 45 Husband = 3 Wife = 2 Brothers = 16 Sisters = 13 Son = 6 Daughter = 4 Others = 8 Unknown = 1 Mean age = 55.3 years (SD = 13.5 years)	Korea	Quantitative survey study
Loughland et al.	2009	Aggression and trauma experiences among carer-relatives of people with psychosis	To investigate reported experiences of aggression and trauma in a community derived sample of carer-relatives, and to examine those factors that might influence exposure to aggression and psychological wellbeing in this group.	106 caregivers Females = 89 Males = 17 Parent = 52 Sibling = 34 Child = 20 Mean age = 54.60 years old (SD = 13.67)	Australia	Quantitative survey study
Barton & Jackson	2008	Reducing symptoms of trauma among carers of people with psychosis: pilot study examining the impact of writing about caregiving experiences	To establish whether writing about experiences of the first episode of psychosis may alleviate trauma-like symptoms among carers of people with psychosis.	37 caregivers, Females = 33 Males = 4 Mother = 73 Father = 8 Others = 18 Mean age = 45.7 years old (SD = 9.4)	United Kingdom	Randomized controlled trial
Boye & Malt	2002	Stress response symptoms in relatives of acutely admitted psychotic patients: A pilot study	To identify specific stress response symptoms in relatives of acutely admitted psychotic patients, and to compare these responses with those of relatives of chronic inpatients.	Acute hospital patients = 25 caregivers Mother = 9 Father = 11 Spouse = 5	Norway	Comparative group design; quantitative survey study

				Mean age = 57 years old (SD = 10.4) Chronic inpatient patients = 21 caregivers Mother = 11 Father = 8 Siblings = 2 Mean age = 61 years old (SD = 11)		
Neurocognitive Disorders						
Author(s)	**Years of publication**	**Title of study**	**Aim(s) / purpose**	**Study population and sample size**	**Country**	**Study design**
Passoni et al.	2015	Eye Movement Desensitization and Reprocessing Integrative Group Treatment Protocol (EMDR-IGTP) Applied to Caregivers of Patients with Dementia	To investigate the effectiveness of the Eye Movement Desensitization and Reprocessing Integrative Group Treatment Protocol (EMDR-IGTP) on the “caregiver syndrome”.	44 caregivers Females = 34 Males = 10 Spouse = 30 Son/daughter = 13 Sibling = 1 Mean age = 66.07 years old (SD = 11.32)	Milan	Randomized controlled trial

2.5.6 *Stage 5: Collating, Summarising, and Reporting the Results*

The final stage in the methodological framework (Arksey & O'Malley, 2005) – reporting of results, is presented in Figure 1.

Figure 1 *PRISMA Format for Selection of Studies*



2.6 Results

2.6.1 *Characteristics of the Studies*

This review comprised nineteen articles, one dissertation, and two poster presentations published from 2002 to 2023. Among them, ten studies focused on caregivers of individuals with NDD, ten on caregivers of individuals with psychosis or schizophrenia, one on caregivers of individuals with a personality disorder, and one on caregivers of individuals with dementia (Table 2). The studies included primary caregivers, who were mostly mothers, and a detailed breakdown of these caregiving relationships can be found in Table 2. A compilation of the disorders identified in the studies analysed within the scoping review can be found in Table 3. Caregivers' ages ranged from 24 to 76 years old, with most caregivers for individuals with NDD looking after young children, except for one study addressing caregivers of adults with neurodevelopmental disorders (Baker et al., 2021). Caregivers for individuals diagnosed with psychosis or schizophrenia, dementia, and personality disorder were primarily caring for adults with these conditions.

Among the 22 studies, thirteen studies used a quantitative survey design, three studies were mixed methods design, two studies were qualitative design, one was a feasibility intervention study, two were randomized controlled trials, and one was a single case study. These studies were conducted across diverse geographical regions, encompassing Asia, Oceania, North Africa, Europe, and North America.

Table 3

Summary of neurodevelopment, psychiatric and neurocognitive disorders included in the studies:

Neurodevelopmental disorders	• Autism spectrum disorder • Asperger's syndrome • High functioning autism • Pervasive developmental disorder – not otherwise specified • Intellectual disability • Down syndrome • Cerebral palsy • Learning disability • Prader-Willi syndrome
Psychiatric Disorders	• Psychosis / psychotic disorder • Schizophrenia disorder • Schizoaffective disorder • Bipolar disorder • Personality disorders (as defined by DSM-5)
Neurocognitive Disorders	• Dementia

2.6.2 *Key Findings*

A summary and analysis of these 22 studies was conducted based on identified relevant information that is significant and relevant to the original research question. These are presented in the following sections.

2.6.2.1 Investigation of PTSS in Caregivers. Considering the small number of studies in this review, it appears that PTSS research in caregivers of individuals with NDD, psychiatric, and neurocognitive disorders is primarily exploratory. Findings from the varied study designs suggest that these caregivers are susceptible to PTSS. Many studies explored the connection between PTSS and aggression/violent behaviours but did not establish a clear relationship between PTSS, aggression, and violent behaviours.

In studies involving caregivers of NDD individuals, researchers theorized factors linked to PTSS risk by exploring potential traumatic events. For instance, two studies examined whether receiving a NDD diagnosis would result in PTSS (O'Neil, 2004; Casey et al., 2012). Other studies examined the effects of caregiving and its relationship with PTSS (Mazaheri et al., 2013; Roberts et al., 2014) and behavioural problems of the child (Stewart et al., 2017) as factors associated with PTSS.

Recently, there has been a focus on applying the traumatic stress framework to caregivers of children with NDD. Four studies investigated this approach for understanding caregiver well-being. Stewart and colleagues (2017) examined parenting stress within a traumatic stress framework with mothers of children with autism spectrum disorder (ASD), and whether trauma-related symptomatology was prevalent in a subpopulation of mothers of children with ASD. Schnabel and colleagues (2020) explored a trauma-based diagnostic framework with mothers of children with ASD. Another study (Stewart et al., 2020) investigated whether a traumatic stress framework can be utilised to understand the elevated stress in parents of children with ASD and rare diseases who exhibit challenging behaviours. More recently, Baker and colleagues (2021) adopted a trauma-informed perspective for a deeper understanding of caregiving experiences and even explored the applicability of the complex posttraumatic stress disorder (C-PTSD) framework, building on the emerging evidence that C-PTSD may occur due to prolonged chronic trauma in adulthood (Karatzias, 2019; McDonnell, 2013; Palic et al., 2016). C-PTSD is a psychological condition that arises from prolonged, repeated, or chronic exposure to traumatic experiences, often interpersonal in nature. Unlike PTSD, which is typically associated with a single traumatic event, C-PTSD involves sustained trauma, such as ongoing institutional abuse, repeated childhood adversity, or cumulative stressors in adulthood. In the context of families caring for individuals with learning disabilities and/or autism, C-PTSD reflects the enduring emotional and psychological

impact of repeated adverse events—including neglect by services, restrictive interventions, and systemic failures—which can lead to persistent difficulties in emotional regulation, breakdown in trust, hyperarousal, and disturbances in self-identity and relationships (World Health Organization, 2019; Baker et al., 2021). These complex responses go beyond the typical PTSD symptom cluster, reflecting the multi-layered trauma experienced over time by family caregivers.

The research on PTSS in caregivers of individuals with personality disorders was exploratory. Bailey and colleagues (2014) identified symptoms resembling PTSD, anxiety, and mood disorders among these caregivers. The study considered PTSS, depression, and anxiety as components of well-being. While the origin of these challenges was unclear, the findings emphasized that PTSS adversely affected caregiver well-being.

Studies involving caregivers of individuals with psychosis and schizophrenia aimed to understand PTSD and its potential causes. For example, four studies focused on the impact of aggression and violent behaviours on caregivers, exploring their association with trauma experiences (Charfi et al., 2021; Hanzawa et al., 2013; Kageyama & Solomon, 2018; Loughland et al., 2009). The first study investigated the link between aggression, trauma, and caregivers' psychological well-being (Loughland et al., 2009), while the second study examined the effects of trauma on family caregivers of people with schizophrenia who exhibited violent behaviour (Hanzawa et al., 2013). The third study explored the connection between schizophrenia patients' violence towards caregivers and the likelihood of caregiver PTSD (Kageyama & Solomon, 2018). The fourth study assessed the prevalence of caregiver-targeted aggression, its psycho-traumatic impact, and associated factors (Charfi et al., 2021). Notably, advanced age, male caregiving, and the parent-child relationship emerged as factors linked to PTSD onset.

In the remaining studies, one examined stress response symptoms in relatives of acutely admitted psychotic patients (Boye & Malt, 2002), another assessed PTSS in caregivers of people with psychosis, exploring the link between PTSS and caregiving experiences (Kingston et al., 2016). Two studies investigated the use of writing as an intervention for caregivers of individuals with a first episode of psychosis (Barton & Jackson, 2008; Lowenstein, 2018). One recent study identified factors associated with PTSD in caregivers exposed to aggression (Daoud et al., 2021a), finding that decreased patient contact, male and older caregivers, schizophrenia or affective disorder diagnosis in patients, and poor treatment adherence were associated with caregiver PTSD. Another study clarified the relationship between violence directed at caregivers and PTSD development, revealing that over half of the caregivers had significant PTSD levels related to patient aggression (Daoud et al., 2021b).

Among the 22 studies, four were intervention studies involving caregivers. Two of these interventions explored the potential of writing to reduce trauma symptoms in caregivers of individuals with psychosis. Barton and Jackson (2008) found that caregivers experiencing trauma-like symptoms had significantly reduced trauma severity through writing about their experiences with the first psychotic episode. In a separate study, a single caregiver used journaling to process her son's psychosis, which she considered a traumatic experience, and found therapeutic benefits from writing these narratives (Lowenstein, 2018).

The third intervention study focused on caregivers of individuals with NDD (Nguyen et al., 2016). These caregivers were trained in problem-solving skills to assess if this approach could reduce negative affectivity, including depressive symptoms, negative mood, and post-traumatic stress. Mothers completing the training showed significant decreases in negative affectivity and improvements in problem-solving skills. They also displayed less negative mood and fewer post-traumatic stress symptoms.

In the fourth intervention study, caregivers of individuals with dementia participated in an EMDR-focused intervention (Passoni et al., 2015). Caregivers endorsing traumatic events causing trauma-related symptoms were recruited for a randomized controlled trial. Treated caregivers experienced reduced trauma symptoms (intrusion, avoidance, and hyperarousal), and these effects were maintained after two months. Given the absence of PTSS prevalence studies amongst caregivers of individuals with neurocognitive disorders in this scoping review, this study appeared to be based on the assumption that PTSS or PTSD might exist in this caregiving population.

2.6.2.2 Investigation of PTSS in Caregivers. Ten out of the 22 studies offered information about the occurrence of PTSS/PTSD among caregivers. Among caregivers of individuals with NDD, the rates varied from ten to fifty-two percent. In a recent study with caregivers of individuals with NDD, although no specific PTSD tool was used, ten percent of caregivers reported a previous PTSD diagnosis (Baker et al., 2021). Casey et al. (2012) found that twenty percent of the 265 caregivers in their study experienced PTSS symptoms on the Impact of Event Scale-Revised (IES-R). Among them, eight percent had moderately distressing or greater scores on the avoidance subscale, fourteen percent had scores of moderately distressing or greater on the intrusion subscale, and about sixteen percent had scores of moderately distressing or greater on the hyperarousal subscale. Families with two or more children with ASD were more likely to experience PTSS. An initial study on mothers of children with ASD (Schnabel et al., 2020) with twenty-seven participants found that twenty-two percent met criteria for PTSD due to traumatic parenting experiences. In the case of mothers of children with intellectual disability, fifty-two percent of the 85 mothers showed at least moderate levels of post-traumatic stress symptoms (Kielb et al., 2019). Finally, in the study involving siblings, ninety-two percent of thirteen siblings showed moderate to severe PTSD symptoms (Mazaheri et al., 2013).

Caregivers of individuals diagnosed with schizophrenia and psychosis faced PTSS risk ranging from twenty-four to fifty-five percent. In Japan, twenty-four percent of 353 parents of adult children with schizophrenia reported high IER-S scores, suggesting a high risk of developing PTSD (Kageyama & Solomon, 2018). In the Korean study, thirty percent of a hundred caregivers had IES-R scores indicating a 'high likelihood of post-traumatic stress disorder' (Hanzawa et al., 2013). In the study by Loughland and colleagues (2009), thirty-two percent of 106 caregivers reported potentially significant PTSD levels. Another study found nearly half of the caregivers, forty-four percent of 32 caregivers, reported PTSS (Kingston et al., 2016). Furthermore, the study exploring PTSD in caregivers exposed to aggression showed fifty-five percent of caregivers had potentially significant PTSD levels (Daoud et al., 2021).

2.6.2.3 Events Identified as Traumatic Events. Five studies identified traumatic events linked to trauma and PTSS in caregivers of children with NDD. These events included news-breaking (O'Neil, 2004) and receiving the NDD diagnosis (Casey et al., 2012). Additionally, behavioural issues experienced by caregivers (Schnabel et al., 2020; Stewart et al., 2017; Stewart et al., 2020) were considered traumatic. These behavioural problems shared similarities with events identified as traumatic in caregiver studies involving individuals with psychosis and schizophrenia.

Stewart and colleagues (2020) did not specify the problem behaviours that predicted PTSD symptomatology in caregivers. However, two other studies provided details. In the previous study by Stewart et al. (2017), caregivers identified three main traumatic events: threats of severe injury or death to the child due to their behaviour, threats of injury to the parent from the child, and threats of injury to others. These events were recurrent and unpredictable. Some caregivers experienced traumatic events when the child eloped without road safety knowledge or engaged in self-injurious behaviours requiring physical restraint.

Similarly, in the recent study by Schnabel and colleagues (2020), caregivers reported feeling threatened when their child exhibited physical violence toward them or witnessed violent behaviour directed at the child's father. They also reported traumatic events related to the child's suicidal ideation and behaviour.

Baker et al. (2021), using a C-PTSD framework, extensively explored various traumatic events experienced by caregivers. Their findings highlighted the complex and multi-layered nature of trauma in these caregivers. The identified traumatic events included separation from family, limited visiting, seclusion, delayed care support, and the use of restraints (physical, mechanical, or chemical) on loved ones. Itis noteworthy that these traumatic events, originally experienced by individuals with NDD, also had a significant impact on the caregivers themselves.

Aggression and violence were common traumatic events reported by caregivers of individuals with psychosis and schizophrenia. Three studies provided details about these behaviours. In the study by Loughland and colleagues (2009), reported aggression types included verbal, physical, self-directed, and sexual aggression. Despite verbal aggression being more prevalent, seventy-seven percent of the 106 caregivers experienced moderate to severe levels of aggression, with twenty-four percent fearing for their lives. Among those facing moderate to severe aggression, fifty-two percent reported PTSD symptoms indicating a high likelihood of PTSD diagnosis.

Similarly, Kageyama and Solomon (2018) identified similar aggressive and violent behaviours in their study, grouping them into three categories: psychological violence, aggressive acts, and acts of violence. Psychological violence included shouting, swearing, punching and kicking gestures, and threats like "I will kill you." Aggressive acts encompassed property destruction, punching, kicking, pushing, and throwing objects. Acts of violence involved weapon use, choking, or causing physical injury likely to result in severe harm, such

as threatening with a knife, beating with an object, or getting injured with a knife. The study found that caregivers with higher Impact on Event Scale - Revised (IES-R) scores, indicating greater PTSD risk, experienced significantly more violent incidents compared to caregivers with lower IES-R scores.

In their recent study, Charfi and colleagues (2021) found that seventy-six percent of caregivers experienced moderate to severe aggression. The most common type of aggression reported by caregivers was verbal, followed by physical, self-directed, and sexual violence. Verbal aggression was particularly concerning to caregivers, seen as frightening and threatening due to the potential physical harm or retaliation towards them or their loved ones. Given the threatening nature of these events, it makes sense that caregivers exposed to such behaviours during caregiving would experience traumatic stress or PTSS.

2.6.2.4 PTSS Symptoms, Cognitive Appraisal, and Coping. Caregivers commonly reported PTSS symptoms including intrusive re-experiencing, avoidance of reminders, and hyperarousal (Boye & Malt, 2002; Casey et al., 2012; Hanzawa et al., 2013; Mazaheri et al., 2013; Stewart et al., 2017). Hypervigilance and sleep problems were noted in caregiver and sibling studies (Baker et al., 2021; Mazaheri et al., 2013; Stewart et al., 2017). Caregivers of NDD individuals also experienced physiological reactivity, prolonged stress, and persistent trauma-related emotions (Stewart et al., 2017). Additionally, siblings reported anger and heightened startle responses (Mazaheri et al., 2013).

Researchers identified associations between cognitive appraisals and PTSS. Persistent and distorted negative self-beliefs were associated with PTSS in caregivers (Kingston et al., 2016; Stewart et al., 2017). Self-blame and negative self-cognitions strongly correlated with PTSS, with negative self-cognitions having a more pronounced impact on PTSS onset and maintenance among caregivers (Kingston et al., 2016). One study also revealed a significant

positive correlation between intrusive rumination and overall PTSS levels, with intrusive rumination acting as a predictor of PTSS (Kielb et al., 2019).

Contrarily, among caregivers of individuals diagnosed with schizophrenia, those in the high PTSD subgroup did not show more negative appraisals of future or past aggression compared to the low PTSD subgroup (Loughland et al., 2009). Instead of self-blame, caregivers in the high PTSD subgroup attributed aggressive behaviours to the illness. One study found evidence for a strong relationship between avoidant coping and PTSS in caregivers, although the nature of the avoidant coping was not described (Kingston et al., 2016).

2.6.2.5 Summary of Measures Used to Assess PTSS / PTSD. The assessment measures for PTSS and PTSD varied widely in the studies. For caregivers of individuals with IDD, multiple measures were employed (Table 4), such as the Modified PTSD Symptom Scale – Self-report, Trauma Intensity Questionnaire, IES-R, Los Angeles Symptom Checklist – PTSD Self-report, UCLA PTSD Index, Brief Trauma Questionnaire, Clinician-Administered PTSD Scale for DSM-5 (CAPS-5), The Life Event Checklist (LEC-5), and PTSD Checklist for DSM-5 (PCL-5). Among these studies, three used the IES-R to evaluate trauma symptoms (Casey et al., 2012; Kielb et al., 2019; Nguyen et al., 2016). In contrast, all studies with caregivers of individuals with schizophrenia and psychosis used the IES-R to assess trauma symptoms.

The IES-R appears to be a commonly used measure for assessing trauma symptoms. It was also employed in the study with caregivers of individuals with neurocognitive disorders. In the study with caregivers of individuals diagnosed with personality disorder, although a specific trauma symptom tool wasn't used, caregivers' scores on the Difficulties in Emotion Regulation Scale (DERS) were reported to indicate similarity to a clinical sample of individuals with posttraumatic stress disorder (Bailey et al., 2014).

Table 4

Measures Used to Assess Trauma Symptoms in All Studies in Reverse Chronological Order (n = 19)

Authors / Year of Publication	Modified PTSD Symptom Scale – Self-report	Trauma Intensity Questionnaire	Impact of Event Scale (IES-R)	Los Angeles Symptom Checklist – PTSD Self-report	UCLA PTSD Index	Brief Trauma Questionnaire	Clinician Administered PTSD Scale for DSM-5 (CAPS-5)	The Life Events Checklist (LEC-5)	PTSD Checklist for DMS-5 (PCL-5)	Event-Related Rumination Inventory – ERRI	Family Support Scale	Brief Symptom Inventory (BSI)	Center for Epidemiologic Studies Short Depression Scale (CES-D10)	Beck Depression Inventory –Revised (BDI)	Mini-International Neuropsychiatric Interview (MINI)	Burden Assessment Scale (BAS)
Neurodevelopmental Disorders																
Stewart et al. (2020)								x	x							
Schnabel et al. (2020)							x								x	
Kielb et al. (2019)			x							x						
Nguyen et al. (2016)			x											x		
Roberts et al. (2014)						x							x			
Mazaheri et al. (2013)					x							x				
Casey et al. (2012)			x	x												
O' Neil (2004)	x	x									x					

Psychiatric Disorders															
Daoud et al. (2021)			x												
Daoud et al. (2021)			x												
Charfi et al. (2021)			x												
Kageyama & Solomon (2018)			x												
Kingston et al. (2016)			x												
Bailey et al. (2014)															x
Hanzawa et al. (2013)			x												
Loughland et al. (2009)			x												
Barton & Jackson (2008)			x												
Boye & Malt (2002)			x												

Neurocognitive Disorders															
Passoni et al. (2015)			x												

2.6.2.6 Psychosocial Difficulties and Impact of Trauma Symptoms. Two studies in the scoping review reported psychosocial difficulties among caregivers (Bailey et al., 2014; Casey et al., 2012), while one study specifically focused on psychosocial difficulties among mothers (Stewart et al., 2017). These difficulties included job instability, financial management issues, hostility, violence, suicidal thoughts, marital problems, self-consciousness, and depression (Casey et al., 2012). Another study highlighted that trauma-related symptoms contributed to impairing caregivers' social and occupational functioning, particularly due to challenging behaviors in the family (Stewart et al., 2017). The study involving caregivers of individuals diagnosed with personality disorder briefly mentioned elevated burden and interpersonal strains among these caregivers (Bailey et al., 2014).

2.6.2.7 Interventions Used to Process Trauma. The use of writing as an intervention for trauma-like symptoms was explored in two studies (Barton & Jackson, 2008; Lowenstein, 2018). Caregivers who participated in writing exercises showed reduced avoidance of reminders and feelings related to their relative's episode, and those with trauma-like symptoms experienced a significant decrease in trauma severity (Barton & Jackson, 2008). Journaling, as a form of writing, was also described by a caregiver as a way to make sense of her son's psychosis, which she considered traumatic (Lowenstein, 2018). The author suggests that writing, similar to exposure therapy, may serve as a therapeutic technique, and incorporating narrative writing exercises into therapy could be beneficial for caregivers.

The effectiveness of Eye Movement Desensitization and Reprocessing Integrative Group (EMDR) as a treatment for reducing trauma-like symptoms in caregivers of individuals diagnosed with dementia was studied with forty-four primary caregivers (Passoni et al., 2015). Immediate treatment with EMDR significantly reduced subjective distress related to traumatic events, leading to a reduction in Intrusion, Avoidance, and Hyperarousal symptoms.

This reduction in distress, measured using the IER-S tool, was sustained even after two months.

2.7 Discussion

This scoping review aimed to explore the current literature on PTSS among adult caregivers of individuals with neurodevelopmental, psychiatric, or neurocognitive disorders. The review identified several factors associated with traumatic stress in caregivers, but many of the studies provided preliminary results, indicating the need for further research in this area.

The study of traumatic stress in caregivers of individuals with NDD is a growing field of interest, particularly in international research on caregiver mental health and well-being. An exploratory research approach was common, with studies investigating the likelihood of traumatic stress (Casey et al., 2012; Mazaheri et al., 2013; O'Neil, 2004) and the value of framing these experiences within a traumatic stress framework (Baker et al., 2021; Kielb et al., 2019; Schnabel et al., 2020; Stewart et al., 2017). This suggests an increasing recognition of the significance of trauma in the mental health and well-being of caregivers, indicating a broader understanding in this area.

Studies with caregivers of individuals diagnosed with psychiatric disorders, including psychosis, schizophrenia, and personality disorders, also seemed to be in the exploratory stage. Most of the research in this area focused on understanding traumatic stress (Boye & Malt, 2002; Loughland et al., 2009), its psychological impact (Hanzawa et al., 2013; Kageyama & Solomon, 2018; Kingston et al., 2016), and exploring interventions to alleviate trauma symptoms (Barton & Jackson, 2008; Lowenstein, 2018). As shown in Table 5, the collective findings drawn from these study designs consistently indicate that caregivers of individuals with NDD, psychiatric disorders, and neurocognitive disorders are vulnerable to experiencing PTSS. Many studies explored connection between PTSS and aggression/violent

behaviours, however they did not conclusively establish a direct link between PTSS, aggression, and acts of violence. No specific prevalence studies were found, suggesting a need for large prevalence studies in all caregiver populations.

Table 5

Summary of Critical Findings:

- Post-Traumatic Stress Symptoms (PTSS) research in caregivers of individuals with Neuroevelopmental Disabilities (NDD), psychiatric disorders, and neurocognitive disorders is primarily exploratory. Caregivers of individuals with these conditions are susceptible to PTSS based on findings from various study designs.
- The prevalence of traumatic stress appears similar between caregivers of individuals with NDD and caregiver of those diagnosed with psychosis and schizophrenia.
- Female caregivers were the majority of participants in all the studies.
- Many studies explored the connection between PTSS and aggression/violent behaviors but did not conclusively establish a direct link between PTSS, aggression, and violent behaviors.
- Caregivers of individuals with psychosis are at an increased risk of experiencing violence, which may explain the higher rates of PTSS for these caregivers.
- Caregivers of individuals with NDD often encounter recurring, unpredictable behavioral challenges, leading to feelings of threat, causing stress and strain due to repeated exposure. Behavioral challenges encountered by NDD caregivers share aggressive similarities with traumatic events reported in studies of psychosis and schizophrenia caregivers.

The occurrence of traumatic stress appears similar between caregivers of individuals with NDD and caregivers of those diagnosed with psychosis and schizophrenia. The reported occurrence rates range from ten to fifty-two percent for NDD caregivers (Baker et al., 2021; Casey et al., 2012; Kielb et al., 2019; Schnable et al., 2020; Stewart et al., 2017), and from twenty-four to fifty-five percent for caregivers of individuals with psychosis and schizophrenia (Daoud et al., 2021; Hanzawa et al., 2013; Kageyama & Solomon, 2018; Kingston et al., 2016; Loughland et al., 2009).

Previous research has shown that caregivers of individuals with psychosis are at an increased risk of experiencing violence (Labrum et al., 2021), making the high occurrence rate of PTSS among these caregivers understandable. The similarly high rates of PTSS in caregivers of individuals with NDD may be related to the recurring and complex nature of traumatic events they face, particularly challenging behaviors reported in studies (Schnabel et al., 2020; Stewart et al., 2017). These events can occur frequently and continue over time as the individual with NDD ages, leading to multi-layered and complex trauma experiences, as highlighted in Baker and colleagues' study (2021). Behavioral challenges encountered by NDD caregivers share aggressive similarities with traumatic events reported in studies of psychosis and schizophrenia caregivers. Considering the repeated exposure to traumatic events, the significant rates of traumatic stress in NDD caregivers are not surprising.

Differences in methodology might explain varying rates of traumatic stress reporting among caregivers of individuals with NDD. For example, the assessment tools used could impact symptom detection. Studies with NDD caregivers employed established tools like the PTSD Checklist for DSM-5 and Clinician-Administered PTSD Scale, while the IES-R was predominant in studies with caregivers of individuals with schizophrenia and psychosis. However, it is important to note that the rates of PTSS for both groups of caregivers may not be representative of population prevalence due to small sample sizes in most studies (Kielb et al., 2019; Kingston et al., 2016; Schnabel et al., 2020; Stewart et al., 2017).

It is interesting to note that receiving an NDD diagnosis was identified as a traumatic event in studies with NDD caregivers (Casey et al., 2012; O'Neil, 2004). Despite not meeting all PTSD criteria, these caregivers experienced PTSS, closely linked to a PTSD diagnosis. The events characterized as traumatic in the studies under consideration appear to deviate from the DSM-5 definition of traumatic events outlined in Criterion A, a pivotal component of PTSD/PTSS. In scrutinizing these investigations, it becomes apparent that they adopt a

broader perspective to comprehend the impact of events on caregivers, potentially leading to PTSS. While the DSM-5 specifies specific criteria for an event to be deemed traumatic, it is evident that these studies broaden their scope, acknowledging a wider range of experiences that may elicit distress and contribute to the manifestation of PTSS in caregivers. This nuanced approach to understanding the potential stressors and their impact in caregiving contexts may offer valuable insights into the varied manifestations of trauma-related symptoms in this population and can contribute to ongoing efforts to understand the nature of trauma in research (Marx et al., 2023).

In all the studies in the scoping review, female caregivers were the majority of participants, aligning with the traditional caregiving role in most communities. Thus, generalizing findings to male caregivers requires caution. Additionally, six out of the nine studies on caregivers of individuals with NDD focused on mothers under the age of fifty (Casey et al., 2012; Roberts et al., 2014; Nguyen et al., 2016; Schnabel et al., 2020; Stewart et al., 2017; Stewart et al., 2020), while the other three included parents aged fifty or older (Kielb et al., 2019; Mazaheri et al., 2013; O' Neil, 2004). This highlights a focus on younger parents caring for young children with NDD. Given that NDD is a pervasive developmental disorder, expanding research to caregivers of adults with NDD would offer valuable insights into caregiver trajectories and evolving needs for both caregivers and their adult children.

The cognitive model of PTSD suggests that the way individuals process traumatic events can lead to feelings of severe threat (Ehlers & Clark, 2000). This association between cognitions and trauma symptoms is a key aspect of the model, and multiple studies in this review found links between cognitive appraisals and PTSS. Caregivers of individuals with NDD and those with psychosis and schizophrenia shared similar negative beliefs about their caregiving, which were associated with PTSS (Kingston et al., 2016; Stewart et al., 2017). Intrusive thoughts and ruminations were also linked to PTSS among caregivers of individuals

with psychosis and schizophrenia (Boye & Malt, 2002; Hanzawa et al., 2013; Kielb et al., 2019). Lastly, the studies with caregivers of individuals with dementia and personality disorders (Bailey et al., 2014; Passoni et al., 2015) suggest that caregiving in these groups might be traumatic. However, due to the limited research in these populations, further studies are needed to better understand the occurrence and factors associated with PTSS in these caregivers.

The studies included in this scoping review investigating PTSS in caregivers were conducted across diverse geographical regions, encompassing Asia, Oceania, North Africa, Europe, and North America. The inclusion of research studies from these different regions is noteworthy because it provides insights into how cultural and societal factors can influence the experience of PTSS among caregivers. Cultural norms, social support systems, healthcare structures, and stigmas surrounding mental health can differ significantly between these regions, impacting the occurrence and manifestation of PTSS. By conducting research in these diverse regions, the findings can be more representative of a global population of caregivers. PTSS is not limited by geographical boundaries, and caregivers worldwide may face similar challenges and stressors. The geographical diversity allows for comparative analyses between different cultural contexts. Researchers can explore how cultural factors influence the development, recognition, and coping mechanisms related to PTSS. Such comparative studies can lead to a deeper understanding of the universal and culturally specific aspects of PTSS in caregivers as proposed by Allwood (2024). These findings can guide the development of culturally sensitive support programs and mental health services tailored to the unique needs of caregivers in different regions. Collectively, the studies from diverse geographical locations contribute to building a comprehensive knowledge base on PTSS in caregivers. This allows for a more holistic understanding of the phenomenon and facilitates

the development of evidence-based interventions that can be adapted to various cultural and societal contexts.

2.8 Strength and Limitations

This scoping review followed a rigorous protocol and included a diverse range of caregiver groups, enabling comprehensive coverage. However, it might have missed earlier studies on PTSS/PTSD in caregivers of psychiatric disorders due to the selected date range. The included studies themselves had design limitations, impacting the conclusions of this scoping review. Different ways of defining and measuring trauma symptoms, ranging from PTSS to PTSD, and the diverse use of assessment tools, particularly in studies with NDD caregivers, hindered direct comparisons and limited definitive recommendations on suitable tools. Moreover, varying sample sizes across studies made occurrence rate comparisons challenging.

2.9 Implications for Future Research, Practice, and Policy

The following section will propose future directions for advancing traumatic stress research in caregivers, as well as practice and policy (Table 6), with a particular focus on those caring for individuals with IDD.

Future research on PTSS in caregivers of individuals with NDD should integrate both quantitative and qualitative approaches. This combination would provide a comprehensive understanding of the phenomenon by quantifying its occurrence and exploring caregivers' lived experiences. This comprehensive approach could inform effective interventions aimed at reducing PTSS symptoms among this caregiver population.

Future research should consider including parents of adults with NDD, particularly those in the older age group. This would provide insights into the experiences of long-term caregivers who may have received more support from healthcare services over time. Age-

related factors may influence the presence and management of traumatic stress in caregivers. Older caregivers may have developed better coping strategies but could also face health or financial challenges. While only one study suggested that higher parental age predicted lower PTSD symptoms (O'Neil, 2004), this underscores the value of investigating caregivers of adults with IDD. Such research could offer valuable insights to support caregivers in this context.

Interestingly, the behavioural issues observed in studies of caregivers of individuals with NDD share aggressive similarities with traumatic events reported in studies of caregivers of individuals with psychosis and schizophrenia. Caregivers of individuals with NDD noted the recurrent and unpredictable nature of these behaviour problems, which distinguishes them from isolated events. They reported feeling threatened when their child exhibited physical violence towards them or other caregivers. Given the extended duration of caregiving for individuals with NDD, it is reasonable to assume that repeated exposure to such challenging behaviours, which may include aggression and violence, can be stressful and demanding.

In addition to common issues like caregiver stress, burden, depression, and anxiety, further research could specifically investigate the unique impact of these behaviour problems on caregivers' mental health and overall well-being due to their extended caregiving experiences. Behaviour problems exhibited by care recipients often pose distinctive challenges that might exacerbate existing stressors. Exploring the unique impact of these behaviour issues allows for a nuanced understanding of how these challenges contribute to caregivers' mental health struggles.

Extended caregiving experiences, especially when coupled with challenging behavior problems, can significantly impact caregivers' mental health and overall well-being over time. Conducting longitudinal research could help to highlight the cumulative toll these challenges

take on caregivers. It enables the identification of patterns, trajectories, and potential thresholds at which caregiver mental health may be disproportionately affected.

This broader perspective could inform better support practices, including implementing trauma-informed care practices that involve creating environments that foster safety, trust, and understanding. A longitudinal view of caregiving, beyond the immediate challenges they face, acknowledges the potential long-term effects of trauma on caregivers, including psychological, emotional, and even physical health repercussions resulting from the cumulative stress and trauma experienced. Shedding light on these long-term effects is pivotal in formulating comprehensive support strategies that encompass not just the immediate care needs but also address the sustained well-being of caregivers. Institutions and support systems can tailor the development of targeted interventions and support systems aimed at mitigating, preventing, or addressing the long-term effects of trauma, ensuring sustained mental health and effective coping among caregivers.

Trauma-informed care offers a framework for healthcare providers and institutions in helping to avert persistent traumatic stress responses in an individual (Bruce et al., 2018). It can operate as a proactive framework aimed at mitigating and preventing persistent traumatic stress responses among caregivers. By integrating trauma-informed principles into caregiving practices, healthcare providers and institutions prioritize a supportive environment that recognizes and responds to the potential trauma experienced by caregivers. Through this framework, caregivers receive guidance and support that not only addresses immediate needs but also actively works towards averting the long-term negative impacts of continuous stress and trauma. This could support immediate care provision and assist in preventing further trauma and foster healing and resilience among caregivers.

When considering future research directions in this field, it is valuable to expand the perspective beyond the conventional deficit/symptom model. While understanding the

challenges and symptoms faced by caregivers is crucial, there is merit in exploring alternative perspectives. A more comprehensive approach should include exploration into the resilience and protective factors that contribute to caregivers' well-being amidst challenging circumstances. Investigating post-traumatic growth, whereby individuals experience personal development and positive transformation following adversity, could offer valuable insights into the potential positive outcomes of caregiving experiences. Additionally, integrating considerations for genetic factors and cultural factors influencing symptom manifestation may provide a more nuanced understanding of the interplay between biological predispositions, culture, and environmental stressors in the caregiving context. This holistic approach not only enriches the understanding of caregivers' experiences but also guides the development of more targeted interventions and support systems.

Table 6

Implications for Practice, Policy and Research:

Implication for Practice	• In addition to various challenging factors related to caregiving, for someone with complex needs, caregivers are also often confronted with threats posed by challenging behaviours from their relatives. The impact of the combination of these factors is significant to the mental health and wellbeing of caregivers. • PTSS can negatively influence caregivers' ability to continue providing care for their adult children, for example, it has been reported that treatment effectiveness for the individual with IDD diminishes when caregivers' mental health needs are unmet (Osborne et al., 2008). • Understanding the potential threats caregivers might be exposed to and the subsequent PTSS they might experience can serve as a foundation to delivering trauma-informed care to these caregivers in support of their mental health and wellbeing. • Given the challenges caregivers face, particularly those caring for individuals with NDD, it is essential to expand research beyond stress, burden, depression, and anxiety. This broader perspective could inform better support practices, including trauma-informed care, and shed light on the long-term effects of trauma in caregiving.
Implication for Policy	• Trauma-informed care offers a framework for healthcare providers and institutions in helping to avert persistent traumatic stress responses in an individual (Bruce et al., 2018). Trauma-informed care can be the approach used when working with caregivers as it is guided by knowledge of trauma and its impact on an individual.
Implication for Research	• Future research on PTSS in caregivers of individuals with NDD should integrate quantitative and qualitative methods to gain a holistic understanding. This approach can clarify prevalence rates while delving into caregivers' lived experiences, informing better interventions for PTSS symptoms in this group. • Future research should involve older parents of adults with NDD to explore the experiences of long-term caregivers who may have received increased healthcare support. Age-related factors may influence the presence and management of traumatic stress in caregivers. • Further research should investigate the longitudinal impact of these behavior problems on NDD caregivers' mental health and overall well-being due to their extended caregiving experiences.

2.10 Conclusions

While research on PTSS and PTSD within the caregiver population remains in its emergent stages, it holds immense significance. Informal caregivers stand as cornerstones within society and families, their roles pivotal in the well-being of their relatives. As caregivers, especially those providing caregiving to individuals with NDD, confront multifaceted challenges, it is imperative to expand research beyond the well-documented stress, burden, depression, and anxiety. This expansion not only fosters theoretical advancements but also drives methodological refinements and necessitates improvements in policies and practices. A deeper exploration into PTSS and PTSD among caregivers offers an avenue for identifying critical areas for further inquiry, ultimately aiding in the provision of comprehensive support for adults with NDD and their aging caregivers.

2.11 Summary

The scoping review revealed that caregivers of individuals with NDD, psychiatric disorders, and neurocognitive disorders are significantly vulnerable to experiencing PTSS. Caregivers reported trauma stemming from various caregiving-related stressors, including exposure to aggression, violent behaviours, and the emotional toll of receiving a diagnosis or managing challenging behaviours. Up to half of the caregivers in the reviewed studies reported PTSS, with symptoms such as intrusive thoughts, hyperarousal, and avoidance being common across different caregiver groups. Although research has primarily focused on caregivers of children with NDD, emerging evidence suggests that caregivers of adults face similar or even more complex challenges due to prolonged exposure to stressors over time. However, the reviewed studies employed various tools to measure PTSS, making it difficult to standardize findings or establish prevalence rates.

The findings from this scoping review underscore the need for a more systematic investigation into the prevalence and impact of PTSS in caregivers of adults with NDD. Most of the existing literature focuses on qualitative or exploratory research, leaving a significant gap in quantitative data that could better inform the understanding of PTSS in this population. Given the prolonged caregiving burden and recurring exposure to traumatic events, a quantitative study would provide crucial data on the prevalence, severity, and specific contributing factors to PTSS among caregivers of adults with NDD. Such a study would not only help validate the findings from the scoping review but also offer evidence to guide targeted interventions and support mechanisms tailored to this vulnerable group. This quantitative investigation would be instrumental in shaping future mental health services and policy initiatives aimed at improving the well-being of these caregivers and the adults with NDD whom they care for.

Chapter 3

Quantitative Analysis of Post-Traumatic Stress in Singaporean Caregivers of Adults with Neurodevelopmental Disorders.

3.1 Research Rationale Based on Scoping Review Findings

The scoping review presented in Chapter 2 explored post-traumatic stress symptoms (PTSS) among family caregivers of individuals with neurodevelopmental, psychiatric, and neurocognitive disorders. Findings revealed that up to half of caregivers reported PTSS, particularly in relation to distressing caregiving experiences such as dealing with aggression, behavioural issues, or receiving a diagnosis for their care recipient (Lim et al., 2024). However, the review also noted that due to the wide variability in measurement tools used across studies, it was difficult to draw consistent conclusions about prevalence rates. Family caregivers of individuals with neurodevelopmental disorders (NDD) often experienced trauma related to caregiving responsibilities, particularly when managing challenging behaviours, while caregivers of those with psychosis faced trauma related to aggression and violence (Lim et al., 2024). In addition, the review concluded that cognitive appraisals, such as the family caregiver's perception of the caregiving experience, were strongly associated with PTSS across multiple studies.

These findings highlighted the need for a deeper and more systematic investigation into the experiences of family caregivers, particularly those supporting adults with NDD. Many of the studies have taken an exploratory research approach to investigate the likelihood of traumatic stress in caregivers and the value of conceptualizing their experiences within a traumatic stress framework. There is also a growing interest internationally in investigating mental health and well-being among family caregivers and understanding the long-term effects of caregiving-related trauma as caregivers and their care recipients' age. The scoping

review therefore provided a rationale for conducting a quantitative study to explore the occurrence and impact of PTSS in caregivers. While international studies report PTSS occurrence rates between 10% and 55%, with studies reporting rates between 10% and 52% for family caregivers of individuals with NDD and between 24% and 55% for family caregivers of those with psychosis and schizophrenia (Lim et al., 2024), Singaporean family caregivers remain under-researched in this regard, offering a critical opportunity for local, quantitative exploration.

3.1.1 *The Singapore Context*

Singapore presents a fascinating multicultural tapestry, reflecting its diverse Asian heritage, with Chinese, Malay, and Indian ethnicities comprising the majority of the population (Department of Statistics, 2020). This rich blend of cultures is intertwined with religious affiliations, as Buddhism holds the largest following, followed by Islam, Christianity, Taoism, and Hinduism (Singapore Department of Statistics, 2019b) with religious identity in Singapore intricately linked to ethnic identity. In addition to the diverse religious tapestry, Singapore recognizes three prominent Asian cultures: Chinese-Confucian, Malay-Islamic, and Indic cultures (Chua, 2005).

These cultural underpinnings are further enriched by Singapore's historical legacy as a British colony and its rapid journey toward globalization since achieving independence in 1965. As a result, the values and practices of its people bear the influence of Western ideals and philosophies. Nonetheless, beneath this overlay of westernization lies a predominant collectivist value system, characterized by a profound emphasis on family and kinship (Foo et al., 2015). This intricate interplay of East-meets-West creates a unique sociocultural landscape within Singapore, giving rise to distinct caregiving practices that likely vary significantly from one family to another. It is within this context that family caregivers

navigate their roles and develop their coping styles, reflecting the profound influence of culture, religion, and history on their experiences. Understanding these cultural dynamics is essential for developing effective support and intervention strategies tailored to the unique needs of family caregivers in Singapore. By exploring the cultural influences on caregiving, we can better appreciate the complex interplay between cultural beliefs, caregiver stress, and PTSS. Thus, with no study having been conducted in this area in Singapore, this quantitative study sought to be the first to examine and explore these aspects.

Given the dearth of research and literature on this population, this quantitative research study is the focus of this chapter, representing a logical and evidence-based progression from the initial scoping review, with the goal of enriching our understanding of this complex caregiving environment. This study focused on caregivers of adults with NDD in Singapore's Institute of Mental Health (IMH), a tertiary psychiatric hospital. This study employed a quantitative approach to identify the prevalence of specific factors, experiences, and challenges faced by primary family caregivers of adults with NDD. The aim was to identify the potential threats primary family caregivers may be exposed to during caregiving for individuals with NDD and the impact on their mental health and well-being. This study also sought to expand the current understanding of PTSS among primary family caregivers of adults with NDD by investigating its occurrence and impact in non-Western cultural contexts, where limited research has been conducted to date.

3.2 Position Statement

Typically, a position statement is presented in the qualitative phase of a research study. However, since this project follows a mixed-method sequential explanatory design, the position statement was more appropriately included in the quantitative phase to provide context for the entire research project.

As a principal clinical psychologist with more than 15 years of experience working in a tertiary mental health hospital in Singapore, I have had the privilege of working extensively with adults with NDD who also present with co-morbid mental health conditions, and behaviours of concern. Throughout my career, I have provided care across inpatient, outpatient, and community settings, working not only with my patients but also with their family caregivers as part of a holistic therapeutic approach. It is through this work that I have come to understand the profound adversities and psychological toll of caregiving faced by family caregivers in their journey to care for their adult children.

In my clinical practice, I have observed how the mental health of family caregivers, many of whom experience heightened anxiety, depressive symptoms, stress, and other mental health challenges, often mirrors the complexities they face in managing the behaviours of concern associated with their adult children with NDD. Over time, it became evident that the emotional and psychological strain family caregivers experience can significantly impact their caregiving capabilities and overall well-being. This realization deepened my commitment to exploring the experiences of family caregivers, particularly the trauma symptoms that can emerge from long-term caregiving.

On a personal level, my dedication to this field is informed by my lived experience. My own family experience has been shaped by the caregiving adversities of my parents, who are the primary caregivers for my younger brother, who has autism. Growing up, I witnessed the emotional and psychological toll it took on them, particularly in coping with the behaviours of concern that accompanied his diagnosis and co-morbid mental health condition. Although I often felt confused and frustrated by the difficulties they encountered, I lacked the words to express these observations. Over time, I saw how fear, anxiety, and stress became part of their daily lives as they navigated the complexities of caregiving.

While my decision to pursue this research on post-traumatic stress symptoms in family caregivers initially stemmed from my clinical work, I now recognize that my personal experiences have also played a profound role in shaping my research interests. The adversities I witnessed at home have been a constant, quiet presence in my life, waiting to be understood and articulated, and the challenges I observed in my clinical work reflect the struggles I have seen at home. This convergence of personal and professional experience has inspired my research, which aims to give voice to the often-unseen trauma caregivers endure and to provide a platform for advocating for their mental health and well-being, ultimately and hopefully, improving outcomes for both family caregivers and the individuals they care for.

With both clinical experience and personal insights shaping the focus of this study, it becomes clear that understanding PTSS in family caregivers of adults with NDD requires more than recognizing the challenges these caregivers face—it demands a deeper exploration of the psychological processes underpinning their experiences. The complex interplay of trauma, caregiver burden, and coping mechanisms highlights the importance of examining not only the direct effects of caregiving on mental health but also the cognitive and emotional factors that influence the development and maintenance of PTSS. The following section will delve into the factors influencing PTSS in family caregivers, providing a theoretical framework for understanding how trauma-related symptoms arise and persist within this unique caregiving context.

3.3 Factors Influencing Post-Traumatic Stress Symptoms

The cognitive model of posttraumatic stress disorder (Ehlers & Clark, 2000) posits that an individual's processing of trauma leads to ongoing distress by perpetuating a sense of current threat through maladaptive appraisals. This cycle of symptoms and coping responses is maintained by individual differences in memory and appraisal processes, highlighting the crucial role of cognitive processes in the development and maintenance of PTSD. Applying the cognitive model of posttraumatic stress disorder to family caregivers of individuals with NDD who exhibit challenging and aggressive behaviours could provide valuable insights into understanding and addressing the psychological impact of caregiving in this population.

Previous studies have shown that caregivers of individuals with neurodevelopmental disorders often face high levels of stress, emotional burden, and trauma-related symptoms due to the challenging behaviours they encounter on a daily basis (Lim et al., 2024). Aggressive behaviours exhibited by adults with neurodevelopmental disabilities (NDD) can be a source of trauma for family caregivers, leading to feelings of fear, anxiety, and hypervigilance (Schnabel et al., 2020; Stewart et al., 2017, 2020). The frequency and severity of these behaviours may contribute to the development of PTSS. Family caregivers' cognition about the trauma, specifically their appraisals and attributions about the aggressive behaviours or significant traumatic caregiving events, can influence the development of PTSS (Kingston et al., 2016; Stewart et al., 2017; Kiełb et al., 2019). For example, significant positive correlation was found between intrusive rumination and overall PTSS levels, with intrusive rumination acting as a predictor of PTSS (Kiełb et al., 2019). Moreover, family caregivers may hold negative appraisals about the challenging behaviours exhibited by individuals with neurodevelopmental disorders, such as feeling responsible for the behaviours or believing they are unable to cope effectively. These negative appraisals may contribute to feelings of helplessness, guilt, and anxiety. By identifying and challenging these negative appraisals,

family caregivers can reframe their thoughts and develop more adaptive coping strategies. Based on these findings, it was logical to explore the role of family caregivers' cognition as a mediating factor in the development of PTSS. Specifically, the researcher hypothesised that family caregivers' appraisals and attributions about the traumatic events would play a mediating role in the relationship between traumatic events and the development of PTSS.

The way family caregivers cope with stress during significant caregiving events can also significantly influence their experience of PTSS. Research has shown that avoidant coping mechanisms are linked to increased PTSS in caregivers of individuals with mental health disorders, (Kingston et al., 2016). Specifically, caregivers who employ avoidant coping strategies experience more severe PTSS, highlighting the importance of adaptive coping mechanisms in mitigating the effects of caregiving-related stress. Furthermore, negative or maladaptive coping styles were identified as risk factors for PTSD in two separate studies (Dew et al., 2004; Richardson et al., 2016). Coping styles are thus likely to play a moderating role in the severity and impact of PTSS, with maladaptive coping strategies potentially exacerbating symptoms.

Similarly, research examining psychiatric morbidity in family caregivers of advanced cancer patients has revealed a longitudinal link between caregiver burden and post-traumatic stress disorder (PTSD). Caregivers who reported higher subjective burden at the outset were more likely to develop PTSD later on, indicating that caregiver burden plays a significant role in exacerbating the severity of PTSD symptoms (Rumpold et al., 2017). Caregiver burden, can thus impact the experience of posttraumatic stress symptoms in caregivers significantly, potentially acting as a moderating factor in their severity and impact.

Finally, the experience and interpretation of trauma is deeply embedded in an individual's cultural framework, comprising beliefs, norms, and practices (Zheng et al., 2020). This highlights that culture is not a secondary factor in understanding trauma and its

psychological consequences; rather, it is a fundamental thread woven into the intricate fabric of an individual's response to and recovery from traumatic events. Culture plays a role in shaping how trauma is perceived, processed, and coped with, making it an important consideration in the comprehensive understanding of trauma's impact. Research exploring cultural differences in emotion regulation strategies in the context of PTSD has revealed the complex interplay between culture and emotional processing (Ford & Mauss, 2015; Seligowski et al., 2015). Studies have consistently shown that cultural background significantly shapes individuals' preferences for emotion regulation strategies, resulting in diverse psychological outcomes (Ford & Mauss, 2015). Thus, cultural factors, including social context, cultural norms and values surrounding caregiving and disability, would play a role in moderating the experience of PTSS.

Cultural factors were also one area of exploration in this research, aimed at understanding their impact and influence on caregiving and caregivers' experiences of trauma within Singapore's multicultural context. Given Singapore's diverse cultural landscape, understanding how cultural beliefs shape caregiving for adults with NDD would provide insights into caregiving for this group of individuals. The study sought to uncover how cultural obligations and justifications influence family caregivers' attitudes and coping strategies, especially given the unique demands of NDD caregiving.

Keeping in view the above discussed factors influencing caregiving, this quantitative study investigated the complex interplay between aggressive behaviours, caregiver cognitions, and post-traumatic stress symptoms in caregivers of adults with neurodevelopmental disabilities. Additionally, the study examined the extent of trauma symptomatology and how it relates to mental well-being of NDD caregivers and other factors such as caregiver burden, coping strategies, and cultural beliefs shedding light on the nuanced factors that contribute to family caregiver well-being and mental health.

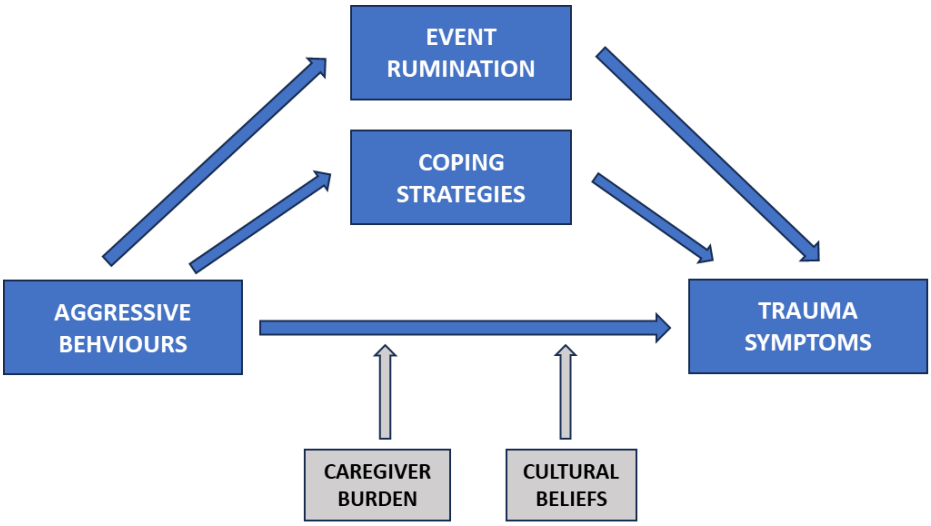
In light of the broader aims of the study the following research questions were addressed –

- What percentage of primary family caregivers meet criteria for PTSS?
- What specific PTSS symptoms are primary family caregivers expected to present with?
- What caregiving events are associated with PTSS?
- What coping styles lead to better psychological wellbeing and lower PTSS for primary family caregivers?
- What cognitive appraisals lead to better psychological wellbeing and lower PTSS for primary family caregivers?
- What is the impact of caregiver burden and cultural beliefs on psychological wellbeing of primary family caregivers?

Figure 2 presents the conceptual framework of this study, emphasising the hypothesised relationships between traumatic events (specifically, aggressive behaviors), primary family caregivers' cognition, and PTSS symptoms.

Figure 2

Conceptual Framework for the Present Study



Additionally, it highlights the hypothesised mediating role of family caregivers' cognition, and coping strategies in the development of PTSS, as well as the proposed moderating influences of caregiver burden, and cultural beliefs. This framework thus serves as a guide for current research questions and informs the analysis of the data collected. Based on the literature reviewed and the research questions raised, several hypotheses were developed. These hypotheses are grounded in the cognitive model of PTSD (Ehlers & Clark, 2000) and supported by evidence highlighting the impact of aggressive behaviours, maladaptive cognitive processing, and coping strategies on PTSS among family caregivers. Additional factors, such as caregiver burden and cultural beliefs, are considered as potential moderators in these relationships.

The literature highlighted that family caregivers of individuals with NDD are frequently exposed to aggressive behaviours, including aggression toward property and physical aggression. These behaviours are often traumatic, evoking fear, anxiety, and hypervigilance, which contribute to the development of PTSS (Schnabel et al., 2020; Stewart et al., 2017, 2020). According to the cognitive model of PTSD (Ehlers & Clark, 2000), exposure to trauma, especially when perceived as a threat to safety, disrupts cognitive and

emotional processing, leading to ongoing symptoms. Aggressive behaviours in particular can act as chronic stressors, reinforcing the caregivers' sense of threat and exacerbating PTSS.

Intrusive cognition, characterized by repetitive and distressing memories of traumatic events, is a hallmark symptom of PTSD. Research by Kiełb and colleagues (2019) demonstrated that intrusive rumination significantly correlates with higher PTSS severity, highlighting how maladaptive cognitive processes fuel anxiety, helplessness, and emotional dysregulation. For caregivers, intrusive thoughts may stem from persistent recollections of aggressive incidents or challenging caregiving moments, further fuelling anxiety, helplessness, and emotional dysregulation. The cognitive model supports this by identifying maladaptive appraisals as key in maintaining trauma-related symptoms.

Additionally, coping strategies play a critical role in managing trauma-related stress. Disengagement coping strategies, such as avoidance, denial, or emotional withdrawal, have been shown to be maladaptive in trauma contexts (Kingston et al., 2016; Dew et al., 2004). These strategies prevented caregivers from effectively processing their experiences and exacerbated distress and PTSS over time. Caregivers using disengagement coping may fail to address the underlying stressors and their emotional responses, leading to chronic symptomatology. By avoiding or suppressing their feelings, they risk reinforcing the cognitive and emotional mechanisms that maintain PTSS (Ehlers & Clark, 2000). In contrast, engagement coping strategies, which involve actively addressing problems and emotional responses, may mitigate PTSS symptoms. As such, it was hypothesized that PTSS reported by primary family caregivers will be significantly predicted by total aggression, event rumination, engagement coping, and disengagement coping. More specifically,

- Total aggression will positively predict PTSS
- Intrusive cognition will positively predict PTSS, while deliberate rumination will negatively predict PTSS

- Disengagement coping will positively predict PTSS, and engagement coping will negatively predict PTSS

Ehlers and Clark's (2000) cognitive model of PTSD highlights how maladaptive cognitive appraisals and emotional processing disruptions maintain trauma symptoms. Intrusive rumination, characterized by repetitive distressing memories of traumatic caregiving events, perpetuates PTSS by reinforcing feelings of helplessness and emotional dysregulation (Kiełb et al., 2019). Similarly, disengagement coping strategies, such as avoidance and emotional withdrawal, prevent caregivers from effectively addressing their emotional responses to aggressive incidents, leading to chronic trauma symptoms (Kingston et al., 2016; Dew et al., 2004). Together, these mechanisms act as mediators in the relationship between aggressive caregiving experiences and the severity of PTSS. Therefore, the following mediation hypotheses were developed:

- The relationship between aggressive behaviours and PTSS will be mediated by:
    a) Intrusive imagination
    b) Coping strategies

Finally, the experience of caregiver burden amplifies the psychological impact of traumatic caregiving events. Research by Rumpold and colleagues (2017) found that higher subjective burden at the outset of caregiving increases the likelihood of developing PTSD symptoms over time. Aggressive behaviours exacerbated caregiver burden by increasing the emotional and physical demands of caregiving, leading to greater vulnerability to PTSS. This suggests that caregiver burden moderates the impact of aggressive behaviours, such that caregivers with higher perceived burden experience more severe PTSS. Cultural beliefs and norms shape how caregivers perceive and cope with traumatic caregiving events. In Singapore’s multicultural context, caregiving is often influenced by cultural expectations, obligations, and justifications (Zheng et al., 2020). Cultural values may either exacerbate or

buffer the effects of aggressive behaviours on PTSS. Furthermore, studies on cultural differences in emotion regulation (Ford & Mauss, 2015; Seligowski et al., 2015) support the moderating role of cultural beliefs in psychological outcomes, making it a crucial factor in understanding how aggressive behaviours impact PTSS severity. Based on this understanding, it was hypothesized that,

- The relationship between aggressive behaviours and PTSS will be moderated by:
    a) Caregiver burden
    b) Cultural beliefs

The hypotheses presented build on established theoretical frameworks and empirical findings to propose relationships between aggressive caregiving experiences, cognitive and coping mechanisms, caregiver burden, and cultural beliefs in predicting PTSS severity among primary family caregivers of individuals with NDD. The rest of the chapter outlines the methodological framework utilized for conducting the quantitative research study exploring PTSS among primary family caregivers of individuals NDD. The following sections describe the quantitative research methodology, results and discussion along with implications of the findings.

3.4 Methods

3.4.1 *Participants*

The study employed a purposeful sampling approach, targeting a more homogenous sample of participants. Participants were identified by clinicians working at Adult Neurodevelopmental Service (ANDS) in IMH, which provides treatment to adults with NDD who have comorbid mental health disorders. Participants were recruited from two different settings of the service: outpatient and inpatient general adult psychiatric wards.

Prior to data collection, an initial analysis using G*Power determined that a minimum of 110 responses, with an effect size of 0.1 and 95% power, was necessary for conducting the planned multiple regression analysis. However, this target sample proved unfeasible even with an extended recruitment period due to various challenges, which included participant reluctance, language proficiency issues, scheduling conflicts, geographical distance, and limited availability of participants. Considering constraints of the PhD research timeline and the imperative to commence recruitment for the qualitative study within the broader framework of this PhD research project, it was decided to work with the sample collected.

The study's final sample comprised 45 primary family caregivers of adult children (aged 19 years and above) with NDD who at the point of recruitment, were receiving out-patient treatment from at IMH. These primary family caregivers included parents, siblings, and other relatives, and will be further described in the Results section. The participants recruited met specific criteria: being the primary family caregiver of an adult child receiving treatment from ANDS, actively involved in their daily care, Singapore citizens or permanent residents, and having basic proficiency in English reading and writing. Participation was entirely voluntary, and no identifiable information was gathered during data collection.

3.4.2 *Ethical Considerations and Approval of the Study*

Ethical approval and permission to conduct the research study was gained from both Institute of Mental Health (IMH), and National Healthcare Group Domain Specific Review Board (NHG DSRB). This approval was then submitted to the James Cook University (JCU) Human Research Ethics Committee for an acknowledgement of an external approval. The acknowledgement from JCU was subsequently obtained before conducting recruitment of participants. A research collaboration agreement (RCA) was also furnished between IMH and JCU following the ethics approval as part of the requirement in conducting the study at IMH.

This study adhered to strict ethical standards throughout the research process. The study was not thought to pose significant risks to either participants or the researcher, was completely non-invasive and did not involve deception of any kind. Informed consent was obtained from all participants, ensuring their voluntary participation. Participant data were treated with strict confidentiality, stored in a password protected USB drive that was kept securely in a locked cupboard to which only the researcher has access.

3.4.3 *Recruitment and Informed Consent*

For recruitment purposes the researcher disseminated an email soft-copy information sheet of the study to clinicians working within ANDS in IMH, and other clinician groups within IMH (e.g. psychiatrists in general adult service, medical social workers, and occupational therapists). Clinicians were requested to share information about the study with their patients' primary family caregivers. Thereafter, the researcher informed and sought permission from the respective ANDS outpatient psychiatrist and psychologists to situate herself outside their clinics to recruit caregiver participants who accompanied the NDD patients to their appointments. Potential participants were then approached by the researcher and a copy of the Participant Invitation Letter with information sheet was shared with them.

Upon a potential participant's expression of interest to take part in the study, the researcher arranged a time convenient for them to meet face-to-face to complete the questionnaire. This face-to-face approach is chosen to ensure sufficient details were collected about potentially caregiving traumatizing events. Written informed consent was then obtained prior to participants responding to the questionnaires. Additionally, potential participants referred by ANDS professional team members, who received the Participant Invitation Letter, expressed interest to take part in the study, and provided verbal consent for their contacts to be passed to the researcher to arrange for a session to complete the questionnaire, were contacted by the researcher. At this appointment, written consent was then obtained prior to them responding to the questionnaires. Participants were given the right to withdraw their participation with the understanding that their data would not be used at any point in time during the research study.

Prior to signing the consent form, participants were given the opportunity to ask questions and were reminded that their answers would remain confidential. Once consent was obtained, participants completed the questionnaire, taking 45-60 minutes on an average to complete the questionnaire. Participants were provided clarifications when they had difficulty understanding what was required of them from the items in the questionnaire.

The researcher was aware that responding to the questionnaire could potentially be upsetting for participants. For that reason, participants were informed that they could withdraw their participation or stop responding to the questionnaire at any time and inform the researcher. Throughout the questionnaire session with participants, the researcher was mindful of and monitored them for any signs of distress. Following the completion of the questionnaire, the researcher enquired into their wellbeing following discussion of any sensitive issues and provided information on community support services available for emotional support, if needed. After completing the questionnaire, participants were thanked

for their time, and were given a $10 shopping voucher each. None of the caregivers required further follow-up for emotional support after the interviews.

3.4.4 *Confidentiality and Data Protections*

The collected data was treated as confidential. All hardcopy data was stored in a designated locked cabinet that was accessible to the researcher only. The databases did not contain any participant identifiers, and the information linking participant identifiers to their identification codes was stored separately. A password-protected portable media device (USB drive) was used to securely store both the data and the participant information. Additionally, participant identifiers were kept in a separate file from the main dataset.

Only the researcher had access to the completed questionnaires. The researcher and research supervisors at James Cook University, Singapore, had password protected access to the data collected from the questionnaires. Following the data collection and data analysis, all questionnaires were stored in a locked cabinet at IMH, where they will remain for the next three years, in line with the current hospital policy.

3.4.5 *Variables and Measures*

The measures used for the present study were all valid and reliable measures, that were formatted in a uniform manner to ensure easy completion and the burden on the participant reduced as much as possible. Measures for all variables of interest are delineated in the following subsections. Demographic information pertaining to caregiver characteristics, characteristics of adult children with NDD, and the living arrangements of adult children with NDD was gathered, as detailed in Table 1. For some measures (PTSD Checklist for the DSM-5 (PCL-5), Event Related Rumination Inventory, Cultural Justifications for Caregiving (CJCS)), the original instructions were adapted to ensure that the participants described their

views and reactions in relation to their caregiving experiences and events and not in relation to other significant life events.

Table 7

Variables in the Study

Variable Category	Variable	Measure
Parent Characteristics	Age Gender Ethnicity Marital Status Employment Status Educational level	Age in years Gender Ethnicity Marital status Employment status Highest level of education
Child with NDD Characteristics	Age Gender Autism Intellectual Disability	Age in years Gender Diagnosis Diagnosis
Potential Trauma Event	Aggressive Behaviours	Modified Overt Aggression Scale Most Significant Caregiving Events Identified by Caregivers
Post-Traumatic Stress Symptoms	Trauma symptoms	PTSD Checklist for the DSM-5*
Caregiver Cognition	Event Rumination (Total) Subscales - Intrusive Cognition - Deliberate Cognition	Event-Related Rumination Inventory*
Coping Styles	Engagement Coping Disengagement Coping	Coping Strategies Inventory-S
Caregiver Burden	Caregiver Burden	Caregiver Burden Inventory
Cultural Beliefs	Cultural Beliefs in Caregiving	Cultural Justifications for Caregiving*

Note. * Original instructions were adapted to ensure that participants described their views and reactions in relation to caregiving experiences and events and not in relation to other significant life events.

3.4.5.1 Modified Overt Aggression Scale. The Modified Overt Aggression Scale (MOAS, Ratey & Gutheil, 1991) consists of 16 types of aggressive behaviour grouped into four subscales (verbal aggression, physical aggression against objects, physical aggression

against the self [SIB], and physical aggression against others) and assessed the aggressive behaviours by the persons with NDD experienced by participants. Each type of aggressive behaviour is rated on a 5-point scale of increasing severity (0 = absent to 4 = most severe). Total score is obtained with the summation of all the weighted scores on each type of aggressive behaviour. Higher scores indicate more aggression. An example item of verbal aggression on the MOAS is “shouts angrily, curses angrily, or makes personal insults”. The scale used in this study demonstrated good reliability, as indicated by a Cronbach's Alpha of 0.753.

3.4.5.2 PTSD Checklist for the DSM-5. The PTSD Checklist for the DSM-5 (PCL-5, Weathers et al., 2013) is a 20-item self-report measure that assesses whether participants report experiencing DSM-5 symptoms of PTSD in relation to a specific trauma event. Responses are rated on a 5-point Likert scale (0 to 4). It provides a total symptom severity score and symptom clusters which align with DSM-5 PTSD criterions. Participants were asked to identify the worst caregiving event and respond with answers relevant to this event. For this study, the Cronbach's Alpha was calculated to be .854, indicating a high level of internal consistency. The scale's overall statistical parameters further support its reliability in measuring posttraumatic stress symptoms among participants.

3.4.5.3 Event-Related Rumination Inventory. The Event-Related Rumination Inventory (ERRI, Cann et al., 2011) consists of two subscales, each containing ten statements. These statements pertain to either intrusive rumination (e.g., “I could not keep images or thoughts about the event from entering my mind”) or deliberate rumination (e.g., “I thought about whether I could find meaning from my experience”). This questionnaire is designed to assess rumination in relation to a specific life event. Participants were asked to consider the worst caregiving event experienced when responding about their ruminations. The scale is rated based on a 4-point Likert scale (0 = not at all, 3 = often). Total score is calculated by

summing all individual item scores; higher scores indicate more rumination about the event. In this study, both the intrusive and deliberate subscales demonstrated high internal consistency, as measured by Cronbach's Alpha (0.926, and .893 respectively).

3.4.5.4 Coping Strategies Inventory-S. The Coping Strategies Inventory-S (CSI-S32, Tobin et al., 1984) is a 32-item measure comprises of emotional, behavioural and cognitive coping strategies, with a 5-point Likert scale where 1= never to 5= almost always. The inventory is comprised of two Tertiary Subscales: Engagement Focused Coping (EFC) and Disengagement Focused Coping (DFC). High scores on the EFC scale indicate typical coping through optimism and active problem solving, exemplified by items such as "I found somebody who was a good listener." In contrast, high scores on the DFC scale indicate typical coping through withdrawal and negative self-evaluation, as illustrated by items like "I wished the situation had never started." In this study, the scale's reliability was measured using Cronbach's Alpha, which yielded a value of 0.864.

3.4.5.5 Caregiver Burden Inventory. Caregiver Burden Inventory (CBI, Novak & Guest, 1989) is a 24-item multidimensional scale designed to measure caregivers' perception of burden associated with providing care for people with Alzheimer's disease (AD). It consists of five subscales, (a) time dependence, (b) developmental, (c) physical, (d) social, and (e) emotional burden domains among caregivers. It has been used in studies of parents with adult children with NDD (Marsack-Topolewski & Church, 2019; Marsack-Topolewski & Hopp, 2019). As the items are relevant for caregivers of individuals with other types of chronic conditions, such as NDD. For example, one item in the inventory states, "My social life has suffered," which aims to gauge the extent to which caregiving duties interfere with the caregiver's personal life and social activities. Another item in the inventory, "I have to help him/her with many basic functions," seeks to understand the time-related stress and constraints faced by caregivers. These items collectively provide insight into the multifaceted

challenges that caregivers encounter, highlighting the impact on both their social interactions and daily responsibilities.

Ratings are indicated using a 5-point Likert scale (0 = not at all descriptive, to 4 = very descriptive). The item scores in each subscale are averaged to obtain the subscale scores and the subscale scores are averaged to obtain the overall perceived burden score. Higher scores reflect higher perceived burden. In this study, the overall scale demonstrated good reliability, with a Cronbach's Alpha of 0.794.

3.4.5.6 Cultural Justifications for Caregiving. Cultural Justifications for Caregiving (CJCS, Dilworth-Anderson et al., 2004) is a 10-item measure was designed to assess caregivers' cultural reasons for care and the cultural expectations in providing care for elderly relatives with dementia. It was adapted for this study by removing the word 'elderly' from three items, for example: 'It is my duty to provide care to ~~elderly~~ dependent family member'. Responses are rated on a scale (1 = strongly disagree, 2 = somewhat disagree, 3 = somewhat agree, 4 = strongly agree). All scores are summed and higher scores represent strong cultural reasons for caregiving. Cronbach's alpha coefficient was .894 in this study.

3.4.6 *Research Design and Analysis*

This study employed a quantitative research design as the first study in a mixed methods study, utilizing an explanatory sequential mixed-methods approach (Creswell & Creswell, 2017). The choice of this quantitative design was based on its suitability for investigating the research questions and hypotheses, as well as its capacity to provide insights into the relationships between variables (Trochim & Donnelly, 2008). The study collected data through questionnaires administered to caregivers of adults with NDD.

All data was analysed using IBM SPSS Statistics version V29.0.1.1. Data screening and assumption testing was conducted prior to the main data analysis to ensure data quality.

The main analysis included descriptive statistics, correlations and regression analysis. Initially, the aim was to investigate the proposed model (Figure 1) by conducting a moderated-mediation analysis, but unforeseen recruitment challenges resulted in smaller sample size, and the plan of analysis had to be adapted. Instead, correlation and regression analyses were conducted to examine the relationships between aggressive behaviours, caregiver cognition, and PTSS, and separate analyses were conducted using simple moderation analysis and mediation analysis to examine the impact of caregiver burden, coping strategies, and cultural beliefs on PTSS and mental wellbeing. With this examination of the relationships between aggressive behaviours, caregiver cognitions, and PTSS, the groundwork for further qualitative exploration in the next phase of the study (presented in Chapter 4) was laid.

Simple moderation analysis was conducted using the PROCESS macro (Hayes, 2018) to examine whether caregiver burden and cultural beliefs moderated the relationship between aggressive behaviours and post-traumatic stress symptoms, and a simple mediation analysis was also conducted using PROCESS macro to examine whether disengagement coping and engagement coping mediated the relationship between aggressive behaviours and post-traumatic stress symptoms. The following sections discuss the findings from the regression, moderation, and mediation analyses. Correlation and regression analyses were conducted to examine the relationships between aggressive behaviours, caregiver cognition, and PTSS, as well as the impact of caregiver burden, coping strategies, and cultural beliefs on PTSS and mental well-being.

3.5 Results

The findings of this quantitative study are presented in a logical and structured manner, aligned with each research question. Results of data screening, assumption testing, and descriptive analysis, are followed by the correlational analysis, and specific hypothesis testing. This presentation allows for a clear and concise exploration of the research questions, enabling a comprehensive understanding of the study's outcomes.

3.5.1 *Data Screening*

Data was screened for missing values and univariate outliers. A check for skewness and kurtosis was performed on all variables, including independent variables, the dependent variable, moderator variables, and mediator variables, to ensure normal distributions. This study involved a clinical sample wherein a normal distribution was not expected, due to the wide variations in symptoms severity and prevalence (Ford & Courtois, 2021; Kwak & Park, 2019). The severity and impact of trauma symptoms can vary widely among individuals, and symptoms tend to cluster at the higher end of the spectrum, leading to a positively skewed distribution. This is particularly true when examining vulnerable caregivers who are at high risk of developing PTSS due to their prolonged exposure to traumatic events and stressors. These inherent characteristics make it challenging to meet the assumptions of parametric statistical tests. Data transformation was considered but not applied, as it would significantly affect the interpretability of results (Pallant, 2000). Statistical significance for all findings was determined based on a criterion alpha level of .05.

Prior to conducting the main regression analysis, several assumptions were evaluated. Uneven distribution and variability were observed through stem-and-leaf plots and boxplots, along with significant Shapiro-Wilk test confirming the expected non-normality. However, the data was analyzed in its original form, without any transformations. The Mahalanobis

distance for the predictor variables (total aggression, intrusive cognition, deliberate cognition, engagement coping, and disengagement coping) used in the regression analysis ranged from .67 to 15.47, which did not exceed the critical χ^2 of 20.52 for $df = 5$ (at $\alpha = .001$) for any case in the data file, indicating that multivariate outliers were not of concern. Furthermore, tolerance and VIF values ranged from .548 to .870 and 1.15 to 1.83 respectively. These values are within the limits of > .10 for tolerance and < 10 for VIF (Bennett et al., 2022), indicating that multicollinearity would not interfere with the ability to interpret the outcome of the analysis.

3.5.2 *Descriptive Analysis*

The initial research questions guided a descriptive analysis to examine the occurrence and characteristics of PTSS among primary family caregivers. Specifically, this analysis aimed to determine the percentage of primary family caregivers who meet the criteria for PTSS, as well as identify the specific symptoms they experience. The demographic characteristics of the primary family caregivers involved in the study offered valuable insights into the composition of the sample and shed light on the caregiving landscape within the population under examination, reflecting a diverse representation across age, gender, caregiving relationship, ethnicity, and employment status.

3.5.2.1 Caregiver Characteristics. The demographic characteristics of the primary family caregiver sample were as follows: the mean age was 58.44 years, with a range of 29-80 years. The age distribution was skewed towards older caregivers, with 71.1% (n=32) of them between 51-64 years old. Females comprised majority of the sample (66.7%, n=30), with 27 mothers, one sister and two female relatives; and 15 males (14 fathers and one male sibling). The ethnic distribution was predominantly Chinese (84.4%, n=38), with only three Malay and four Indian caregivers. Caregivers' employment status was diverse. A significant portion of

caregivers (44.4%) reported being unemployed, which included those who were either retired or not currently working. This was followed by those engaged in full-time employment (37.8%) and part-time employment (17.8%).

3.5.2.2 Characteristics of Adult Child with NDD. The demographic characteristics of the 45 adults with NDD revealed a gender distribution of 66.7% male (n=30) and 33.3% female (n=15). A substantial majority, (n=33, 73.3%) of the adult-children with NDD fell within the age range of 19 to 30 years, while 22.2% (n=10) of them were between 31-40 years old, and 4.4% (n=2) were between 41-50 years old. In terms of diagnostic characteristics, 19 adult children of participants (42.2%) were diagnosed with Intellectual Disability (ID) only, Autism Spectrum Disorder (ASD) was present in 26 participants (57.8%), and 11 participants (24.4%) were identified as having co-morbid ASD and ID.

3.5.2.3 Most Significant Caregiving Event Experienced. The most significant caregiving event experienced and reported by participants, identifying it as the most traumatic experience was used as a reference point for participants to respond to the PCL questionnaire. These events were categorized into four themes (Table 2), of which physical aggression and violence emerged as the most frequent event, followed by verbal aggression. Non-violent offending behaviours/non-aggressive challenging behaviours (such as theft and shop lifting) and safety and security risks (elopement, victim of motor vehicle accident and victim of sexual assault) were less prevalent, with only three and four such instances reported respectively. Notably, four participants reported no significant caregiving events.

Table 8

Most Significant Caregiving Events Identified by Caregivers

Event Themes	Number of Events
Physical Aggression and Violence	24
Verbal Aggression	10
Non-violent offending / Non aggressive challenging behaviours	3
Safety and Security Risks	4
No Significant caregiver event	4

3.5.2.4 Occurrence of PTSD According to the DSM-5 Criterion. Out of the total sample of 45 participants, three participants (6.7%) met the PCL-5 cut-off score of 31, indicating a provisional diagnosis of PTSD. When assessed according to the DSM-5 diagnostic criteria, five participants (11.1%) met the criteria for PTSD. The PTSS reported by caregivers on the PCL-5 subscales and according to the DSM-5 diagnostic criteria are presented in Table 9. It is important to note that while PTSD criteria were assessed based on DSM-5 symptom clusters, this study did not explicitly assess Criterion A in its traditional form (i.e., exposure to actual or threatened death, serious injury, or sexual violence). This presents a limitation, as caregiving-related events—though highly distressing—may not always meet the strict DSM-5 Criterion A threshold. However, recent literature has argued for the recognition of cumulative, chronic stressors and exposure to repeated aggression in caregiving contexts as potentially traumatic experiences (Lim et al., 2024). Nonetheless, the use of DSM-5 criteria in this study should be interpreted cautiously, and the findings highlight the need for ongoing discussion about how trauma and PTSD are conceptualised in caregiver populations.

Table 9

Post-Traumatic Stress Symptoms Reported

Basis of Post-Traumatic Stress Symptoms	Number of Caregivers Reporting Symptom	Percentage (%)
Intrusion	6	13.33
Avoidance	2	4.44
Negative Cognition and Mood	2	4.44
Alterations of Arousal and Activity	1	2.22
DSM-5 Diagnostic Criteria		
Met Criteria B (Intrusion symptom)	19	42.22
Met Criteria C (Avoidance symptom)	8	17.77
Met Criteria D (Negative cognition and mood symptom)	10	22.22
Met Criteria E (Alterations of arousal and activity symptom)	10	22.22

3.5.2.5 Means, Standard Deviations and Correlations. Means and standard deviations for all variables of interest in this study along with bivariate correlations between them were computed to examine the relationships between trauma symptoms, aggression, coping strategies, cognitive processes, and overall well-being (see Table 10).

Table 10

Means and Standard Deviations

Variables	Means	Standard Deviation	Range of Scores for Current Sample	Range of Scores for Measure
Age	58.44	7.76	29 – 77	NA
Intrusion	3.94	3.64	0 – 13	0 – 20
Avoidance	1	1.52	0 – 7	0 – 8
Negative Cognition and Mood	3.4	4.19	0 – 15	0 – 28
Alterations of Arousal and Reactivity	3.2	3.09	0 – 12	0 – 24
Total Trauma Symptoms	11.51	10.97	0 – 44	0 – 80
Verbal Aggression	1.16	.90	0 – 3	0 – 4
Auto Aggression	1.11	1.38	0 – 6	0 – 8
Aggression to Property	3.96	3.79	0 – 12	0 – 12
Physical Aggression	2.76	3.28	0 – 12	0 – 16
Total Aggression	8.98	6.86	0 – 26	0 – 40
Event Rumination	21.13	12.4	0 – 48	0 – 60
Intrusive Cognition	8.87	7.02	0 – 22	0 – 30
Deliberate Cognition	12.29	6.98	0 – 28	0 – 30
Engagement Coping	55.87	12.26	22 – 70	16 – 80
Disengagement Coping	33.36	9.88	16 - 69	16 – 80
Psychological Wellbeing	45.53	6.06	27 – 56	8 – 56
General Wellbeing	28.31	7.69	8 – 46	0 – 84
Cultural Beliefs of Caregiving	33.47	5.79	15 – 40	10 – 40
Caregiver Burden	31.64	15.55	3 – 64	0 – 96

The correlation analysis revealed significant relationships between various variables. Total trauma symptoms were strongly correlated with intrusive cognition ($r = .708$, $p < 0.01$) and event rumination ($r = .723$, $p < 0.01$), and moderately correlated with disengagement coping ($r = .462$, $p < 0.01$) and caregiver burden ($r = .489$, $p < 0.01$). Total aggression demonstrated a moderate correlation with event rumination ($r = .358$, $p < 0.05$). Additionally, disengagement coping was significantly correlated with caregiver burden ($r = .295$, $p < 0.05$). Correlation for all variables of interest is presented in Table 11.

Table 11

Correlation Matrix of Trauma Symptoms, Aggression, Event Rumination, Coping, Cultural Beliefs, and Caregiver Burden

	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1.	**Total Trauma Symptoms**	-												
2.	**Verbal Aggression**	.246	-											
3.	**Auto Aggression**	.222	.004	-										
4.	**Aggression to Property**	.311*	.307*	. 243	-									
5.	**Physical Aggression**	.371*	. 159	. 151	. 492**	-								
6.	**Total Aggression**	.426**	. 378*	. 409**	. 877**	.802**	-							
7.	**Intrusive Cognition**	.708**	. 372*	. 072	. 351*	.371*	.435**	-						
8.	**Deliberate Cognition**	.571**	. 242	. 013	. 057	.282	.201	.570**	-					
9.	**Event Rumination**	. 723**	. 347*	. 049	. 228	.368*	.358*	.886**	.886**	-				
10.	**Engagement Coping**	. 255	. 135	-.101	-.169	.203	.002	.378*	.527**	.511**	-			
11.	**Disengagement Coping**	. 462**	. 136	-.119	.078	.333*	.196	.277	.316*	.335*	.230	-		
12.	**Cultural Beliefs of Caregiving**	. 243	.107	.109	.078	.112	.133	.219	.070	.164	.180	.266	-	
13.	**Caregiver Burden**	. 489**	. 237	. 057	.382**	.290	.392**	.344*	.340*	.386**	-.041	.295*	.181	-

*. Correlation is significant at the 0.05 level (2-tailed); **. Correlation is significant at the 0.01 level (2-tailed).

3.5.3 *Hypothesis Testing*

This following section will present the analysis and results for the respective hypotheses of the study.

3.5.4 *Predictors of PTSS*

Total trauma symptom was used as the criterion variable in the regression analysis instead of subscale scores to provide a holistic measure of overall trauma impact. This approach was to ensure a broader representation of trauma symptoms while addressing the limitations of the small sample size, which could reduce the reliability and validity of analyses based on individual subscales. It was hypothesized that Total Aggression, event rumination and coping strategies would predict trauma symptoms. Separate regression analyses with total aggression, types of event rumination (intrusive cognition, deliberate cognition) and coping strategies (engagement coping and disengagement coping) were conducted to address these hypotheses (see Table 12).

With Total aggression as the predictor, the overall regression model was significant, $F(1, 43) = 9.556$, $p < .003$, indicating that the predictor, total aggression accounted for a significant proportion of variance in trauma symptoms. The model explained approximately 18.2% of the variance in trauma symptoms (adjusted $R^2 = .163$). To further investigate the subtypes of aggressive behaviours, aggression to property and physical aggression were included as predictors in the regression analysis of trauma symptoms. This decision was informed by the significant correlations identified in the earlier correlation analysis (see Table 11). The regression analysis revealed that the overall model was significant, $F(2, 42) = 3.986$, $p = .026$, with the model explaining 16% of the variance in trauma symptoms, suggesting that the predictors together contribute to the explanation of variance in trauma symptoms. The effect size for the model ($f^2 = 0.190$) indicated a medium effect. However, neither aggression

to property nor physical aggression was found to be significant predictors (See Table 12). Thus, this hypothesis was partially supported.

The overall model with intrusive rumination and deliberate rumination as predictors was significant, $F(2, 42) = 24.976$, $p = <.001$, with the model explaining 54.3% of the variance in trauma symptoms, suggesting that the predictors together contributed to the explanation of variance in trauma symptoms. The effect size for the model ($f^2 = 1.19$) indicates a very large effect. Among the predictors, intrusive cognition was found to be a significant positive predictor of trauma symptoms ($\beta = .467$, $p < .001$), suggesting that higher levels of intrusive thoughts are associated with greater trauma symptoms, while deliberate rumination was not statistically significant. These findings highlight the prominent role of intrusive cognition in influencing trauma outcomes.

With disengagement coping and engagement coping as predictors of trauma symptoms, the overall model was significant, $F(2, 42) = 6.528$, $p = .003$, explaining 23.7% of the variance in trauma symptoms, suggesting that the predictors together contribute to the explanation of variance in trauma symptoms. The effect size for the model ($f^2 = .310$) indicates a medium to large effect. Disengagement coping was found to be a significant positive predictor of trauma symptoms ($\beta = .426$, $p = .004$). In contrast, engagement coping did not negatively predict trauma symptoms. The analysis yielded an effect estimate with a 95% confidence interval of [0.163, 0.783]. As the confidence interval does not include zero, the effect is statistically significant, suggesting a positive relationship between the predictor and the outcome. However, the range of the confidence interval indicates some degree of uncertainty, with the true effect potentially being small (0.163) or moderate (up to 0.783). While the result supports the presence of an effect, further research with a larger sample is needed to refine the estimate and improve precision. These findings highlight the critical role

of disengagement coping in exacerbating trauma symptoms among participants, while engagement coping is not significantly related to trauma symptoms.

Table 12

All Predictors of Total Trauma Symptoms Reported

Predictor Variables	***B* [95% CI]**	***Std. Error***	***β***	***t***	***Sig***	***sr²***
Total Aggression	.681 [.237, 1.126]	.220	.426	3.091	.003	-
Aggression Behaviours as Predictors						
Aggression to Property	.488 [-.461, 1.437]	.470	.169	1.037	.306	.021
Physical Aggression	.964 [-.132, 2.059]	.543	.289	1.775	.083	.063
Event Rumination as Predictors of Trauma Symptoms						
Intrusive Cognition	.885 [.485, 1.286]	.198	.467	4.465	<.001	.217
Deliberate Cognition	.390 [-.013, .793]	.2	.248	1.955	.057	.041
Coping Strategies as Predictors of Trauma Symptoms						
Engagement Coping	.140 [-.109, .390]	.124	.157	1.134	.263	.023
Disengagement Coping	.473 [.163, .783]	.154	.426	3.079	.004	.172

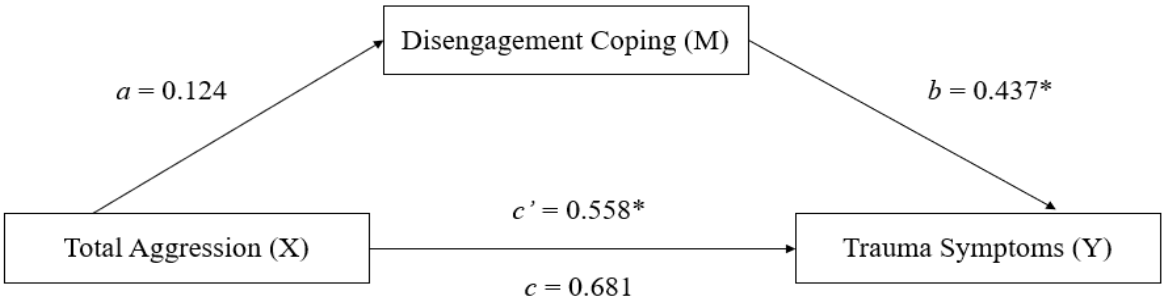
Note: N = 45, CI = confidence interval

3.5.5 *Mediators of the Relationship Between Aggressive Behaviours and Trauma Symptoms*

To examine this potential mediating role of disengagement coping in the relationship between total aggression and participants' trauma symptoms, a mediation analysis was conducted for the second hypothesis (Figure 3), using Model 4 of PROCESS macro for SPSS (Hayes, 2022). The model examined whether participants' use of disengagement coping strategies after experiencing a distressing caregiving event mediated the relationship between aggressive behaviours exhibited by individuals NDD and trauma symptoms in participants.

Figure 3

Mediation Analysis: Total Aggression, Disengagement Coping, Trauma Symptoms



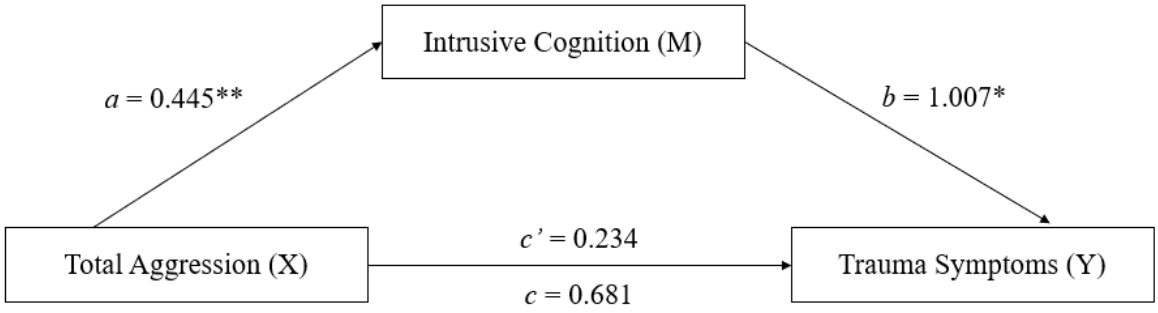
Note: All values in the figure are completely standardised; * = p < .05

The overall model was significant, $F(2, 42) = 10.39$, $p < .001$, explaining 33.09% of the variance in trauma symptoms. The analysis (Figure 3) revealed that the direct effect of total aggression on trauma symptoms was statistically significant (β = .558, $p = .010$, 95% *CI* [.143, .973]). This indicated that total aggression was a positive predictor of trauma symptoms. The effect of disengagement coping on trauma symptoms was also significant, β = 0.437, p = 0.004, 95% *CI* [.149, .725]). This indicated that participants who employed disengagement coping strategies experienced significantly higher trauma symptoms. The indirect effect of total aggression on trauma symptoms through disengagement coping (β =

.124, *SE* = .120, 95% *CI* [-.080, .395]), however was not significant as the 95% confidence interval included zero, indicating that the indirect effect was not statistically significant. This suggests that while disengagement coping strategies are associated with trauma symptoms, they do not significantly mediate the relationship between total aggression and trauma symptoms.

Figure 4

Mediation Analysis: Total Aggression, Intrusive Cognition, Trauma Symptoms



Note: All values in figure are completely standardised; * = p < .05; ** = p < .01

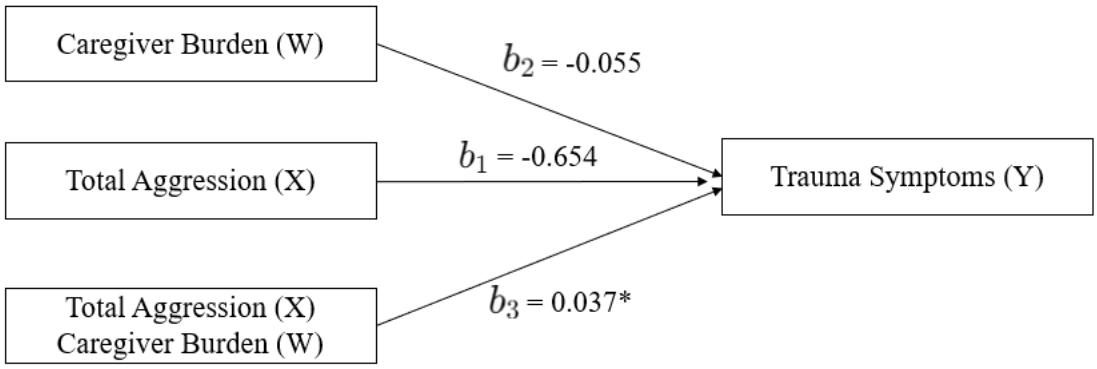
The results showed that the overall model was significant, $F(2, 42) = 22.66$, $p < .001$, explaining 51.90% of the variance in trauma symptoms. The indirect effect of total aggression on trauma symptoms through intrusive cognition was significant (β = .448, *SE* = .213, 95% *CI* [.144, .970]), indicating a mediating role of intrusive cognition in the relationship between total aggression and trauma symptoms. However, the direct effect of total aggression on trauma symptoms was no longer significant (β = .233, $p = .226$, 95% *CI* [-.150, .617]). This finding suggests that total aggression does not have a significant direct effect on trauma symptoms when intrusive cognition is included in the model. This indicate that increasing levels of aggression experienced by participants influence intrusive cognitive thought processes which in turn impacts trauma symptoms.

3.5.6 *Moderators of Trauma Symptoms*

The third hypothesis posited that the relationship between aggressive behaviours and PTSS will be moderated by Caregiver Burden and Cultural Beliefs.

Figure 5

Moderation Analysis: Total Aggression, Caregiver Burden, Trauma Symptoms



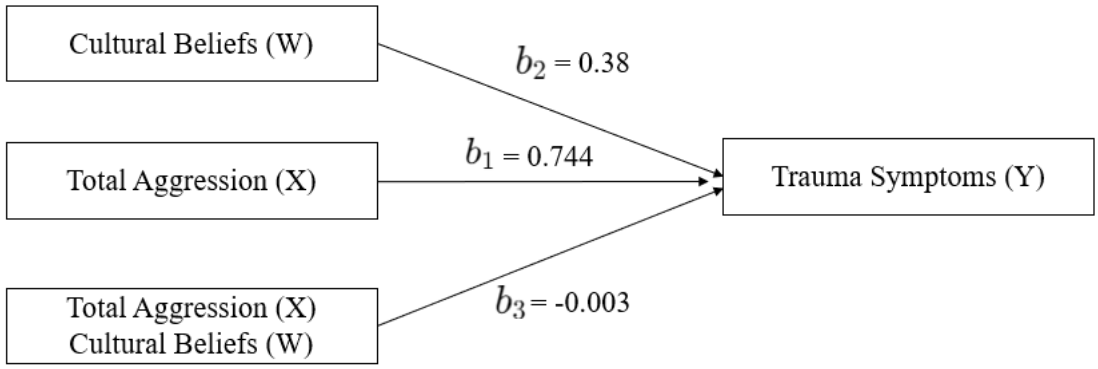
Note: W, independent variable; M, moderator; Y, dependent variable

The results showed that the overall model, with caregiver burden as the moderator, was significant, $F(3, 41) = 8.31$, $p < .001$, explaining 37.82% of the variance in trauma symptoms. The main effects of total aggression (β = -0.654, *SE* = 0.541, $t(41) = -1.210$, $p = 0.233$, 95% *CI* [-1.746, 0.438]) and caregiver burden (β = -0.055, *SE* = 0.174, $t(41) = -0.318$, $p = 0.752$, 95% *CI* [-0.407, 0.296]) on trauma symptoms were not significant. However, a significant interaction between total aggression and caregiver burden (β = .037, $p = .033$, 95% *CI* [.003, .071]) was noted, indicating that the relationship between total aggression and trauma symptoms varied as a function of caregiver burden. Specifically, the results indicated that the relationship between total aggression and trauma symptoms was not statistically significant at low levels of caregiver burden (15th percentile) (β = -.081, $p = .800$, 95% *CI* [-.727, .564]). However, at moderate levels of caregiver burden (50th percentile), the

relationship became statistically significant (β = .539, *p* = .018, 95% *CI* [.099, .980]). This significance was further observed at high levels of caregiver burden (84th percentile), where the relationship was stronger (β = 1.210, *p* = .005, 95% *CI* [.387, 2.035]), indicating a significant positive association between total aggression and trauma symptoms as the level of caregiver burden increased. These findings suggest that caregiver burden moderates the relationship between aggressive behaviours and trauma symptoms, with the strongest impact observed at higher levels of caregiver burden.

Figure 6

Moderation Analysis: Total Aggression, Cultural Beliefs, Trauma Symptoms



Note: W, independent variable; M, moderator; Y, dependent variable

The results of the analysis where cultural beliefs was the moderator, revealed a significant overall model (*F*(3, 41) = 3.80, *p* = .0172), accounting for 21.74% of the variance in trauma symptoms. However, the interaction between total aggression and cultural beliefs was non-significant (β = -.0031, *SE* = 0.053, *t*(41) = -0.059, *p* = .953, 95% *CI* [-.109, .103]), suggesting that the relationship between aggressive behaviours and trauma symptoms was not significantly influenced by cultural beliefs. The results suggest that aggressive behaviours and cultural beliefs do not interact in predicting trauma symptoms in participants.

3.6 Summary of Results and Discussion

The descriptive analysis examined the occurrence and characteristics of PTSS among participants, focusing on demographics, significant caregiving events, the occurrence of PTSD, and key correlational relationships. The participant sample had a mean age of 58.44 years, with most (71.1%) aged between 51–64 years. Females (66.7%) were the majority, consisting mainly of mothers, while Chinese participants predominated (84.4%). Employment status varied, with 44.4% unemployed (retired or not working). Among the adults with NDD, 66.7% were male, and most (73.3%) were aged 19–30 years. Diagnostically, 42.2% had Intellectual Disability (ID) alone, while 57.8% had Autism Spectrum Disorder (ASD), and 24.4% had co-morbid ASD and ID.

Physical aggression and violence were the most frequently reported traumatic caregiving events, followed by verbal aggression. Non-violent offending behaviours and safety risks were less common, and four participants reported no significant traumatic event. PTSD occurrence showed that 6.7% of participants met the PCL-5 cut-off, while 11.1% fulfilled DSM-5 PTSD diagnostic criteria. Intrusion symptoms were the most frequently reported (13.3%), with avoidance (4.4%), negative cognition and mood (4.4%), and alterations in arousal (2.2%) less common. Correlational analysis revealed strong links between trauma symptoms, intrusive cognition ($r = .708$), and event rumination ($r = .723$). Moderate correlations were observed with disengagement coping ($r = .462$) and caregiver burden ($r = .489$).

Regression analysis highlighted intrusive cognition ($\beta = .885$) and disengagement coping ($\beta = .473$) as significant predictors of trauma symptoms, while aggression explained 18.2% of trauma symptom variance. Mediation analysis revealed that intrusive cognition fully mediated the relationship between aggression and trauma symptoms, whereas disengagement coping did not. Moderation analysis indicated that caregiver burden significantly moderated

the link between aggression and trauma symptoms, with stronger associations observed at higher caregiver burden levels. Cultural beliefs, however, did not significantly moderate this relationship. These findings emphasize the critical role of intrusive cognition, disengagement coping, and caregiver burden in shaping participants' trauma experiences.

Results from the quantitative study are discussed in the following section in light of previous research as well as the unique characteristics of the present sample of participants.

3.6.1 *Caregiver Characteristics*

The demographic data revealed several key trends among primary family caregivers of adults with NDDs. The majority of participants were female (66.7%), which is consistent with broader caregiving trends indicating a higher prevalence of female caregivers (Baker et al., 2021; Stewart et al., 2020; Casey et al., 2012). Most participants fell within the 51-64 age group (71.1%), highlighting the middle-aged population's significant role in caregiving. This demographic of participants has implications for relevant support services, particularly regarding health and wellbeing of the participants. The ethnic distribution showed a predominance of Chinese participants (84.4%), which also reflected the demographic composition of the study's geographic context of Singapore.

Employment status data indicated that a significant proportion of participants were unemployed (44.4%), which could be due to the demanding nature of caregiving responsibilities and the aging population of the participants. The relationship data showed that mothers were the primary family caregivers in most cases followed by fathers and in a few cases siblings This suggests that caregiving responsibilities predominantly fall on parents, emphasizing the need for family-centric support systems.

3.6.2 *Characteristics of Adult Children with NDD*

The co-occurrence of ASD and ID in a quarter of the adult-children of participants (24.4%) suggested a complex interplay between these neurodevelopmental disorders. The findings suggested that a significant proportion of individuals with NDDs also exhibited characteristics of ID, impacting their cognitive and adaptive functioning. The high comorbidity rates suggest that a comprehensive diagnostic evaluation is essential to capture the full range of neurodevelopmental difficulties of individuals with NDD, and the resultant caregiving challenges that may arise due to such co-morbidities. Moreover, the findings highlight the need for tailored interventions addressing the unique needs of individuals with co-occurring neurodevelopmental disorders.

Gender distribution showed a notable difference amongst the adults with NDD, with males representing a significantly larger proportion (66.7%) of the sample compared to females (33.3%). This data is aligned with existing literature suggesting higher prevalence rates of NDDs, including ASD, in males compared to females (Zeidan et al., 2022). The age distribution among the adults with NDD revealed that a substantial majority, 73.3%, fell within the age range of 19 to 30 years, which is predominantly younger adults, with relatively few participants in the older age categories. The data implied that the sample may be more representative of early adulthood. Individuals within this age group might present with needs that can become more complex and demanding, prompting parents to seek more specialized support and treatment options (Lunsky et al., 2011). For example, the transition from youth to adulthood can bring new challenges, such as employment, independent living, and social integration, which might require additional interventions and support. As adult-children with NDDs grow older, they may experience changes in their health and functioning that necessitate caregivers to seek out appropriate care options. Over time, the cumulative stress

and emotional burden of caregiving could lead family caregivers to seek help for themselves and their adult children, particularly if they have not previously accessed sufficient support.

3.6.3 *Most Significant Caregiving Event Experienced*

In the context of this study, 'most significant caregiving events' referred to specific incidents within the caregiving experience that participants perceived as the most traumatic event. These events typically involved situations where the participant was faced with intense and immediate challenges, such as managing physical aggression or violent behaviours from the adult with NDD. The findings of this study highlighted the complex and challenging nature of caregiving, with physical aggression and violence emerging as the most significant caregiving event (53.3%) experienced by caregivers. This is consistent with previous research indicating that caregivers are typically at risk of physical harm and emotional distress (Sabapathy et al., 2016; Turnbull & Ruef, 1996; Unwin & Deb, 2011). On the other hand, non-violent offending behaviours/non-aggressive challenging behaviours and safety and security risks were less common, but still present, highlighting the need for a more comprehensive approach to caregiver support.

3.6.4 *Occurrence of PTSS and PTSD Among Caregivers*

The findings from this study revealed significant insights into the occurrence and nature of PTSS among participants. The data indicated that intrusion symptoms were the most commonly reported, with 82.22% of participants experiencing them. This high percentage suggests that intrusive thoughts and memories related to their caregiving experiences were a significant source of distress. Similarly, alterations in arousal and activity were reported by 77.77% of participants, highlighting a pervasive sense of hyperarousal and associated behavioural changes. Negative cognition and mood symptoms were also prevalent, affecting

64.44% of participants, which points to the substantial impact of caregiving on mental health. Avoidance symptoms, although less common, were still reported by 42.22% of participants, indicating efforts to evade reminders of traumatic caregiving events. Such high occurrence of PTSS across multiple domains highlights the considerable psychological burden experienced by participants (Stewart 2017; Baker et al, 2021).

With regard to the occurrence of PTSD, the findings suggested a significant occurrence of PTSD among participants, with 11.1% meeting the DSM-5 diagnostic criteria. This is consistent with previous research indicating that caregivers are at risk of developing PTSD due to their exposure to traumatic stressors (Baker et al., 2021; Stewart et al., 2020; Kielb et al., 2019; Roberts et al., 2014). The lower percentage of participants meeting the criteria based on the cut-off score highlighted the importance of using a comprehensive diagnostic approach, rather than relying solely on symptom severity. Furthermore, the discrepancies between PTSS reported on PCL-5 subscales and PTSS reported based on DSM-5 diagnostic criteria highlighted the complexity of assessing PTSD symptoms. The PCL-5 subscales capture a broader range of symptoms, while the DSM-5 criteria provide a more stringent diagnostic threshold. The findings suggest that participants may experience subthreshold symptoms that, while not meeting the full diagnostic criteria for PTSD, still significantly impair functioning and necessitate support and intervention.

The correlation analyses revealed significant patterns and correlations among trauma symptoms, aggression, coping strategies, cognitive processes, and overall well-being. The findings suggest that trauma symptoms are associated with increased aggression, rumination, cognitive processing, and disengagement coping, as well as reduced psychological and general well-being. Aggressive behaviours were linked to cognitive rumination, avoidance coping strategies, and increased caregiver burden. The strong correlations between trauma symptoms and cognitive processes suggest a close relationship between the two. These

findings have important implications for the development of interventions aimed at addressing trauma and aggression. It has been found that therapy, particularly cognitive-behavioural therapy (CBT), has demonstrated efficacy in addressing the cognitive processes and coping strategies that contribute to trauma symptoms (Foa, 2006). Prolonged Exposure (PE) therapy, a form of CBT, encourages individuals to confront and process trauma memories through repeated imaginal and in vivo exposure (McLean & Foa, 2011). This approach may help caregivers organize fragmented memories, reduce avoidance behaviour, and desensitize their responses to trauma reminders. Such exposure would allow caregivers to re-evaluate their fears, helping them develop more realistic and adaptive beliefs. Therapists can enhance this process by focusing on coping strategies, such as stress inoculation training (SIT), which equips caregivers with skills like relaxation techniques, controlled breathing, and cognitive restructuring to better manage anxiety and strengthen coping mechanisms (Foa, 2006). By targeting cognitive processes, coping strategies, and caregiver burden, such interventions could potentially reduce the impact of trauma on the participants.

3.6.5 *Predictors of PTSS*

The regression analyses presented in this study sought to identify the factors predicting PTSS among participants. The first hypothesis proposed that PTSS would be significantly predicted by aggressive behaviours exhibited by adults with NDD, event rumination (both intrusive and deliberate), and coping strategies (engagement and disengagement). Overall, the findings partially supported this hypothesis, revealing significant associations between some of these predictors and PTSS. This highlights the considerable role that the identified factors play in shaping participants' experiences of PTSS.

Specifically, total aggression emerged as a significant predictor of trauma symptoms. This aligns with literature highlighting the chronic and traumatic nature of aggression in

caregiving contexts, where aggressive behaviours reinforce a sustained sense of threat, contributing to hypervigilance and fear (Schnabel et al., 2020; Stewart et al., 2017, 2020). Although the overall model with subtypes of aggression – aggression to property and physical aggression was significant, neither subtype was an individually significant predictor. This partial support for the hypothesis suggests that while specific aggressive behaviours are impactful, they may not independently explain PTSS variance.

Intrusive cognition strongly predicted PTSS, supporting its role as a hallmark PTSD symptom. Persistent, distressing memories of aggressive caregiving incidents likely perpetuate anxiety and emotional dysregulation, as supported by earlier study (Kiełb et al, 2019). This finding aligns with existing literature that highlights the role of rumination in the development and maintenance of PTSS (Ehler & Clark, 2000), suggesting that participants who repeatedly think about distressing caregiving events are more likely to exhibit trauma symptoms. This result also aligns with previous research highlighting the complexity of trauma symptomatology and the need to consider multiple factors, including cognitive processes, in understanding its development and maintenance of trauma symptoms (Carlson & Dalenberg, 2000). Contrary to expectations, deliberate cognition was not a significant predictor of PTSS. While deliberate rumination was hypothesized to mitigate distress, its non-significance here may indicate limited utility in reducing trauma symptoms within this caregiving context.

Disengagement coping, a maladaptive coping strategy involving avoidance or withdrawal from stressful experiences, significantly predicted PTSS, underscoring its detrimental impact on caregiver well-being. This finding is consistent with research indicating that avoidance strategies prevent effective emotional processing, thereby exacerbating trauma symptoms over time (Kingston et al., 2016; Dew et al., 2004). Engagement coping did not significantly predict PTSS, suggesting it may not play a protective role in this context. This

result highlights the complexity of caregiving trauma, where engagement coping might not offset the effects of chronic stressors like aggression.

These findings have important implications for understanding the psychological processes underlying PTSS in caregivers of adults with NDD. The significant role of event rumination, particularly intrusive cognition, points to the need for interventions that target maladaptive thought processes and encourage more adaptive coping mechanisms. Future research with larger samples size may further elucidate the potential interplay between aggression and trauma, particularly in the context of cognitive coping mechanisms. By addressing cognitive processes such as rumination in therapeutic interventions, clinicians may mitigate the development or exacerbation of trauma symptoms, providing more effective support for caregivers. Additionally, the significant impact of disengagement coping underscores the need for therapeutic approaches that reduce avoidance behaviours and promote effective emotion regulation. Although aggressive behaviours were not found to be direct predictors of trauma symptoms, they likely interact with other cognitive and coping factors to influence caregiver distress. Therefore, the complex interplay of behavioural and psychological factors should be addressed holistically in interventions for caregivers experiencing PTSS.

Future research could aim to replicate these findings with larger samples to increase the precision of estimates and better understand the relationship between aggressive behaviours, cognitive processes, and trauma symptoms in caregivers. This will help clarify whether the observed correlations hold in larger, more diverse populations and provide a more robust understanding of these dynamics. The regression analysis results also revealed that disengagement coping strategies was a significant predictor of trauma symptoms, suggesting that participants who utilized disengagement coping strategies, may be more likely to experience trauma symptoms.

The results aligned with previous research highlighting the importance of coping styles in understanding trauma symptomatology and caregiver burden (Littleton et al., 2007; Walke et al., 2018). Disengagement coping strategies, such as avoidance, may exacerbate trauma symptoms by preventing participants from effectively processing and managing their stress. This may lead to increased emotional distress and a greater sense of burden in managing their caregiving responsibilities. The findings suggest that interventions targeting coping skills, particularly focusing on reducing disengagement coping strategies and promoting more adaptive coping mechanisms, may be beneficial in alleviating trauma symptoms and caregiver burden in this population.

3.6.6 *Mediators of the Relationship between Aggressive Behaviours and PTSS*

Findings from the mediation analysis revealed that total aggression and disengagement coping significantly predicted trauma symptoms directly, however, the indirect effect of total aggression on trauma symptoms via disengagement coping was not significant. These findings suggest that while disengagement coping is associated with higher trauma symptoms, it does not significantly mediate the relationship between aggression and trauma symptoms. The non-significant indirect effect may indicate that disengagement coping, although maladaptive, does not fully explain the link between aggression and PTSS. Other mechanisms, such as cognitive appraisals or environmental factors, may play a more substantial role. This also suggests that simply focusing on coping strategies like disengagement might not reduce the impact of aggression on trauma. The findings highlight the need to explore more adaptive coping strategies that may help participants manage the emotional and psychological demands associated with caring for individuals exhibiting aggressive behaviours. Focusing interventions on more active, problem-solving or emotion-

regulation strategies might provide a more protective effect, potentially reducing both trauma symptoms and caregiver burden.

Engagement coping, despite being found as a non-significant predictor in the current analysis, may still play a crucial role as an adaptive coping mechanism for supporting caregiver well-being. Engagement coping strategies could help caregivers manage the stress associated with their caregiving responsibilities in healthier ways, ultimately fostering resilience and reducing the likelihood of burnout or the development of trauma symptoms. One possible reason for its non-significance in this study could be that participants experiencing high levels of distress might already feel overwhelmed, reducing the perceived effectiveness of active strategies like engagement coping. However, in less acute situations or with appropriate training, engagement coping could help facilitate better emotional regulation, allow caregivers to actively address the stressors at hand, and cultivate a sense of control and competence in their caregiving roles.

Additionally, engagement coping could help in promoting a more positive outlook and enhancing social connections, both of which are crucial for emotional well-being of caregivers. By promoting constructive actions and fostering support networks, engagement coping may help caregivers build a buffer against the stressors of caregiving, which can be essential for long-term mental health and well-being. Therefore, even though it may not significantly predict trauma symptoms in the current analysis, engagement coping still holds promise as an adaptive strategy that interventions could encourage to improve overall caregiver resilience and psychological health. Training caregivers to utilize engagement coping effectively may help them navigate the complex challenges of caregiving with greater emotional balance and proactive problem-solving. These results highlight the limitations of disengagement coping strategies and suggest that interventions aiming to reduce trauma symptoms in caregivers could focus on promoting more adaptive coping mechanisms.

The mediation analysis examining the role of intrusive cognition in the relationship between traumatic events (total aggression) and post-traumatic stress symptoms (total trauma symptoms) revealed significant findings, supporting the hypothesis. Intrusive cognition was found to significantly mediate this relationship. Specifically, while the direct effect of aggression on trauma symptoms was not significant when accounting for intrusive cognition, the indirect effect through intrusive cognition was highly significant. These results suggest that aggressive behaviours likely trigger intrusive cognitive thought processes, which in turn contributed to the development of trauma symptoms in the participants. These findings indicate that the impact of traumatic events, such as aggressive behaviours, on trauma symptoms is not direct, but rather operates indirectly through intrusive thoughts. The results suggest that as participants experience increasing levels of aggression from their adult-children, they may be more prone to engaging in repetitive, intrusive thoughts, which heighten their trauma symptoms. This mediating role of intrusive cognition highlights the importance of cognitive processes in understanding the relationship between traumatic events and trauma symptoms.

The results aligned with existing literature emphasizing the significance of cognitive appraisals and intrusive thoughts in the development and maintenance of post-traumatic stress symptoms (Ehlers & Clark, 2000; Foa & Rothbaum, 2001). Intrusive thoughts may create a cycle of distress, where caregivers continuously re-experience stressful events mentally, exacerbating their trauma symptoms over time. The findings have implications for the development of interventions aimed at reducing trauma symptoms in caregivers, and implications of interventions aimed at coaching caregivers in managing the significant caregiving events identified to be traumatic. Targeting intrusive cognitive thought processes through cognitive-behavioural therapies or mindfulness-based interventions may be an

effective strategy in mitigating the impact of traumatic events on (Foa & Rothbaum, 2001) trauma symptoms.

In summary, while disengagement coping contributes to PTSS severity, it does not mediate the relationship between aggression and trauma symptoms. In contrast, intrusive cognition plays a significant mediating role, highlighting the centrality of maladaptive cognitive processes in the trauma response. The findings emphasize the role of cognitive mechanisms, particularly intrusive thoughts, in translating the impact of caregiving-related aggression into trauma symptoms. This aligns with the cognitive model of PTSD (Ehlers & Clark, 2000), which underscores the importance of addressing maladaptive thought patterns to mitigate trauma. These findings underline the importance of addressing both cognitive and behavioural responses to trauma in designing effective caregiver interventions.

3.6.7 *Moderators of PTSS*

The third hypothesis posited that the relationship between aggressive behaviours and PTSS will be moderated by caregiver burden and cultural beliefs. The results from the moderation analysis supported caregiver burden as a significant moderator in the relationship between aggressive behaviours and PTSS, with the strongest relationship observed at higher levels of burden. This means that the effect of aggressive behaviours on trauma symptoms is not uniform but varies based on the degree of burden experienced by the participant. This interaction suggests that as the level of caregiver burden increases, the impact of aggressive behaviours on trauma symptoms also intensifies. At low levels of burden, aggression had no significant effect on trauma symptoms. However, at moderate and high levels of burden, the interaction between aggressive behaviours and trauma symptoms became significant, such that increase in burden intensified the experience of trauma symptoms among participants.

These findings suggest that participants who experienced higher levels of burden may be more vulnerable to the negative effects of aggressive behaviours on trauma symptoms because their emotional and physical resources were likely already depleted. When caregivers are under significant stress and burden, they may have less emotional and physical resilience to manage and mitigate the impact of aggressive behaviours. As a result, the compounded stress from both high caregiver burden and exposure to aggressive behaviours could lead to more severe trauma symptoms in this group of participants. This finding highlights the critical need for supportive interventions that aim to reduce caregiver burden and enhance coping mechanisms to protect caregivers from the psychological toll of aggressive behaviours.

The findings from the moderation analysis have important implications for the development of interventions aimed at reducing trauma symptoms in participants. Targeting caregiver burden through supportive interventions may be an effective strategy to mitigate the impact of aggressive behaviours on trauma symptoms. For example, providing caregivers with access to respite care, counselling services, and stress management programs could help alleviate their overall burden and improve their ability to cope with aggressive behaviours. Additionally, training caregivers in effective behavioural management techniques may help reduce the frequency and severity of aggressive incidents, further diminishing their impact on trauma symptoms.

On the other hand, findings did not support the hypothesized moderating role of cultural beliefs in the relationship between aggressive behaviours and trauma symptoms. The analysis revealed no significant interaction between cultural beliefs and aggressive behaviours, suggesting that cultural beliefs did not significantly impact and the experience of trauma symptoms in this context. While cultural beliefs may shape how caregivers perceive and approach their caregiving roles, they do not appear to alter the relationship between aggressive behaviours and trauma symptoms. This suggests that cultural values and norms

may not directly affect how aggression contributes to PTSS. Alternatively, the role of cultural beliefs could be more nuanced, potentially interacting with other variables not captured in this analysis.

In summary, the significant moderating effect of caregiver burden highlights its critical role in shaping the psychological outcomes of caregiving. Participants experiencing higher burden are more vulnerable to the adverse effects of aggression, underscoring the need for targeted support to alleviate burden and build resilience. The absence of a significant moderating effect for cultural beliefs suggests that individual-level psychological processes, such as coping and cognition, may have a greater influence on trauma symptoms than cultural or societal factors. However, this does not diminish the broader role of cultural context in caregiving experiences, which might require alternative methods of exploration. Together, these findings contribute to a more comprehensive understanding of the dynamics influencing trauma symptoms in caregivers.

3.7 Limitations

In considering the limitations of this study, several factors may affect the interpretation, generalizability, and robustness of the findings. Notably, interaction effects typically require larger sample sizes to detect meaningful associations. The smaller-than-recommended sample size in this study likely reduced the statistical power, limiting the ability to draw firm conclusions. While several hypothesised relationships emerged as statistically significant—underscoring their potential relevance—non-significant results should be interpreted with caution, as the study was underpowered to detect small to moderate effects. These may reflect insufficient power rather than a true absence of effect. Therefore, the findings should be considered preliminary, and future studies with larger samples are essential to more accurately estimate effect sizes, confirm observed patterns, and enhance the

reliability of the conclusions drawn. Additionally, future research would benefit from the use of simplified analytic models with fewer variables to improve statistical power and reduce the risk of overfitting. Streamlined models can offer more stable estimates and clearer insights, particularly in studies with limited sample sizes.

The current study faced challenges in recruiting participants, who may experience emotional burden and time constraints. Participants may have been hesitant to participate due to the emotional toll of discussing their experiences or may have had limited time availability due to caregiving responsibilities. The sample size and demographic characteristics also may not have been representative of the larger population of caregivers of individuals with NDD, potentially limiting the generalizability of findings.

Considering that participants needed to allocate time from their schedules for completing the questionnaire, offering an online questionnaire format could be a practical solution. This approach would allow participants to complete the questionnaire from home at their convenience and enable them to do so in multiple sittings if needed, thereby reducing time pressure and potentially increasing participation. This approach could have potentially enhanced participant engagement and interest in the study, thus contributing meaningful data to the study. However, conducting the study face-to-face ensured the accuracy and reliability of the responses but at the cost of a smaller sample size due to the added time and logistical constraints on participants.

As to the measures used in this study, the Cultural Justifications for Caregiving Scale (CJCS) was chosen for this study because it appeared relevant to understanding the cultural reasons that influence caregiving among those supporting adults with neurodevelopmental disorders. Additionally, to the best of the researcher's knowledge, this is the only scale specifically designed to assess cultural justifications for caregiving, making it particularly suitable for this study. The aim was to measure the extent to which cultural justifications or

obligations play a role in caregivers' motivations and experiences. However, the CJCS may not have been fully suitable for measuring cultural factors influencing caregiving of adults with NDD due to several limitations. Although the CJCS reliably measures cultural motivations and expectations around caregiving, it was initially designed for caregivers of elderly relatives with dementia, whose challenges differ from those encountered by caregivers of adults with NDD. Dementia care often involves a progressive cognitive and physical decline and aligns closely with cultural norms about elder care, whereas caregiving for adults with NDD entails managing long-term behavioural and emotional needs. This mismatch in caregiving demands may mean that the CJCS items, which were developed in consideration of cultural expectations about duty toward the elderly, are less relevant for NDD caregivers, who may face different societal pressures, including stigma and limited cultural acknowledgment for lifelong caregiving.

While cultural justifications may shape caregiving attitudes, they do not necessarily reflect the intense stress that often accompanies caregiving for adults with NDD, where experiences such as burnout, emotional fatigue, and managing complex behaviours are common. Simply removing the term "elderly" from some items may not have sufficiently captured these nuances, as caregiving responsibilities for individuals with NDD extend beyond age-related expectations and involve advocacy, long-term developmental concerns, and managing challenging behaviours.

The study's reliance on self-report measures may also have introduced biases and limitations, such as participants' ability to accurately recall and report their experiences. Self-report measures are subjective and may be influenced by various factors, including memory lapses, social desirability bias, and emotional state of the participant. This could lead to inaccurate or incomplete data, potentially impacting the validity and reliability of the findings.

In particular, data collection may have been impacted by social desirability bias, as participants may underreport traumatic symptoms or overreport positive coping strategies to present themselves more favourably. This bias could have resulted in inaccurate data, as participants may feel inclined to provide responses that are perceived as socially acceptable rather than their genuine experiences, especially since this data was collected face-to-face. This tendency to underreport could be particularly problematic when examining sensitive topics like traumatic symptoms, where participants might downplay the severity of their distress due to shame, guilt, or fear of judgment. Consequently, this underreporting could lead to an underestimation of the true occurrence and severity of trauma symptoms, skewing the study's findings.

In addition to potential social desirability bias, participants may hesitate to acknowledge or report experiencing trauma related to their own child due to various reasons, including deeply ingrained societal beliefs and cultural norms surrounding caregiving roles and familial responsibilities. In some cultural contexts, there may be a reluctance to perceive or label experiences within the family unit as traumatic, as it may conflict with prevailing cultural notions of parental duty and unconditional love. Moreover, participants might hold the belief that acknowledging trauma could be construed as a sign of weakness or failure in fulfilling their caregiving role, further contributing to underreporting.

The study did not examine the potential impact of participants' preexisting mental health conditions, which might have influenced their susceptibility to trauma and coping strategies. Understanding how caregivers' own mental health histories, such as previous anxiety, depression, or trauma exposure, interact with their caregiving experiences would provide a more complete picture of the factors influencing PTSS.

Although the study briefly addressed Singapore's multicultural landscape, the complexity of how cultural norms, family expectations, and caregiving practices influence

PTSS was not explored in depth. This study was not able to thoroughly examine the intersection of cultural beliefs and caregiver trauma experiences, which may differ significantly between caregivers of various ethnic backgrounds within Singapore. This limitation emphasizes the need for future research to explore how cultural differences influence caregiving experiences, perceptions of traumatic events, and coping mechanisms in a more nuanced way.

3.8 Implications for Research and Practice

3.8.1 *Implications for Further Research*

Given the complexity and depth of PTSS in primary family caregivers of adults with NDD, a qualitative study would provide rich, nuanced insights into the lived experiences of these caregivers. Such an investigation would allow researchers to explore not only the manifestation of PTSS but also the contextual factors influencing their caregiving journey.

A qualitative approach would enable a deeper understanding of how primary family caregivers interpret and make sense of their distressing experiences. Primary family caregivers could share personal narratives about how their caregiving roles have impacted their mental health, specifically focusing on events or periods that may have been particularly traumatic. This exploration could uncover the emotional, psychological, and social dimensions of caregiving, thereby giving voice to individual experiences that may not be fully captured by quantitative measures.

The subsequent qualitative study will investigate primary family caregivers' strategies for managing aggressive behaviours, the challenges they face, and the impact of available interventions and support systems. By understanding the support systems and resources that primary family caregivers find helpful in managing PTSS, this qualitative exploration will inform the development of more effective support services, ultimately contributing to

improving the mental health and well-being of primary family caregivers and the individuals they support.

The current study found that cultural beliefs were not a significant moderator of PTSS among participants. However, this does not imply that cultural beliefs are irrelevant to the caregiving experience. Since the Cultural Justifications for Caregiving Scale (CJCS) may have had limitations in capturing the nuanced cultural justifications influencing caregiving in this context, it remains essential to investigate cultural influences. Participants in this study reside in a multicultural environment, where diverse cultural norms, values, and expectations likely shape their caregiving roles in complex ways. A qualitative approach, such as in-depth interviews, could provide valuable insights into how these cultural beliefs impact caregiving practices, coping mechanisms, and attitudes. Such exploration would contribute to a better understanding of the unique challenges and needs of primary family caregivers, facilitating the development of culturally sensitive interventions and support systems tailored to their sociocultural context.

3.8.2 *Implications for Practice*

The findings from this study provide several important considerations for clinical practice, particularly in developing interventions to support family caregivers of adults with NDD. While disengagement coping was found to be a significant predictor of trauma symptoms, the study's results highlight the potential benefits of fostering adaptive coping mechanisms, such as engagement coping. Even though engagement coping was not found to be a significant predictor of trauma symptoms in this study, it remains a promising avenue for caregiver support. Strategies that encourage active problem-solving, emotional regulation, and seeking social support could help family caregivers manage stress more effectively and promote their psychological well-being.

The study highlighted the significant role of event rumination, particularly intrusive cognition, in contributing to trauma symptoms. Practitioners could focus on interventions that target maladaptive cognitive processes, such as cognitive-behavioural therapy (CBT), mindfulness-based interventions, or trauma-focused therapies to help caregivers reframe negative appraisals and reduce ruminative thoughts. Helping family caregivers process and integrate their caregiving experiences in a healthier way may reduce the severity of trauma symptoms and enhance their coping capacity.

Given that caregiver burden significantly moderates the relationship between aggressive behaviours and PTSS, reducing the perceived burden through supportive resources is paramount. Interventions could include providing access to respite care, support groups, counselling services, and psychoeducation. Additionally, providing family caregivers with practical tools and strategies for managing aggressive behaviours in care recipients would reduce stress and enhance their sense of self-efficacy.

A holistic approach to family caregiver support should include a comprehensive assessment of family caregivers' psychological, emotional, and social well-being. Tailored interventions could then be designed based on individual needs, taking into account the family caregiver's coping strategies, burden level, and cultural background. Such personalized interventions are likely to be more effective in addressing the diverse experiences of family caregivers and mitigating the risk of PTSS.

3.9 Conclusion

The quantitative study outlined in this chapter provides key insights into the occurrence and impact of PTSS among primary family caregivers of adults with NDD in Singapore. The study found that over 40% of participants experienced intrusion symptoms, with smaller yet significant proportions meeting the diagnostic criteria for PTSD. The

findings revealed significant relationships between PTSS, aggressive behaviours, caregiver burden, cognitive processes (specifically intrusive rumination), and coping strategies (particularly disengagement coping). The role of intrusive rumination emerged as a critical cognitive factor, acting as a mediator between aggressive behaviours and PTSS. Additionally, caregiver burden significantly moderated the relationship between aggressive behaviours and trauma symptoms, suggesting that higher burden amplifies the psychological impact of such behaviours. These results highlight the need for targeted interventions that address maladaptive cognitive processes and provide caregivers with adaptive coping mechanisms. While cultural beliefs were not found to significantly moderate the relationship between aggressive behaviours and PTSS, the unique cultural context of Singaporean family caregivers still presents an important backdrop for understanding caregiving experiences.

Building upon these findings, a subsequent qualitative study was conducted to delve deeper into the lived experiences of primary family caregivers and explore the nuanced factors contributing to their traumatic stress. By conducting in-depth interviews, the qualitative phase aims to provide a more holistic understanding of how primary family caregivers interpret their distressing experiences, navigate cultural influences, and manage the challenges of their caregiving roles. The qualitative study aims to explore how primary family caregivers perceive traumatic events, identify which specific events they find most traumatic, and examine the impact of these events on their mental health. Additionally, the qualitative phase will examine the impact of cultural beliefs on caregiving experiences and support needs, uncovering how cultural factors shape caregiver burden, coping strategies, and help-seeking behaviours. This exploration will provide valuable insights into the cultural dimensions of caregiving and guide the development of culturally sensitive support services.

Chapter 4

Qualitative Exploration of Trauma and Psychological Impacts in Caregiving of Adults with Neurodevelopmental Disorders

4.1 Research Rationale Based on Quantitative Study Findings

Caregiving for adults with neurodevelopmental disorders is a complex and demanding role, often fraught with significant challenges. Literature discussed from studies reviewed highlight and the scoping review study (Lim et al., 2024) consistently highlighted the risk of physical harm and emotional distress among caregivers, particularly in the face of physical aggression and violence. The quantitative study built on these findings, providing a broad understanding of the experiences and psychological impacts on primary family caregivers of adults with NDD in Singapore.

The study's findings highlighted the complexity of caregiving, with physical aggression and violence standing out as the most significant events, accounting for 53.3% of what participants identified as the most traumatic incidents within their caregiving experience. Other notable events included verbal aggression, non-violent offending behaviours, non-aggressive challenging behaviours, and safety and security risks. This aligns with existing literature, emphasizing the perilous nature of caregiving environments. Notably, 11.1% of participants in the quantitative study met the DSM-diagnostic criteria for PTSD, reinforcing previous research that links caregiving to a heightened risk of developing PTSD due to exposure to traumatic stressors. Correlation analyses revealed intricate patterns among trauma symptoms, aggression, coping strategies, cognitive processes, and overall well-being. Trauma symptoms were associated with increased aggression, rumination, cognitive processing, and

disengagement coping, alongside diminished psychological and general well-being. These findings suggest an influence of cognitive and emotional factors on the caregiving experience.

Aggressive behaviours alone did not significantly predict trauma symptoms, however, event rumination emerged as a critical factor, explaining a significant portion of the variance. In line with cognitive models of PTSD, this suggests that cognitive processes are pivotal in understanding the development of trauma symptoms in caregivers. Disengagement coping strategies also significantly predicted trauma symptoms and caregiver burden, indicating their detrimental role in caregiver distress. Findings indicated that intrusive cognition mediated the relationship between aggression and trauma symptoms. Additionally, caregiver burden moderated the impact of aggressive behaviours on trauma symptoms, while cultural beliefs did not.

Although cultural beliefs were not found to moderate the relationship between aggressive behaviours and trauma symptoms, this result may be attributed to the limitations of the Cultural Justifications for Caregiving Scale (CJCS). The scale may not have captured the nuanced cultural factors associated with caregiving for adults with NDD, which often involved unique long-term demands and societal pressures. Despite this limitation, it remains important and relevant to explore cultural influences on caregiving within this context, as part of a broader effort to understand PTSS among these primary family caregivers. This exploration can provide deeper insights into how cultural factors shape caregiving experiences and impact trauma responses in this group of primary family caregivers. A qualitative study could provide a more nuanced and in-depth understanding of how cultural beliefs influence caregiving experiences. This approach allows for flexibility, enabling primary family caregivers to share insights that standardized measures, like the CJCS, may not have captured.

Building on the quantitative findings, this qualitative study aims to explore the lived experiences of primary family caregivers in greater depth, focusing on the nuanced and personal dimensions of caregiving. While the quantitative study offered important insights into trauma symptoms and associated predictors among caregivers, it was limited in its ability to capture the depth and complexity of lived experiences. Specifically, the quantitative tools could not fully illuminate how participants made sense of traumatic events, coped with distress, or perceived their roles and responsibilities. A qualitative approach was therefore essential to provide a richer, contextualised understanding of these processes, allowing for a more holistic account of caregiving under chronic stress. Furthermore, although cultural beliefs did not significantly moderate relationships in the quantitative phase, this may be due to measurement limitations of the CJCS. Standardised instruments may not adequately capture the culturally nuanced and context-specific ways in which participants frame and respond to their roles. A qualitative inquiry enables the exploration of these subtleties, offering insights that might not emerge from structured assessments alone. By examining the narratives and perspectives of primary family caregivers, this study seeks to uncover how they make sense of their experiences, how they cope with challenges, and how cultural influences shape these processes. In doing so, it aims to identify stressors and support needs that may otherwise go unnoticed in quantitative studies. This chapter details the methodology used in this qualitative research study, encompassing the research design, participant selection, data collection procedures, instruments, data analysis techniques, and ethical considerations. Additionally, this chapter will include a section on the results of the qualitative analysis, accompanied by a brief discussion, to provide immediate context and interpretation of the findings within the framework of the study.

The research questions for this study were formulated based on the findings of the quantitative analysis and aimed to address the following objectives:

a. To probe PTSS experiences: This involves exploring primary family caregivers' experiences with PTSS by examining their perceptions and interpretations of distressing caregiving events that have led to PTSS, as well as the impact of these events on their caregiving responsibilities. Therefore, the research question is:

    i. What are the perceptions and interpretations of distressing caregiving events that have led to PTSS among primary family caregivers, and how do these experiences impact their caregiving responsibilities?

b. To examine cultural and belief influences: This entails investigating the extent to which primary family caregivers' cultural backgrounds and belief systems influence their caregiving experiences and their responses to PTSS. Hence, the research question is:

To what extent do caregivers' cultural backgrounds and belief systems influence their experiences and responses to PTSS in the context of their caregiving roles?

4.2 Methods

4.2.1 *Participants*

This qualitative study involved 10 primary family caregivers of adult children who, at the time of recruitment, were receiving treatment from the Adult Neurodevelopmental Disorder Service (ANDS) at the Institute of Mental Health (IMH). These participants were selected from a pool of primary family caregivers who had participated in the preceding quantitative study and consented to engage in face-to-face interviews. Purposive sampling was employed to ensure the inclusion of participants from diverse cultural backgrounds.

Participants comprised an equal number of male and female primary family caregivers, specifically five fathers and five mothers. The ethnic composition of the participants included six Chinese, two Malay, and two Indian participants. This diverse ethnic representation reflects the multicultural nature of Singaporean society and allows for an exploration of how different cultural backgrounds influence caregiving experiences. The ages of the participants ranged from 54 to 70 years (M = 61.3, SD = 4.96), providing a broad age spectrum. This age range captures the experiences of participants in different stages of later adulthood, offering insights into how age-related factors may impact caregiving roles and stressors.

Participants also identified certain significant caregiving events that were experienced as traumatic. The significant caregiving events were categorized into physical aggression, verbal aggression, non-violent offending behaviours or non-aggressive challenging behaviours such as stealing, and behaviours that pose safety and security risks. The most frequently reported type of significant caregiving event was physical aggression and violence, mentioned by nine participants. These incidents involved actions that directly threatened the physical safety of the participant, the care recipient, and other family members. Verbal aggression was reported in two instances. While not physically harmful, these actions create a

hostile and stressful environment, potentially impacting the participant's emotional and psychological well-being. One participant reported their adult child's stalking behaviour towards the opposite gender as a significant caregiving event. While the behaviour itself is not directed at participants, it presents serious difficulties due to the violation of trust and the potential for legal and social consequences. Additionally, three participants reported behaviours that posed safety and security risks, specifically absconding from home and suicidal attempts. These incidents highlight that, beyond aggression and violence, participants must also contend with ensuring the safety and well-being of their care recipients. This responsibility likely adds another layer of complexity and stress to their caregiving roles. For a complete description of the participants' characteristics and significant caregiving events, please refer to Table 13.

Table 13

Demographic Characteristics and Significant Caregiving Events

Pseudonym	Caregiver Gender	Ethnicity	Age	Significant Caregiving Event Identified As Traumatic by Caregivers
Ahmad	Male	Malay	60	Physical Aggression and Violence
Saanvi	Female	Indian	55	Physical Aggression and Violence, Safety and Security Risks – Suicidal Attempt and Abscondment from Home
Christine	Female	Chinese	63	Physical Aggression and Violence
Kenneth	Male	Chinese	70	Physical Aggression and Violence, Safety and Security Risks – Suicidal Attempt and Abscondment from Home
Rohan	Male	Indian	56	Physical Aggression and Violence
Alice	Female	Chinese	65	Physical Aggression and Violence, Non-violent offending behaviours
Melissa	Female	Chinese	54	Verbal Aggression, Safety and Security Risks – Suicidal Attempt
Naomi	Female	Chinese	60	Physical Aggression and Violence
Peter	Male	Chinese	64	Physical Aggression and Violence, Safety and Security Risks – Abscondment from Home
Syafiq	Male	Malay	66	Physical Aggression and Violence

4.2.2 *Procedure*

Upon completion of the questionnaires in quantitative study, participants were asked if they consented to be contacted for a face-to-face interview as part of the mixed-method study. 10 participants who agreed to be contacted after the quantitative study were contacted and an information sheet of the study was given to them explaining the purpose and process of the study. An interview session was then arranged upon their agreement to participate.

Before beginning the interview in qualitative study, participants were given opportunity to ask questions and reminded that their answers would remain de-identified. Participants took an average of 60 minutes to complete the interview. At the end of the interview, participants were thanked for their time, and were given a $10 shopping voucher each. Interviews were conducted in a meeting room within the hospital that was free from

noise and disturbance. These interviews were audio-recorded, transcribed verbatim, and supplemented with field notes.

The researcher was aware that responding to the questions in the qualitative study about their caregiving experiences could potentially be upsetting for participants. For that reason, participants were informed that they could withdraw their participation or stop the interview at any time and inform the researcher, who was then to provide information of community services that provide emotional support. Following the completion of the interview, the researcher enquired into their wellbeing following any discussion of sensitive issues. Throughout the interview session with participants, the researcher was mindful and monitored for any signs of distress. None of the participants appeared overly distressed or chose to discontinue the interview.

4.2.3 *Ethics Considerations and Approval of the Study*

Similar to the quantitative study, this qualitative study adhered to strict ethical standards throughout the research process. The study was not thought to pose significant emotional distress to either participants or the researcher, were non-invasive and did not involve deception of any kind. Informed consent was obtained from all participants, ensuring their voluntary participation. Participant data were treated with strict confidentiality and stored securely. Ethical approval for the study was obtained from both the Institute of Mental Health (IMH) and the National Healthcare Group Domain Specific Review Board (NHG DSRB), with subsequent acknowledgment from James Cook University (JCU). Before participant recruitment, a Research Collaboration Agreement (RCA) between IMH and JCU was established as required.

4.2.4 *Informed Consent and Consent Process*

In the qualitative study, participants who agreed to be contacted for a face-to-face interview after completing the quantitative study were contacted. An information sheet was verbally shared with them, explaining the purpose and the process of the study. Upon agreeing to participate, an interview session was arranged. At their arrival for this interview session, the informed consent of the participants was obtained prior to the commencement of the interview.

4.2.5 *Confidentiality and Data Protection*

The collected data was de-identified and treated as confidential. All hardcopy data was stored in a designated locked cabinet(s) that were accessible to the researcher only. Electronic data such as the audio recordings were stored in a secured computer that is password protected. When portable media (i.e. USB drive) was used to store the data, participant identifiers were stored separately as well.

Only the researcher had access to the completed questionnaires and audio recordings. The researcher and research supervisors at James Cook University, Singapore, had access to the data collected from the questionnaires and the transcripts of the recording. Access to the research data was password protected. Printed copies of the transcript were stored in a cupboard under lock-and-key that is only accessible by the researcher. Following the data collection and data analysis, all the questionnaires have been stored in a locked archive at IMH, where they will remain for the next three years, in line with the current hospital policy.

4.2.6 *Interview Protocol*

This qualitative research study employed an interview guide designed to explore the diverse experiences of caregivers. The interview guide was developed based on the findings of the quantitative study, with the final research aims for this study determined by those findings. The guide was designed to align with the objectives of the qualitative study, which were: (a) to explore participants' experiences with posttraumatic stress symptoms (PTSS), focusing on their perceptions and interpretations of distressing caregiving events that led to PTSS, as well as the impact of these events on their caregiving responsibilities; and (b) to examine the influence of cultural backgrounds and belief systems on caregivers' experiences and responses to PTSS. The interview schedule was structured to facilitate an in-depth understanding of the participants' perspectives, particularly focusing on both positive aspects and the more challenging, potentially traumatic experiences associated with caregiving. The interview guide was divided into several key sections, each aimed at eliciting comprehensive and nuanced responses from participants.

The interview began with an introductory statement, where participants were informed about the purpose and duration of the interview. Participants were reminded of their right to pause or reschedule the interview if they became uncomfortable and were informed of their right to withdraw their data from the study within a month. Consent for audio recording was obtained prior to commencing the interview.

The initial set of questions focused on general aspects of caregiving, aiming to ease the participants into the conversation by discussing topics they were likely comfortable with. These questions included:

1. Describing their son or daughter.
2. Sharing enjoyable aspects of caregiving.
3. Discussing the biggest challenges faced in caregiving.

Following the initial questions, the interview transitioned to exploring more distressing and challenging experiences. This section was introduced with a statement that prepared participants to discuss any upsetting or traumatic situations they have encountered while caring for their child. The focus questions in this section were designed to delve deeply into these experiences, examining their impact and the participants' coping mechanisms. Key questions included:

1. Identifying the most distressing or frightening events experienced.
2. Understanding the emotional and psychological impact of these incidents.
3. Exploring how participants made sense of and coped with these situations.
4. Investigating the effect of these experiences on the caregiver-child relationship and caregiving practices.

If the distressing incidents discussed did not include aggressive behaviour, additional questions specifically addressed experiences of aggression from the child. This section aimed to compare and contrast the participants' experiences of aggression with other distressing events. Questions include:

1. Describing specific incidents of aggressive behaviour.
2. Comparing these experiences with other distressing events.
3. Assessing whether these incidents are perceived as traumatic and understanding the reasons behind their perception.

The guide also included questions about the participants' interactions with support services during distressing events and their views on how these services could be improved. Additionally, the influence of cultural background on caregiving practices was explored, along with strategies for balancing self-care and caregiving responsibilities. The interview concluded with open-ended questions that provided participants with the opportunity to share any additional information or insights about their caregiving experiences that were not

covered. Participants were also asked about their experience of discussing these topics during the interview, ensuring that their emotional well-being was acknowledged and supported. Participants were then provided with information about support services in case discussing distressing topics during the interview caused any emotional distress.

Ethical considerations were integral to the interview guide. Participants' confidentiality was maintained by removing identifying information, such as the name of the child, during transcription. This comprehensive interview guide was designed to capture the complex and deeply personal experiences of participants. By using a structured yet flexible approach, the guide facilitated the collection of rich, detailed data that provided valuable insights into the challenges and coping strategies of participants, contributing significantly to the study's overall objectives.

4.2.7 *Research Design and Data Analysis*

This research project employed a mixed-methods approach, with the qualitative findings aimed at explaining and providing deeper insights into the quantitative results. An explanatory qualitative approach, based on constructionist epistemology was used to understand participants from different cultures in relation to the traumatic caregiving events and possible PTSS experiences in their caregiving of adult children with NDD.

Qualitative research seeks to discover how humans participate in the meaning making process, which leads to gaining a better understanding of how they make sense of their world (Hatch, 2006; Patton, 2015). Qualitative research relies heavily on comprehensive inquiry of a small target audience to interpret and make meaning of the participants' responses. In this study, this target audience are the primary family caregivers of adult children with NDD. The advantage of qualitative inquiry is that it affords the researcher the opportunity to gain a better

understanding of not only the individual, but also of the systems and context that contribute to their subjective experience (Crowe, Inder, & Porter, 2015).

Reflexive thematic analysis (TA) is an approach to qualitative data analysis that emphasizes the active role of the researcher in the process of identifying, analysing, and interpreting patterns of meaning within data. Unlike more rigid approaches that may rely on predefined coding frameworks or seek to minimize researcher subjectivity, reflexive TA views the researcher's insights, interpretations, and reflexivity as essential components of the analysis (Braum & Clarke, 2019). Themes in reflexive TA are not considered to passively emerge from the data but are actively generated through a deep engagement with the data, informed by the researcher's theoretical assumptions and analytic creativity. This approach allows for a flexible, iterative, and dynamic process of analysis that can adapt to the evolving understanding of the data and the research context.

This method aligns well with the study's aim to delve into the nuanced and multifaceted nature of caregiving. By centering the researcher's reflexivity and interpretive skills, reflexive TA encourages a more nuanced and in-depth exploration of participants' challenges, coping strategies, and the impact of their roles, contributing to a richer and more comprehensive understanding of their experiences. Additionally, this qualitative approach complements the quantitative findings by explaining the relationships observed and exploring them at a deeper, more explanatory level. It facilitates the generation of personal and cultural accounts of reactions to potentially traumatizing events within caregiving relationships.

Reflexive thematic analysis involves six distinct phases, adhering to the guidelines recommended by Braun and Clarke (2006; 2021). The phases encompassed: (1) becoming thoroughly acquainted with the data, (2) generating initial codes, (3) identifying and organizing common themes, (4) reviewing the themes, (5) defining and naming the themes,

and (6) producing the final analysis report. A detailed explanation of each phase involved in conducting the reflexive thematic analysis can be found in Table 14.

Table 14:

Phases of Thematic Analysis

Phases	Descriptions
Data Familiarization	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
Generating Initial Codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
Searching for Themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
Defining and naming Themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

The data coding process for this thematic analysis was carried out meticulously to ensure the trustworthiness and depth of the findings. In line with principles of trustworthiness in qualitative research, careful attention was paid to maintaining credibility, transferability, dependability, and confirmability throughout the analysis (Stahl & King, 2020). Credibility was achieved through deep engagement with the data, where I continuously reflected on and questioned emerging patterns, using thick descriptions to ensure that the themes accurately captured the participants' perspectives. Transferability was supported by providing detailed

contextual information, enabling other researchers to assess the applicability of the findings to different settings.

To ensure dependability, the research process was meticulously documented, providing a clear and detailed record of the decision-making process. This documentation also contributed to confirmability, as it helped to demonstrate that the findings were shaped by the participants' responses rather than any potential personal biases. Reflexivity was practiced throughout the analysis, where I continually reflected on my own assumptions and their influence on the interpretation of the data, further strengthening the trustworthiness of the research. The process also involved applying the set of twenty critical questions designed to assess the quality of thematic analysis (TA) research (Braun & Clarke, 2021). These questions served as a framework to ensure that the analysis was methodologically sound and aligned with the principles of reflexive TA. They guided the evaluation of the research process, helping to verify that the themes identified were not merely summaries of data but represented deeper patterns of shared meaning.

Initially, I immersed myself in the collected interviews and notes, repeatedly reading the transcripts to gain a comprehensive understanding of the content and to begin identifying potential patterns and themes. Following this familiarization phase, initial coding was conducted systematically, I then highlighted significant phrases, sentences, or sections and assigned preliminary codes to these data segments. During this phase, the I consulted with research supervisors to ensure the coding was performed rigorously and consistently, integrating feedback to refine the coding process.

After completing the initial coding, I then organized the codes into potential themes, grouping similar codes together to develop broader categories that encapsulated the essence of the data. These initial themes were then reviewed and refined through discussions with research supervisors. A thorough review and refinement phase followed, involving repeated

checks against the data to ensure that the themes accurately represented the participants' experiences and perspectives. I compared and contrasted different data segments to confirm the consistency and coherence of the themes.

Once the themes were reviewed and refined, the next step involved defining and naming the final themes. Each theme was clearly defined, with detailed descriptions capturing the essence of the data. The names of the themes were chosen to reflect their core meanings and ensure clarity for readers. Finally, the report was produced, systematically presenting the refined themes with supporting quotes from the data. This phase aimed to provide a coherent narrative that encapsulated the participants' experiences and insights, ensuring the findings were presented comprehensively and meaningfully. By following these phases and incorporating multiple iterations and consultations with research supervisors, the analytical process for this thematic analysis was designed to be rigorous and thorough, ultimately enhancing the trustworthiness and depth of the study’s findings.

4.3 Results

The data gathered in this study presented diverse caregiving experiences related to the caregiving journeys and the traumatic experiences encountered by participants. To ensure these narratives are meaningfully interpreted and accurately represented, the findings have been meticulously structured to reflect the nuanced and multifaceted nature of participants' experiences. This comprehensive data offers a detailed view of the caregiving experience, capturing both the daily challenges and the deep emotional impacts faced by participants. This section aims to shed light on these experiences, providing insights into the complex realities of caregiving.

To clearly and coherently present the analysis of the data and findings, the data were organized into four distinct layers that were generated during the analysis. These layers, in which trauma is embedded, resemble a socio-ecological model, though this model is not formally applied in this study and is referenced only to provide context for the findings. This layered approach offers a structured yet flexible framework for exploring the participants' experiences of trauma, emphasizing that such experiences cannot be fully understood without first considering the cultural, familial and personal contexts in which they occur.

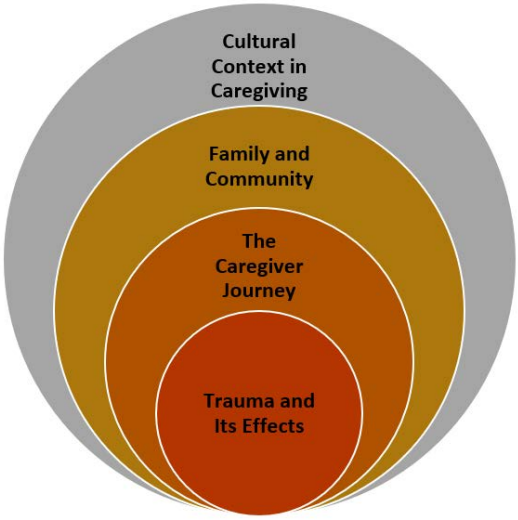
This approach is further illustrated in Figure 7 which outlines the interconnected layers that influenced the caregiving experience and trauma. At the core of the model is "Trauma and Its Effects," which represent the personal challenges and coping mechanisms of the caregiver. Surrounding this core is "The Caregiver Journey," emphasizing the individual's role and identity in the caregiving process. The next layer, "Family and Community," highlights the critical support systems that provided emotional, practical, and social assistance. The outermost layer, "Cultural Context in Caregiving," encompasses the broad societal norms, values, and expectations that shaped and influenced all the inner layers. This hierarchical structure emphasizes the importance of each layer in shaping the caregiver's

experience, with culture providing the overarching context for family dynamics, community support, and individual resilience. However, since the primary focus of the research was on trauma and its effects, themes and subthemes were generated solely for this aspect.

The following sections present the findings of the study, reflecting this conceptual model, starting from the outermost layer and moving inward to explore each layer's influence on the caregiving experience and ultimately participants' experiences with PTSS and the impact on their caregiving responsibilities. By beginning with the broad cultural context, the analysis will examine how societal norms and values set the stage for the caregiving journey. Next, it delves into the role of family and community, illustrating the essential support networks that helped caregivers manage their responsibilities and maintain their well-being. Following this, the focus shifts to the individual participant, exploring their personal experiences, challenges, and the identity they forged through their caregiving role. Finally, the innermost core of trauma and resilience is examined, highlighting the perceptions and interpretations of distressing caregiving events that led to PTSS among participants, the coping strategies employed and overall impact on their caregiving approach. This approach ensured a comprehensive understanding of the multifaceted nature of caregiving, acknowledging the complex interplay between personal, familial, community, and cultural factors. The detailed analysis aimed to provide valuable insights into the caregiving process, emphasizing the importance of supportive structures at all levels to foster caregiver resilience and well-being.

Figure 7

Layers of Influence on Caregiving Experience and Trauma



4.3.1 *Cultural Context in Caregiving: Diversity, Spirituality, and Stigma*

The findings of this study revealed that culture played a pivotal role in shaping the caregiving experiences of participants, deeply influencing how they perceived and managed their roles. Participants consistently highlighted those cultural norms, values, and expectations significantly affected their approach to caregiving and the support they received. Many participants shared that, within their cultures, caregiving was often viewed as a familial duty, creating additional pressure to meet societal and family expectations. One participant explained how the cultural emphasis on family responsibility in their community led to a sense of obligation that was both a source of strength and stress. This sentiment was echoed by Kenneth, who explained how deeply ingrained cultural values, such as respect and care for elders in Chinese culture, reinforced his commitment to his caregiving responsibilities: *"I mean Chinese, we are all Chinese, we are told to have filial piety, towards the elders. Myself, if someone who is no better off than me I will also look after."*

Cultural backgrounds also shaped the participants' attitudes toward disability and their emotional coping mechanisms. For example, the belief in karma and reincarnation is deeply

rooted in Indian culture and plays a significant role in shaping attitudes toward life's challenges. As Rohan shared:

"It's all karma you know, it's fated you are to suffer. So why to make him (son) scapegoat for that?..... So the Karma, the deeds what you did, not just in this birth but in probably even in the earlier births. So always come back and you know, aren't you so we always like sometimes we don't know whether it's true or not but those beliefs system. Basically, at the end. Make your settle down in a way, okay, this all karma you had to… or it's a fate, you have to face it. So like that. It helps a lot in that sense because that's in one way. That helped us not to give up."

"Comparing downward" was a common cognitive coping mechanism utilized among some participants. They shared that observing how individuals with neurodevelopmental disorders were treated in other cultures allowed them to compare their own situations to those less fortunate. This comparison provided them with comfort and a sense of gratitude, helping to maintain emotional stability and prevent overwhelming stress.

The interplay between religious beliefs and caregiving practices was another common thread. Participants discussed how their faith provided a philosophical framework for understanding their experiences, offering emotional support and coping mechanisms. For example, Muslim caregivers described their challenges as tests of faith, which motivated them to persevere and view their caregiving efforts as spiritually significant. Syafiq expressed this sentiment, stating:

"Religious values is that a child for Muslim, a child is a god given to you, entrusted to you, for bad or for worse. So if it is good, you are thankful. If it is not, then you will view it that this is a test, is a test from god to you. So you have to go through the trials and tribulations. So if it is entrusted to me, then it is my responsibility to groom him or to guide

him or to bring him up to the best of my ability. Child is god given to you, you, for bad or for worse, have to take care of him."

Similarly, Alice, drawing from her Christian faith, shared how her beliefs influenced her caregiving approach: "*I'm more to Christian, so Christian, from what I learn, is to care for the family, love, talk to them with praying that he will have more understanding."* These accounts illustrate how different religious belief provided participants with strength, purpose, and a framework for enduring and making sense of their caregiving responsibilities.

Participants also highlighted the impact of stigma, particularly around mental health, on their caregiving experience. Several participants shared their struggles with the cultural stigma associated with mental health institutions and treatment. One participant recounted the fear and embarrassment they felt about being associated with mental health services, and they worried about social judgment and the potential impact on the family's reputation. However, some participants noted that over time, they felt less burdened by this stigma, indicating a possible shift in their attitudes or societal perceptions. This evolving perspective allowed them to speak more openly about their challenges, which they found empowering and stress-relieving.

Overall, the participants' narratives revealed that culture permeated every aspect of the caregiving experience, from shaping norms and expectations to providing a foundation for emotional and practical support through deeply ingrained family values and religious beliefs. These cultural influences not only impacted how participants performed their roles but also affected their attitudes toward disability, their coping mechanisms, and their responses to traumatic events. For these participants, it seemed that cultural contexts were crucial for them in providing effective support and fostering a more inclusive, empathetic approach to their caregiving.

4.3.2 *Family and Community – The Power of Family Dynamics and Community Support*

The participants highlighted the pivotal role that family dynamics and community support played in their caregiving experiences. Some participants spoke of the strong family bonds that provided both emotional and practical support, helping them manage their responsibilities and alleviating feelings of isolation. They emphasized the importance of family involvement, particularly when caring for family members with complex needs and behavioural challenges. For these participants, they expressed deep gratitude towards supportive family members, noting that their assistance significantly lightened the caregiving burden and offered essential help during difficult times.

Participants often described how different family members contributed in various ways—whether through direct caregiving or providing emotional support. They highlighted the vital roles played by children, spouses, and in-laws, each offering distinct forms of assistance. For instance, Saanvi expressed her deep gratitude for the support she received from her family:

"I also am really thankful for the support I have from my family, it was so great, because my brother will call and check on me, my sister-in-law and my youngest son was with me so he said, 'mah… if you can tell them to give an additional number, can speak to me, and as a brother I can also assure him that we will come back to you', you know the main focal point is they only allow him to speak to two people, because it is not fair, too many patients right, so maybe one day father, the next day mother and brother or something like.. yeah… also my very close buddy, who has been with me throughout the ten years, she was another pillar of support. She would call me, 'hey… how are you', because she addressed me as mommy, 'mommy, how are you?' I say 'I'm fine' … 'eh, you wanna come out for tea?' and all that, so this is how I really got another avenue."

This collective effort was seen as crucial not only for managing the complexities of caregiving but also for maintaining the psychological health of both the participant and the family.

Spousal support emerged as particularly essential, with participants sharing that their spouses' involvement allowed them to balance caregiving duties with personal well-being. They discussed how spouses contributed by sharing tasks and enabling the primary family caregiver to pursue personal interests and maintain social connections. Additionally, effective caregiving, according to these participants, often involved negotiating and collaborating on care strategies, underscoring the importance of communication and teamwork within the family.

Participants also spoke of the importance of a broader social support network, including friends, colleagues, church members, and neighbours. These networks provided emotional sustenance, practical help, and opportunities for social engagement, which were viewed as crucial for maintaining both their own mental health and that of their families. Many participants valued the collaboration with professional services, such as therapists, counsellors, and medical staff, noting that these professionals played an integral role in managing the health and behavioural challenges of their loved ones. The participants appreciated how these collaborations not only improved the care their family members received but also reinforced their own capacity to manage caregiving effectively.

Community support, including resources from schools and parent support groups, was also highlighted as vital. Participants noted that these networks provided valuable educational resources and peer support, which were essential in navigating the challenges of caregiving. The participants emphasized the importance of having supportive relationships characterized by non-judgmental listening and appropriate advice, as these interactions helped them build resilience, offering outlets for stress and aiding in decision-making. Peter, for instance, shared

how he finds comfort in discussing his situation with those willing to listen, sometimes receiving helpful suggestions. He expressed his gratitude, saying, "*I'm grateful for support from friends, appreciate having someone to talk to and occasionally receive helpful suggestions or ideas*." Similarly, Naomi emphasized the significance of her friends' support. She recalled a moment when, feeling overwhelmed, she called a friend for consolation, acknowledging that without this support, she might have reached a breaking point and even considered self-harm.

Overall, the participants' narratives revealed that the intricate web of family dynamics and community support is fundamental to the caregiving experience. Strong familial bonds and active community networks provide the emotional and practical resources necessary for participants to fulfil their roles effectively. The collaborative efforts of family members, particularly spouses, were seen as key to balancing caregiving duties with personal well-being. Moreover, the participants stressed that diverse social support networks and professional services were crucial in addressing the complex challenges they face, ensuring both their mental health and the quality of care for their loved ones. By emphasizing communication, collaboration, and a broad support system, these participants were able to alleviate some of the burdens of caregiving while fostering resilience and creating a sustainable caregiving environment.

4.3.3 *The Caregiver Journey – Complexities, Dynamics and Challenges*

The caregiving journey, as shared by the participants, revealed a complex and evolving experience, deeply intertwined with the emotional and practical realities of caring for a loved one with a neurodevelopmental disorder. Participants spoke of the profound challenges they faced from the moment of diagnosis through to the ongoing management of

care. These narratives captured the full spectrum of the caregiving experience, highlighting the continuous adjustments required to meet the changing needs of their loved ones.

Some participants reflected on the initial shock and adjustment period following the diagnosis of conditions such as ADHD or ASD. They described the significant challenges in early identification and the subsequent struggles with managing treatment and educational needs. For others, the delayed recognition of worsening symptoms added layers of complexity, underscoring the difficulties inherent in diagnosing and treating developmental disorders. Kenneth, for instance, recalled, *"It was a very late diagnosis. Because in her early years, probably, maybe the psychiatrist has missed these symptoms because we were looking at her OCD. But we're not too sure, because we were very dependent on whatever the psychiatrist said."*

The emotional and practical toll of caregiving was a recurring theme in the participants' stories. Naomi poignantly described how her life became a series of medical appointments and disciplinary struggles, illustrating the intense demands placed on participants. These responsibilities often influenced family dynamics, career decisions, and daily routines, with participants emphasizing the emotional strain brought on by educational setbacks, behavioural issues, and challenging social interactions experienced by the NDD individual. This emotional burden was a critical aspect of their experience, deeply affecting their well-being and influencing their approach in caregiving.

As their children grew, participants found themselves continuously adapting to new challenges, often at great personal and professional sacrifice. They spoke of the social isolation and emotional fatigue that resulted from prioritizing their children's needs over their own, with many noting how their personal and social lives were significantly impacted. Aging further complicated these challenges, as participants expressed concerns about the sustainability of their caregiving roles and the adequacy of future care. Peter shared his

concerns, saying, *"my age is catching up, I know I'm not in a perfect condition, but mentally I'm quite convinced that I have to at least try."*

Despite these difficulties, the participants demonstrated remarkable resilience and resourcefulness. They shared stories of seeking out specialized schools, advocating for interventions, and adjusting their lives around their children's needs. However, the emotional complexities of caregiving were ever-present. Many participants recounted feelings of guilt, regret, and remorse, particularly in the early stages of their caregiving journey. Melissa expressed ongoing guilt over her initial handling of her son's needs, reflecting the deep emotional impact these early challenges had on her. Over time, these feelings evolved into a determined hope to improve, showcasing the dynamic nature of the caregiving experience.

The participants also discussed the disparities in how they and their partners handled emotions and difficult situations, particularly regarding discipline and boundaries. These differences often led to tension and confusion within the family, with some participants noting that their varying approaches to caregiving could cause conflicts that affected their relationships and the overall family environment. For families dealing with divorce, these complexities were further magnified, especially when parents had divergent views on raising a child with a neurodevelopmental disorder. One participant shared how the lack of support from an ex-spouse was both a relief and a burden, offering more control over decisions but removing a balancing influence in caregiving.

Ultimately, the participants' stories highlight the importance of consistency in caregiving and disciplinary approaches. While differing parenting styles sometimes led to tension, the participants also recognized that, when managed cohesively, these differences could be complementary, providing a balanced approach to supporting their child's development. In essence, the caregiving journey, as described by the participants, is one of continual adaptation, marked by significant emotional and practical challenges. These

participants navigate a complex landscape, balancing their own needs with the demands of caring for a loved one with a neurodevelopmental disorder. Their resilience, resourcefulness, and the deep emotional connections they share with their adult children underscored the profound impact of the caregiving experience on every aspect of their lives.

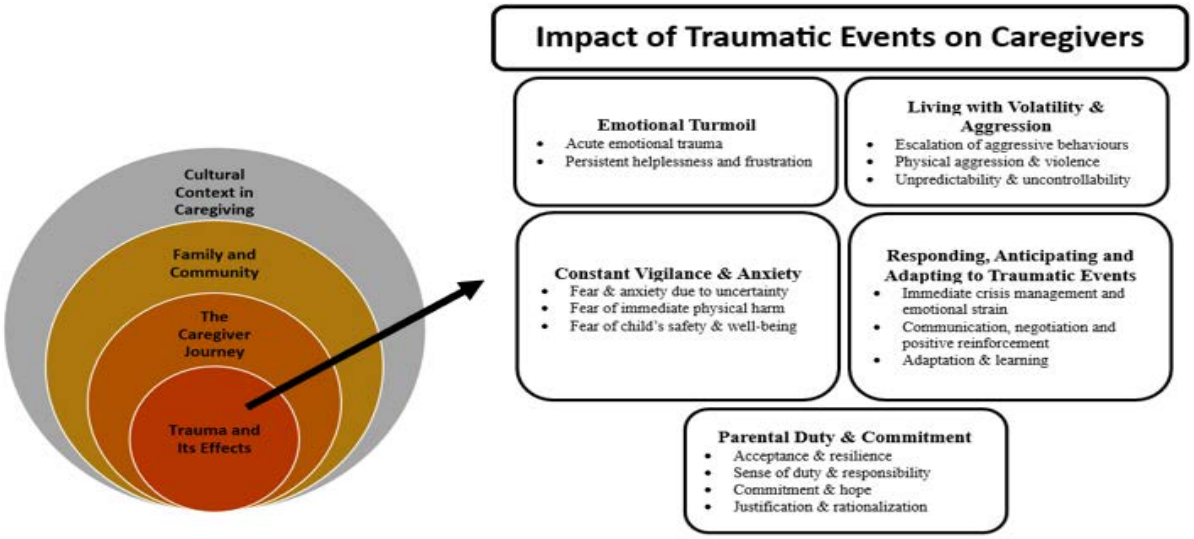
4.3.4 *Trauma and Its Effects – The Impact of Traumatic Events*

As the main focus of the results section, this section delves into the detailed experiences of trauma and the impact it has on the participants. The themes and subthemes within this layer address the primary research aims and questions, offering a thorough exploration of how participants navigated traumatic events and built resilience.

Figure 8 visually represents the multifaceted challenges faced by participants in the wake of traumatic events. At the core of the diagram are five key themes affected by these events: Emotional Turmoil, Constant Vigilance and Anxiety, Challenges of Managing Aggressive Behaviours, Coping Mechanisms and Interventions, and Parental Duty and Commitment. The remainder of this section will present the findings and insights gleaned from the analysis.

Figure 8

Impact of Traumatic Events on Caregivers



4.3.5 *Theme 1: Emotional Turmoil*

Emotional Turmoil reflected the profound psychological distress that participants endured, particularly as it related to trauma. Two key subthemes were generated within this overarching theme: Acute Emotional Trauma and Persistent Helplessness and Frustration. These subthemes collectively portrayed the deep and ongoing emotional turmoil faced by participants. Acute Emotional Trauma captured the intense, immediate distress experienced in response to sudden, severe incidents involving their adult children with NDD, resulting in shock, confusion, and profound emotional pain. In contrast, Persistent Helplessness and Frustration encapsulated the chronic emotional challenges of feeling powerless and unsupported, as participants continually struggled to manage their adult children's behaviours. The connecting thread between these subthemes was the relentless emotional impact of caregiving, where participants were subjected to both immediate traumatic events and sustained psychological strain. This connection to trauma was underscored by the lasting

emotional scars from acute crises and the ongoing burden of frustration and helplessness, highlighting the traumatic nature of the caregiving experience.

4.3.5.1 Acute Emotional Trauma. The participants in this study vividly described the profound psychological distress they endured as caregivers, particularly in relation to trauma. Many participants spoke of the intense and immediate emotional turmoil they experienced during sudden and severe incidents involving their adult children with NDD. Ahmad, for example, reflected on the distress and trauma of dealing with such behaviour for over a decade, saying, "*It was so traumatic that we actually had to consider living separately from him, up to the extent, so maybe get a place for himself away from us, so that he doesn't actually, really mentally pressure us*."

Similarly, Saanvi spoke of her overwhelming sense of "*heightened level of concern, urgency and desperation*" when her son went missing with the intention of ending his life. These episodes, often marked by dangerous behaviours such as suicidal acts or violent aggression, left participants in states of shock, confusion, and deep emotional pain. The participants recounted the overwhelming challenge of trying to comprehend and respond to their adult child's actions, which frequently led to feelings of failure and inadequacy when their best efforts did not yield the desired outcomes. Saanvi, for instance, described the "*worst time*" for her as when her son felt misunderstood despite their best efforts to provide help and support, which seemed insufficient in preventing his suicidal attempt. The life-threatening nature of these incidents further exacerbated the emotional trauma, leaving lasting scars and underscoring the critical, high-stakes challenges they faced.

4.3.5.2 Persistent Helplessness and Frustration. In addition to these acute traumatic experiences, participants in this study also shared their ongoing struggle with pervasive feelings of helplessness and frustration. They described the relentless challenge of managing their adult child's behaviours while feeling unsupported and inadequate, despite their best

efforts. Many reported a deep sense of powerlessness and exasperation. Saanvi, for instance, shared her uncertainty about whether additional support or actions were necessary beyond what she had already provided, a feeling exacerbated by the isolation stemming from a lack of such external support. The heavy burden of ensuring their child's safety only added to their persistent frustration. Participants often spoke of the emotional strain caused by self-blame and doubted about their ability to adequately support their child. Christine revealed how these feelings manifested in her family, with her husband questioning whether they were to blame for their son's condition. She recalled telling him, "My husband was saying, 'don't know whether it's our fault that he has turn out this way', and I will tell him 'No lah it's not a fault lah, we have given him our hours of energy, sweat and made so many sacrifices, how is that our fault."

Peter's frustration was particularly intense when his planned interventions failed to prevent undesirable behaviours, leading to a deep sense of helplessness. He expressed his surprise and frustration that, despite his well-thought-out efforts to provide his son with support, assurance, freedom, and resources, his son still exhibited the behaviour of running away unexpectedly. As Peter shared, "So in fact, I thought everything has been, well planned with him, all the nice talking and all the needed assurance from me, and giving him maximum freedom and necessary resources, but still there is the behaviour of running away." For these participants, findings reflected that even though they understood that their child's actions were not intentional, this knowledge did little to alleviate the ongoing emotional burden.

Rohan reflected on the lack of support during moments of crisis, particularly during aggressive episodes, which left him feeling helpless. He explained,

"*See, always the professional services help. But usually what happens is all this helps, whatever we have is at a time when he is already okay. Alright, but our real challenges are that time when we have the episodes. Right. So that is the time we can't get any help*

immediately. And none of the support whatever we get, unfortunately, what happens is, it is not helping us, at least in this case, is not helping us, to make sure that the episodes don't happen, or help us manage when the episodes happen."

He elaborated, "*No, it to be honest, practically, I think like what they can do, for example, I call somebody. Right? Anybody to come and respond, it'll take some time. However quick it is and like the episode issues happening. Will be usually like at the peak it's even when it is peak it's even difficult to call we cannot call in front of him. You know, we have to, device, find a way to, you know, manage, send the alarm, or something like that, assuming even if something is there. So even somebody do come, it will take few minutes or you know hours depending upon from where they are coming and all. So by the time they come, the episode would have already probably… the damage will happen. Or the peak would have been already happened*."

These shared experiences highlight the chronic, long-term emotional challenges that participants faced. The persistence of these feelings reflected the continuous nature of caregiving, where daily struggles and insufficient support during the aggressive episodes contributed to a sustained and profound sense of emotional distress. The voices of the participants in this study clearly illustrated the deep and enduring psychological impact of their caregiving roles, particularly in the context of traumatic experiences.

4.3.6 *Theme 2: Living with Volatility and Aggression*

This main theme was broken down into three subthemes that highlighted the profound difficulties participants faced in managing aggressive behaviours, contributing to their posttraumatic stress symptoms and experiences. This theme focused on the direct and tangible experiences of caregivers dealing with volatile and aggressive behaviours. It examined how escalating aggression, physical violence, and unpredictable outbursts disrupted the home

environment, compromised safety, and led to significant emotional strain. The emphasis was on the behavioural manifestations of aggression and the immediate impacts on the participants' surroundings and sense of safety.

Escalation of Aggressive Behaviour addressed the progressive intensification of aggression, where verbal outbursts escalated to physical agitation, leading to property destruction and creating a volatile and unsafe home environment. Physical Aggression and Violence focused on the direct physical harm that participants may have endured, significantly impacting their sense of safety as they contended with regular violent episodes, both at home and in public, exacerbating their PTSS. Unpredictability and Uncontrollability highlighted the unpredictable nature of these aggressive behaviours, which left participants feeling powerless and isolated, as they constantly anticipated harm, limiting their ability to manage their adult child's behaviour and participate in normal activities.

4.3.6.1 Escalation of Aggressive Behaviour. Participants consistently spoke about the escalating nature of their loved ones' aggressive behaviours and how these episodes progressively intensified over time. They observed a pattern where verbal outbursts would often escalate into physical agitation, creating a tense and unpredictable home environment. The narratives highlighted how this escalation not only disrupted their sense of safety but also intensified their emotional exhaustion and deepened their feelings of helplessness.

Kenneth recounted how his daughter's anger would build up until she began scolding and lashing out, sometimes leading to sudden and violent outbursts. These episodes frequently resulted in significant property destruction, leaving the home in disarray. Kenneth likened the aftermath to a "battlefield," with extensive damage to household items. The constant threat of further violence left participants feeling increasingly helpless and out of control. Ahmad, for instance, shared his experience: "*Physically also, because he was kicking doors, banging*

against wall and so on, things like that. So you was very, very traumatic for myself and my wife."

Participants also shared that these aggressive behaviours were not limited to physical destruction but included the use of abusive language and confrontational stances, which further heightened the tension within the household. In some cases, the adult child's behaviour became so intimidating that participants felt their home was no longer a safe space. Christine recounted how her son verbally abused her husband, saying, "*Because my husband doesn't want to fight him and then this guy (son) will go on shouting and shouting all the abuses and being so rough on him*".

Participants also described their loved one's extreme actions, such as throwing objects, pulling down items in the house, and engaging in physical damage. Rohan, for example, recounted how his son's anger outbursts caused significant damage in the house, saying, "*Some big damage happened—could be a phone damaged, or our TV, or a window*." Saanvi, for instance, recounted a situation where her son's aggression escalated as he used abusive language and advanced in a threatening manner toward her and her younger son. Similarly, Kenneth described how witnessing his daughter's ability to intimidate his wife and other daughter made the situation at home volatile and unsafe. As these episodes became more frequent, participants expressed a growing sense of fear, recognizing that the situation could easily worsen. This escalation not only caused more physical damage but also deepened their sense of vulnerability and emotional strain, leaving them increasingly anxious about the future.

4.3.6.2 Physical Aggression and Violence. This subtheme examined the direct physical harm inflicted on caregivers, the impact on their physical safety, and the challenges of managing violent episodes at home and in public. Many participants spoke about the direct physical harm they experienced as a result of their adult child's aggression. Ahmad recounted

being pushed by his son and hitting the wall, while Syafiq witnessed his son spitting at and attempting to hit his wife. This physical violence significantly impacted their sense of safety and well-being. Several participants recounted incidents where they were hit or pushed by their loved ones, sometimes leading to hospital visits and the need for medical intervention. Christine recalled a particularly traumatic event where she intervened to prevent a physical conflict between her son and husband, only to end up seeking medical attention herself: "*There was one time I fell down and fractured my wrist. After that, whenever I step in, I don't want to step in in a physical way, I'm very frightened*." The recurring nature of both verbal and physical aggression was a major concern, with participants describing their homes as feeling perpetually unsafe. For these participants, these repeated incidents of violence not only threatened their physical health but also left them in a constant state of fear and anxiety, struggling to maintain a sense of security in their own homes.

The regular displays of aggression and violence were deeply traumatic. The increasing physical growth and size of the adult child often amplified the threat, forcing participants to live in constant fear for their safety. These fears were not limited to the home; unpredictable outbursts in public settings added another layer of trauma and stress. Peter gravely described his fear:

"…..*a busy market place at noon, if he lost control, it's not just a normal parent having a big problem with his special child, it's a marketplace, it's a place where you do business, it's a place where you make a simple living, you don't want this setting be damaged or spoilt by him. So I don't think you can imagine that kind of pressure, it's more than double of that of a parent with a autistic child losing control of his temper. So that is really maximum stress. But it happened once*."

This subtheme captures the pervasive impact of physical aggression and violence on the daily lives of participants, emphasizing how these experiences erode their sense of security and control.

4.3.6.3 Unpredictability and Uncontrollability. This subtheme explored the erratic and uncontrollable nature of aggressive behaviour, leaving participants unable to predict or manage outbursts effectively, further contributing to a sense of powerlessness. The participants described the unpredictable nature of their loved ones' aggressive behaviours as one of the most distressing aspects of their experience. Christine shared that they were often on high alert when their son was in public due to his unpredictable aggressive episodes, which posed a serious threat to the safety of others and themselves. For example, her son unexpectedly attacked a male stranger in public, and her husband had to physically intervene to separate them. The lack of control over these behaviours was a significant source of ongoing stress and trauma. Ahmad and Syafiq similarly observed their adult children's tendency to ruminate on past incidents, which triggered sudden and intense outbursts of anger and aggression, seemingly without warning or concern for the consequences.

This unpredictability was not only frightening but also severely limited the family's ability to engage in normal activities and social interactions. The constant fear of an unexpected outburst made it nearly impossible to manage the adult child's behaviour in public, further isolating the family, as Rohan shared. Some participants spoke about their constant vigilance, always being on edge, aware of the potential for harm at any moment. This ongoing stress was compounded by repetitive vocalizations and sudden, uncontrollable outbursts that emphasized the unpredictable and uncontrollable nature of their loved ones' aggressive behaviours. The sense of unpredictability and lack of control left participants feeling trapped in a situation where their ability to protect themselves and maintain a semblance of normalcy was severely compromised.

4.3.7 *Theme 3: Constant Vigilance and Anxiety*

This theme shifts the focus to the emotional and psychological toll of caregiving, emphasizing the chronic state of alertness and fear experienced by participants. It captured how anxiety about immediate harm, uncertainty, and their loved one's long-term well-being creates an ongoing emotional burden. The emphasis was on the mental and emotional repercussions of caregiving rather than the direct physical experiences.

Constant Vigilance and Anxiety highlighted the ongoing state of alertness and fear. Three subthemes were generated, each underlining the persistent and varied nature of fear and anxiety that participants experienced due to their adult children's behaviours, safety concerns, and overall well-being. Fear and Anxiety Due to Uncertainty captured the pervasive anxiety driven by the unpredictability of their adult child's whereabouts and safety. Fear of Immediate Physical Harm emphasized participants' fear of potential violence or accidents caused by their adult child's agitation or anger, posing a direct threat to their safety and well-being. Fear for Child's Safety and Well-being reflected the deep concern for their adult child's vulnerability, particularly during mental health crises or when missing, leading to an overwhelming emotional burden and a persistent fear of loss.

4.3.7.1 Fear and Anxiety Due to Uncertainty. This focused on the unpredictability of the loved one's whereabouts, behaviours, or mental state, creating pervasive worry and disrupting daily life. Participants often spoke about the constant anxiety they faced because of the unpredictability in their adult children's lives. When their adult child went missing, and did not answer their calls, participants shared that it left them worried about where they were and if the adult child was safe. This anxiety intensifies when communication was completely cut off, such as when the phone was turned off. As Peter described, *"And he switched off his mobile in such a way that I can never know his whereabout…. like it just create my anxiety.*

And then it has just become a test how I manage my anxiety. Of course I will not have good sleep for the past few nights."

This ongoing fear disrupted their sleep, especially when they thought about the possibility of needing to involve the police. The thought of the police showing up late at night with bad news was always on their minds. Even though they tried to prepare themselves mentally for the worst, participants worked hard to prevent such outcomes by conducting extensive searches with the help of family members, friends and acquaintances, knowing that their adult child's instability in their mental state and behaviours could lead to serious problems.

Rohan illustrated how the uncertainty of his adult child's fluctuating mental state kept them in a constant state of alertness: *"When he's having one of the bad days, you just don't know what might happen. You try to stay calm, but inside, you're bracing for the worst."* The unpredictability surrounding their adult child's negative thoughts and behaviours exacerbated this tension, especially while waiting for medications to take effect or for their condition to stabilize. The acute anxiety was overwhelming, and participants also had to consider the safety of other family members, further complicating their already heavy emotional burden.

4.3.7.2 Fear of Immediate Physical Harm. This subtheme centered on the participants' fears of potential violence or accidents caused by their adult children, with an emphasis on the anticipation of harm rather than the experience of it. Participants shared their fears about the potential physical harm that their adult children could cause to themselves or others, particularly during moments of anger or agitation. Christine vividly recounted, *"There was a time when my child threatened to take a knife and go after someone. It was terrifying—I was afraid they might hurt someone or themselves."* The possibility of their adult child meeting with an accident or engaging in violent behaviour was a constant source of fear. Ahmad expressed the fear that arose from their adult child's physical aggression: *"When he*

gets angry, it's like he becomes someone else—stronger, more dangerous. It's scary because I don't know if I can keep him from hurting anyone, including me." This fear was compounded by the adult child's physical growth and size, making it challenging for participants to manage their anger and aggression. The traumatic nature of being physically rough-handled by their adult child during these episodes was a stark reality that participants faced, leading to an ongoing fear of potential harm, particularly in public settings like a busy marketplace. These aggressive and violent behaviours were emotionally draining, leaving participants in a heightened state of anxiety.

4.3.7.3 Fear for Child's Safety and Well-being. Lastly, this subtheme highlighted participants' concerns about their adult child's vulnerability, especially during mental health crises, episodes of being missing, or self-harm threats, underscoring the emotional burden of caregiving. Peter shared his experience, saying, *"When he goes missing, I knew he will be back but of course there is still this possibility of he encounter some dangerous situation where there's not way I could help him on the spot or instantly because I don't even know exactly where he is now. But I kind of know he's either here, there or there. In the past I will be very nervous and go to A B or C places to look for him and then end up I'll be very tired, then I'm getting much worse physically, psychologically."*

The sense of urgency and desperation heightened when participants perceived the risks to their adult child as particularly dangerous. Their fears were not just for their adult child's immediate safety, but also for their vulnerability to exploitation, their mental health, and even basic needs like food. The idea of their adult child having suicidal thoughts was particularly distressing for participants. They saw it as a clear sign that their child was deeply overwhelmed, which intensified their concern. As Saanvi recounted,

"*He was actually admitted to the hospital, because he wanted to end his life. That was really very traumatic for me because over the years he has never said anything like taking his*

life away or life was very difficult that he couldn't understand himself, so that was really something that took us by surprise and shock."

The search for their missing adult child was exhausting both physically and mentally, with the constant fear of losing them always weighing on their minds. These participants worried that their child might stray from safety or go missing indefinitely. These fears underlined the persistent and varied nature of anxiety that participants experienced concerning their adult child's behaviours, safety concerns, and overall well-being. Through these narratives, the voices of the participants painted a vivid picture of the constant vigilance and unrelenting anxiety they experienced, as they remained on high alert, perpetually bracing themselves for the unknown.

4.3.8 *Theme 4: Responding, Anticipating and Adapting to Traumatic Events*

The experiences of participants involved a range of coping mechanisms and interventions in response to traumatic events. Immediate Crisis Management and Emotional Strain explores the urgent, intense actions and rapid responses caregivers take during high-stress situations, as well as the profound emotional strain they experience. The subtheme of Communication, Negotiation, and Positive Reinforcement highlights the essential role of these strategies in managing unpredictable aggressive behaviours. Adaptation and Continuous Learning highlights the ongoing process of adaptation and learning as participants adjusted their communication, expectations, and approaches to better support their adult children, continually refining their caregiving strategies through experience and practical insights.

4.3.8.1 Immediate Crisis Management and Emotional Strain. Participants shared the urgency and intensity that defined their responses during high-stress situations, such as medical emergencies and instances of aggressive behaviour. Kenneth described how they would "*quickly call an ambulance, feeling alarmed and anxious*," when their adult child faced

a life-threatening situation. This immediate, almost instinctual response was driven by the pressing need to save their child's life, leaving little room for contemplation. In managing aggressive behaviour, participants explained how they employed immediate strategies to de-escalate and handle crises. Rohan illustrated this approach, explaining,

"The first thing what we would do, once we observe like a faster as quickly as possible, we do with the medical intervention because that is one thing, we know that it takes some time, but at least it has to start and before it escalates we have to give the medicine. So this is one part. And the second part is as much as possible. We try to talk less and observe. Because when sometime when you talk also could be the trigger, make him angry, because he's trying to process something, doing some, you know, kind of a completing some scenario when, some imagination of scenario." This highlights the careful balance participants maintain to prevent further escalation.

In addition to immediate actions, participants emphasized the importance of closely monitoring their child's behaviour in public and adjusting medications when necessary to ensure safety. They also shared the importance of recognizing subtle cues that might lead to aggression. Participants gave their adult children space and offered calm instructions when they were agitated, paying close attention to small details that could potentially trigger aggressive behaviour. They ensured they were attentive when their children approached to talk, using this awareness to pre-empt and manage challenging situations effectively. These measures helped build stronger relationships and prevent potential crises.

However, alongside these immediate actions came profound emotional strain, with many participants expressing the immense strain they felt as they navigated these complex dynamics. *"I've learned not to panic, to stay calm even when I'm terrified inside,"* Christine confessed, revealing the constant psychological endurance required to manage aggressive behaviours. The fear of potential harm or danger loomed for these participants, leading to

mental strain and exhaustion. One participant expressed a deep sense of helplessness when their adult child became aggressive, acknowledging and justifying that physical restraint and medication were sometimes necessary measures to ensure safety.

Participants also spoke about the internal struggles they faced, such as managing their own anger and anxiety to prevent situations from spiralling out of control.

"Whenever that he's in the mood to talk, he be talking, for the one hour he can be talking the same thing, 3 and 4 times, I just have to learn to bear with it, I just have to take a deep sigh, deep breath, and then just cope, play along with this. Because I know if I were to tell him, or chastise him, it will be a trigger," Shafiq explained, highlighting the delicate balance they strive to maintain.

4.3.8.2 Communication, Negotiation, and Positive Reinforcement. Participants emphasized the crucial role of effective communication, negotiation, and positive reinforcement in managing challenging and unpredictable aggressive behaviours. Christine emphasized the importance of using "*simple and clear communication, with regular reminders*," tailored to her adult child's needs. While they strived to maintain calm and avoid showing fear, they also engaged in negotiation, hoping to reach mutual understanding, though they admitted that these efforts did not always yield the desired outcomes.

Timing and brevity in interactions were also highlighted as crucial. *"I try to catch my child at the right moment when he is receptive,"* Melissa shared, illustrating the nuanced understanding they have developed over time. They focused on offering options and allowing their adult children the space to try strategies independently, using "verbal guidance" and carefully considering their tone to encourage receptiveness, as Alice shared. These communication strategies were integral for these participants in managing difficult behaviours and maintaining a sense of calm and control in challenging situations.

Despite the challenges, positive reinforcement played a complementary role as participants emphasized the importance of encouragement and positive reinforcement in empowering their adult children. *"I focus on open communication and a gentle approach,"* Melissa said, describing how they work to boost their adult child's confidence. They prioritized daily check-ins, offering reassurance and creating a supportive environment where their adult children felt comfortable expressing themselves. *"I listen without interrupting, only offering advice when there's a pause, and reflect when he behave well and listened well,"* Shafiq shared, illustrating their patient and persistent efforts to build trust.

4.3.8.3 Adaptation and Learning. Adaptation and continuous learning were central to participants' ability to support their children effectively. It was noted that participants asked made adjustment in how they responded to their children, such as learning and adapting different ways when interacting with their children, highlighting the ongoing process of adaptation. Melissa illustrated her approach:

"*So a lot of times I have to use multiple choice like, you know, give him choices. Is it because of this? That is that and things like that. Then he will choose the answer for me. So when I'm more or less get, you know, the… roughly, if the multiple choice guide me along. I'm more or less will try to understand. And then, I will recap. I will make a statement to say, is this because you are worried about whatever whatever… then that's why you are not doing this and that? Then he will say yes. Then I know him more. …. sometimes I can try to probe and he will say it out to me. But sometimes, he just refuses, but I will just try the next day using a different way and talk to him*."

Over time, participants developed strategies and approaches through experience, integrating these practical insights into their caregiving methods. As Alice explained,

"*Then slowly I learn to when I am very angry I walked away, I will just walked away. Then slowly I learnt to not get angry so easily when he is concerned, you know. But rather think about it and use a different words, different way of talking. Hmm, that makes a big different*."

Participants also spoke of lowering their expectations and designing tasks that were manageable for their adult children, emphasizing the importance of remaining practical. "*I've learned to be adaptable, to adjust my parenting approach based on my child's needs*," Peter concluded, reflecting the resilient and evolving nature of their caregiving journey.

4.3.9 *Theme 5: Parental Duty and Commitment*

Finally, Parental Duty and Commitment underscores the enduring sense of responsibility and dedication participants maintained despite these challenges. The experiences of these participants were profoundly shaped by a strong sense of parental duty and commitment. This theme is central to understanding the participants' navigation through the daily challenges and traumatic events associated with their caregiving roles. Within this overarching theme, four subthemes were identified: Acceptance and Resilience, Sense of Duty and Responsibility, Commitment and Hope, and Justification and Rationalization. These elements collectively shape their approach to caregiving and underscore the profound impact of their roles on their lives.

4.3.9.1 Acceptance and Resilience. Participants consistently expressed a belief that life's challenges are universal, viewing these difficulties as opportunities for growth. This perspective of acceptance toward their caregiving challenges played a vital role in their resilience. By accepting their adult children's conditions, participants found it easier to navigate their roles. For example, Rohan voiced that it was not their son's fault for his behaviour, understanding it as a manifestation of his condition, which helped them to avoid placing blame. Similarly, Kenneth shared how he constantly reminded himself that his

daughter had an illness and needed care, especially during moments when his daughter was unaware of her actions. This acknowledgment that their adult children's behaviours were driven by their conditions, not by defiance, allowed participants to manage their feelings of helplessness and frustration. Despite the overwhelming nature of their children's outbursts, this acceptance fortified their resilience, enabling them to continue providing the care and support their adult children required.

4.3.9.2 Sense of Duty and Responsibility. A deep sense of duty and responsibility permeated the narratives of the participants, shaping their actions and reinforcing their roles as parents. Both mothers and fathers viewed it as their fundamental responsibility to address their children's needs, ensuring their safety and well-being. This recognition of duty was particularly evident in Rohan's commitment to supporting his son, as he reflected, "*So, as father, at least I have my duty to do. To my child. So of course, like our not forever or even after he grows up, but in this situation. Like, I should try to, do my best. So I try to do more than what a parent or father would have normally done*."

Similarly, mothers expressed a profound sense of duty, with Saanvi highlighting how her responsibility motivated her to help her son, prioritizing his safety to prevent self-harm. This ingrained sense of duty was a driving force behind their daily actions, compelling them to make significant personal sacrifices. Some saw their role not merely as caregivers but as protectors and supporters, always prioritizing their children's needs above all else. Kenneth echoed this sentiment, saying, "*I mean is my own child, so if she (daughter) has this illness, I will still care for her, even until now. So it doesn't change my heart*"

4.3.9.3 Commitment and Hope. This subtheme captures the unwavering dedication of participants to their adult children's futures. Participants demonstrated an enduring commitment to supporting their children, holding onto the hope that circumstances might improve over time. As Christine expressed, "*All things said, there's no ease and safety, we*

just have to go day by day and try and try to look ahead, whatever we can do." Rohan echoed this sentiment, saying, "*we never lose hope. Okay, we only hope we are strong enough to keep caring for him and helping him. So that is the only prayer we always have*." Their commitment often extended beyond typical parental duties, as they compensated for their children's challenges with love and an appreciation for the preciousness of life.

However, participants also acknowledged the significant physical and mental toll of managing their adult children's aggression and violence. They expressed hope that these stresses might lessen over time. Ahmad, for example, shared, *"If he continues like this. We have to prepare and actually initiate early for him to actually live separate from us. Hopefully we don't have to go through those kind of stresses and so on physical mental stress things like that."*

Aging emerged as a key concern, with participants expressing worries about their own diminishing strength and ability to care for their adult children. Despite this, their commitment remained unshaken. As Christine put it, "*we still have to prepare him for times when we are not around, not even that, for a time when we are too old and too weak already.*" Similarly, Peter reflected on his willingness to care for his son for as long as possible, acknowledging the inevitable limitations that aging would bring. This enduring sense of responsibility and love helped participants push through their fears about aging, reinforcing their belief that, despite the uncertainty, they could still provide care and support for their children.

This combination of hope and commitment was essential for these participants in sustaining their perseverance and long-term dedication, helping them create a more stable and peaceful environment for their families. Even as they faced the inevitability of aging, they held on to the belief that their efforts, love, and hope would somehow make a difference.

4.3.9.4 Justification and Rationalization. Participants often found themselves rationalizing their decisions and actions to navigate the external judgments and internal doubts they faced. They frequently justified their caregiving choices in the face of societal pressures, particularly when others suggested abandoning their children due to the suffering involved. As Rohan shared,

"*You know, many time many people would have suggested, hey, how long you people, you husband and wife, you keep suffering. You also have a life so take him and leave him somewhere, you know that you can't manage him, but, at least you care for your life. So like it's very difficult for us emotionally to make that kind of decision. When we know that it is not his mistake. You know, whatever good and bad. You know, at the end is our son. So we had to, see what best we could do and always hoping that one day things will become reasonably okay*."

These participants firmly rejected such notions, instead emphasizing that their decisions, such as seeking hospital care, were motivated by the desire to provide appropriate support, not to evade legal consequences. Ahmad, for example, considered admitting his son to the hospital for his aggressive and violent behaviours:

"*The reason is because if he were to be so-called arrested or something for the kind of conduct, so, my concern was that the officers may not have a sufficient background to understand his condition and things like that. And also if I were to actually bring him to IMH, we can actually open the case then maybe it's a point where the police may actually make reference to actually to try and understand him and so on. I'm not saying that he will be, he can get away Scot free being violent or anything but at least the authorities can actually have a reference to get on whether he's truly is autistic and whether is it normal that he's behaviour is like this*."

This subtheme highlights the participants' need to rationalize their actions to themselves and others, reinforcing their commitment to their ethical stance in caregiving. This process of justification and rationalization helped them cope with societal expectations and maintain their focus on providing care.

4.4 Discussion

The study highlighted the significant influence of cultural, familial, community, and individual factors on the development PTSS among participants. This discussion examines these findings in depth, explores their implications for caregiving practices, and suggests potential directions for future research and interventions.

4.4.1 *Cultural Context in Caregiving*

Caregiving motivations have been found to be deeply rooted in cultural self-identity, which mediates the influence of cultural norms and values, such as filial piety, familism, and religious beliefs, on caregivers' sense of duty and responsibility (Zarzycki et al., 2022). These values fostered resilience by reinforcing emotional attachments, love, and reciprocity in caregiving roles. Similarly, findings from this current study highlight that caregiving practices among participants were profoundly shaped by cultural and religious values, which provided vital coping strategies to navigate the emotional demands of caregiving. This aligns with a recent study in Singapore that emphasizes the cultural importance of respectful relationships, such as filial piety (Riches et al., 2023), a value also reflected in this study's findings. This cultural value may have played a role in shaping how caregivers navigate their roles and manage caregiving challenges. For the participants in this study, these strategies, often passed down through generations, appeared to be rooted in broader philosophical or religious contexts that might have provided participants with a sense of purpose and duty. Such resilience, cultivated through cultural and religious influences, might have served as a significant source of emotional strength, enabling participants to navigate the complexities of caregiving with dignity and responsibility amidst challenging scenarios.

Exposure to different caregiving norms and practices across cultures might have enriched participants' approach, allowing them to adopt more holistic and possibly effective

methods. Learning from diverse experiences might also help participants feel less isolated, as they could realize that challenges are universal and varied solutions exist. Religion seemed to play a significant role in providing participants with strength and resilience, potentially offering a higher purpose to their caregiving challenges. As found in a recent study, spirituality-based interventions significantly enhanced resilience, sense of coherence, and family adjustment among parents of children with ASD (Pandya, 2018). Hence, spiritual perspective might have transformed how participants perceived their circumstances, enabling them to endure and remain committed where they might otherwise feel overwhelmed. Religious teachings often promote values of compassion, patience, and unconditional love (Grace, 2017), which could be critical in caregiving settings, especially when dealing with difficult behaviours or significant disabilities. These values might have guided participants in their daily interactions and decision-making processes. Religious communities provided support, underscoring the importance of social networks in caregiving. These communities might have offered emotional and sometimes material support, validating the participants' experiences and efforts (Murray, 2002; VanderWeele, 2017).

The use of prayer and other spiritual practices as coping mechanisms seemed to highlight how participants managed their stress and sought emotional balance. These strategies could have provided a private refuge and a means of processing the emotional toll of caregiving. Religious frameworks that offered explanations for suffering and adversity might have helped participants accept their situations, reducing feelings of unfairness or bitterness. This acceptance seemed to be important for maintaining mental health and emotional stability. Similarly, many participants turn to religion as a way to manage caregiving stress, with prayer and faith offering solace and a sense of hope. Religious coping strategies, such as the belief in divine intervention or the concept of karma, provide participants with a framework for interpreting their experiences, reducing feelings of

responsibility for events beyond their control, and fostering resilience and emotional well-being (Malhotra & Thapa, 2015). Community-oriented religious practices, such as attending religious gatherings or seeking support from faith-based communities, have been found to alleviate emotional burdens by fostering social connections and empathy among participants (Malhotra & Thapa, 2015). The intersection of religion with caregiving appeared to reflect a variety of beliefs, practices, and community influences that may have shaped how participants perceived and managed their roles. These religious dimensions might have added layers of meaning, resilience, and community engagement to the caregiving experience, enriching participants' lives and often providing essential support through their faith (VanderWeele, 2017; Malhotra & Thapa, 2015).

Stigma appeared to act as a significant barrier to seeking and receiving appropriate mental health care for the participants. In some cultural contexts, NDDs are often attributed to parental faults or supernatural causes, leading families to avoid help out of fear of shame, social isolation, or harm to family reputation (Norbury & Sparks, 2013). This stigmatization not only impacts the individuals with NDD but also places immense psychological strain on caregivers, who may experience social withdrawal and reluctance to seek support. Breaking down such stigma may require building supportive communities where these experiences can be openly shared. Advocacy and awareness campaigns led by individuals who have navigated these challenges may be particularly powerful in changing public perceptions. For participants, becoming advocates for mental health could also be a journey of personal growth, helping them find meaning and purpose in their roles and connect with others on similar paths. Encouraging the view that mental health is just as important as physical health might help reduce stigma. Integrating mental health care into general health care settings could normalize treatment and reduce the sense of otherness associated with specialized mental health facilities.

There are many aspects of caregiving that are deeply influenced by culture. Participants in this study seemed to be influenced by cultural contexts in many ways, from defining norms, values, and expectations to providing emotional and practical support. Culture seemed to have shaped the way participants viewed their role, how they interacted with their adult child with NDD, and how they cared for themselves. Attitudes toward disabilities, coping mechanisms, and responses to traumatic events seemed to be influenced by cultural background. Additionally, exposure to cultural practices and religious beliefs could have served as a source of resilience for these participants and broaden their perspective on the challenges of caregiving. The stigma felt by the participants associated with mental health, in particular, highlighted the cultural nuances in caregiving. As such, caregiving could be more inclusive and empathetic when these cultural influences are recognized and understood. Mental health professionals should also take into account the cultural beliefs and practices of the caregivers when designing and providing support services. Cultural sensitivity would help to ensure that caregivers feel supported and that their needs are addressed.

4.4.2 *Family and Community*

The study's findings highlighted the significance of caregiving as a shared family responsibility, emphasizing that the collective approach to caregiving was not only essential for distributing the load but also for strengthening familial bonds. This distribution of responsibility could help to ensure that no single member is overwhelmed and fosters a sense of unity and mutual support within the family. Such collective caregiving practices are deeply embedded in collectivist cultures like those of Asian, Hispanic, and African American communities, where caregiving is seen as a natural and unquestioned part of life, guided by cultural values such as filial piety and familism (Pharr et al., 2014). The support provided by family members to participants encompassed both emotional and practical aspects. Emotional

support appeared to have been crucial in maintaining the participants' morale and mental well-being, while practical support seemed to have directly impacted the efficiency and effectiveness of caregiving tasks. In collectivist cultures, caregiving roles are often clearly delineated based on gender and family hierarchy, ensuring structured distribution of responsibilities and fostering a sense of purpose among family members (Pharr et al., 2014). This synergy between emotional and practical support highlighted the necessity of a holistic support system for these participants.

Findings showed that a particularly pivotal role might have been played by a supportive spouse (Jose & Varma, 2021), whose involvement was often perceived as foundational in sustaining the participants' capacity to manage ongoing challenges. A supportive spouse seemed to offer stability, enabling the primary family caregiver to seek additional resources and take necessary respite. This foundational support appeared to be important, as it provided the participants with the freedom to explore and utilize external support systems without feeling isolated or overwhelmed. Engagement in activities outside the immediate realm of caregiving (Petty, L., & Trussell, 2021; Bedini et al., 2018; Faw 2018), such as outings, holidays, and participation in support groups, seemed to further underscore the importance of self-care and external support networks. These activities are not mere luxuries but essential components of participants' well-being. They offered opportunities for these participants to recharge, gain new perspectives, and continue their roles with renewed vigour and resilience.

The findings highlighted the dynamic nature of caregiving, where ongoing negotiation and adaptation within the family appeared to be necessary. Caregiving for these participants seemed to demand flexibility as families must continually adjust to changes in the care recipient's condition, available resources, and the personal needs of each family member. This adaptability appeared to be the key to effective caregiving and maintaining family harmony.

The study suggested that families could effectively mobilize both internal and external resources to navigate the complexities of caregiving. It emphasizes the critical role of collective effort and support in ensuring the well-being of both the caregiver and the care recipient (Pharr et al., 2014). By recognizing and utilizing a broad spectrum of support, from family dynamics to external networks, families could create a sustainable and enriching caregiving environment. This holistic approach might not only enhance the quality of care provided but could also enrich the caregivers' experience, ensuring their long-term well-being and effectiveness.

4.4.3 *The Caregiver Journey*

The findings of this study highlighted the intricate and demanding landscape of living with and managing developmental disorders within a family context. Findings emphasized the dynamic and often lifelong nature of caregiving for individuals with developmental disabilities, underscoring an interplay among medical, educational, and emotional aspects which has been well documented in other studies (Tuchman & Cuccaro, 2011; Tuchman et al., 2013; Coppus, 2013; Dillenburger & McKerr, 2009; Braddock et al., 2008). Findings also suggested the indispensable role of both formal and informal support systems in helping families adapt to and manage the persistent demands associated with developmental disorders. The findings highlighted critical gaps in current support frameworks, particularly during the transition to adulthood for individuals with NDD. Caregivers often redefine adulthood based on independence and self-care rather than traditional societal milestones (Nucifora et al., 2024). This underscores the need for more integrated and sustainable care approaches that better address transitional phases, educational settings, and caregiver support.

Participants' emotional journeys seemed to be marked by an initial period of upheaval, followed by long-term navigation of stress guilt, and resilience, which mirror similar

emotional experiences of caregivers of children with ASD (Rizzo et al., 2024). These emotional experiences of participants appeared to be profoundly connected to the children's developmental trajectories and the participants' personal growth and adaptation strategies. These themes appear to depict a caregiving relationship fraught with emotional challenges but also characterized by profound personal growth, reflection, and an unwavering commitment to providing better care. They illustrated the complex interplay between personal emotional responses and the practical demands of caregiving, shaping both the participants' experience and their relationship with their children (Rizzo et al., 2024).

The findings also illuminated the profound impact of communication challenges on both the individuals with developmental disabilities and the participants. For those with communication barriers, the inability to express needs and feelings effectively not only limits social interactions but also impacted authority relationships. Participants reported to face emotional distress and continually adapting communication methods to meet these challenges. Poor communication abilities in care recipients have been linked to higher levels of daily disturbances and caregiver stress, with repetitive or stereotypical communication patterns described as "exhausting" and a source of ongoing emotional distress (Rattaz et al. 2017). This ongoing effort to refine communication strategies reflected a proactive approach but also indicated the continual stress and uncertainty involved in such adaptations. Effective communication appeared to be foundational for ensuring the needs of the individuals are adequately met and for fostering a supportive family environment. Additionally, meaningful, reciprocal communication between caregivers and care recipients was associated with improved perceptions of caregiving roles, further highlighting the necessity for professional intervention and support in developing and maintaining effective communication strategies (Hines et al., 2012). Providing families with tailored tools and techniques is essential to mitigate stress and strengthen the caregiver-care recipient relationship.

Within the caregiving dynamic, the findings suggested that diversity in parenting styles can introduce significant challenges, especially regarding consistency and emotional alignment between parents. However, these differences seemed to also present opportunities for a holistic approach to caregiving for participants. It has been found that families with moderate levels of cohesion and adaptability were better equipped to handle caregiving demands, emphasizing the importance of finding a balance between emotional bonding and independence (Altiere & von Kluge, 2008). As such, the key to transforming divergent parenting methods into effective strategies appeared to lie in communication and mutual respect between parents. These findings highlight the necessity for external support systems, such as family counselling or therapy, to help parents navigate their differences more effectively and leverage complementary parenting styles. Such interventions can align parenting approaches, reduce emotional burdens on both parents and the child, and foster a more harmonious family dynamic while strengthening resilience and overall family functioning (Altiere & von Kluge, 2008).

In conclusion, the study's findings provided a comprehensive understanding of the complex experiences of participants managing developmental disorders. They highlighted the critical importance of robust support systems and effective communication strategies, as well as the need for professional guidance to navigate the emotional and practical challenges of caregiving. These insights highlighted the importance of developing integrated and sustainable support approaches to enhance the well-being of both individuals with developmental disabilities and their caregivers.

4.4.4 *Trauma and Its Effects*

The findings from Theme 1: Emotional Turmoil provided a nuanced understanding of the profound psychological distress participants experienced, particularly in the context of the traumatic events. The two subthemes, Acute Emotional Trauma and Persistent Helplessness and Frustration, represented both the acute and chronic dimensions of caregiver distress, highlighting the deep and enduring psychological toll of caregiving in traumatic contexts.

Acute Emotional Trauma captured the intense and immediate emotional turmoil participants experienced during sudden, severe incidents involving their adult children with NDD. Such events, often life-threatening, evoked shock, confusion, and a profound sense of failure when participants were unable to prevent or resolve crises. Participants described moments of heightened urgency, desperation, and emotional pain, such as dealing with suicidal behaviours or violent aggression. Research highlights the profound emotional impact on caregivers in similar situations, where they frequently report feeling overwhelmed by the responsibility of monitoring suicide risk and providing emotional support (Marshall et al., 2023). These experiences reflected the acute stress response often linked to PTSS, marked by heightened arousal and emotional dysregulation. The perceived inability to protect their child or prevent harm further compounded their distress, fostering feelings of inadequacy and helplessness.

In contrast, Persistent Helplessness and Frustration reflected the ongoing, chronic emotional challenges of caregiving. Participants described a relentless struggle to manage their adult child's behaviours while feeling unsupported and powerless as the aggressive behaviours unfolded. This sense of helplessness was exacerbated by gaps in available support during critical moments, as illustrated by Rohan's account of inadequate crisis intervention during episodes of aggression. Participants often internalized blame for their adult child's condition or behaviours, as evidenced by Christine's husband questioning whether they were

at fault. These feelings of self-blame and doubt, coupled with the emotional strain of failed interventions, as in Peter's experience, highlighted the chronic trauma inherent in caregiving. The persistence of these feelings reflected the unrelenting nature of caregiving, where daily struggles and insufficient external support could have amplified emotional distress for these participants. Addressing these challenges requires sustainable support systems, such as ongoing psychoeducation, caregiver training, and accessible crisis response services. These findings situated caregiving within a trauma-informed framework (Butler et al., 2011), where the burden of experiencing trauma highlight the need for interventions that prioritize caregiver safety, empowerment, and collaboration with professionals. The challenges highlighted in the narratives further emphasized the importance of establishing rapid-response strategies and community-based support networks. These measures could bridge the temporal gap between the onset of aggressive episodes and the arrival of professional help, reducing the strain on caregivers during critical moments.

The findings from Theme 2: Living with Volatility and Aggression provided a sobering look at the profound impact of aggressive behaviours on participants, particularly in the context of their PTSS. This theme focused on the direct and tangible experiences of participants dealing with volatile and aggressive behaviours. It examined how escalating aggression, physical violence, and unpredictable outbursts disrupted the home environment, compromised safety, and led to significant emotional strain. The emphasis was on the behavioural manifestations of aggression and the immediate impacts on the participants' surroundings and sense of safety. The three subthemes — Escalation of Aggressive Behaviour, Physical Aggression and Violence, and Unpredictability and Uncontrollability — offer a comprehensive analysis of the multidimensional challenges faced by participants, shedding light on the intersection of behavioural trauma, safety concerns, and systemic inadequacies.

Escalation of Aggressive Behaviour illustrated the progressive intensification of aggression, where verbal outbursts escalated into physical actions, leading to property destruction and creating an unsafe home environment, likened to "battlefields," with visible damage as reminders of the traumatic events. This escalation left participants feeling helpless, emotionally drained, and increasingly fearful of future incidents. These findings aligned with the findings from the study conducted by Walden and colleagues (2000), which noted similar patterns among parents of adult children with intellectual disabilities, where escalating aggression was a significant source of stress, particularly for those who felt trapped in caregiving roles. These patterns of escalation not only disrupted the physical environment but also heightened participants' emotional vulnerability, fostering anxiety about the potential for worsening aggression. The fear of further violence and the constant need for vigilance revealed the ongoing psychological toll of caregiving in such volatile circumstances, highlighting the critical need for preventive interventions to de-escalate aggressive behaviours before they reach crisis levels.

Physical Aggression and Violence shifts focus to the direct physical harm inflicted on participants, which further undermines their sense of safety and control. Participants recounted incidents of being physically attacked, pushed, or injured by their adult children, with some requiring medical attention. The recurring nature of these violent outbursts created an environment of perpetual threat, where participants felt unsafe in their own homes. The increasing physical size and strength of their adult children amplified the danger, making it harder to manage aggression safely. These incidents extended into public settings, adding social scrutiny and isolation to participants' distress. These findings are consistent with the study conducted by Walden and colleagues (2000), who noted that caregivers of individuals with higher levels of aggression experienced greater emotional burden and received less support, exacerbating their distress.

Unpredictability and Uncontrollability captured the erratic nature of aggressive behaviours, which left participants unable to anticipate or manage outbursts effectively. The unpredictable onset of aggression seemed to intensify participants' sense of powerlessness and constant vigilance. Christine's account of her son's sudden attack on a stranger in public and Rohan's description of the family's isolation due to the fear of public outbursts highlighted how unpredictability restricts their ability to participate in normal social activities, exacerbating their isolation and emotional distress. The lack of control over their adult child's behaviours, coupled with the constant anticipation of harm, trapped participants in a cycle of hypervigilance and stress, further contributing to their PTSS. This subtheme underscored the importance of equipping participants with tools to manage unpredictability and providing them with support networks that could help respond to crises effectively.

These insights frame caregiving as a form of chronic stress, characterized by ongoing exposure to unpredictable and aggressive behaviours. The impact of this stress is not confined to immediate emotional strain but can also lead to lasting psychological challenges, including symptoms akin to posttraumatic stress, often worsened by insufficient support systems. The combination of escalating aggression, direct physical harm, and the unpredictability of outbursts created a high-stress caregiving environment that perpetuated a sense of fear, helplessness, and isolation. These findings also highlighted the inadequacies in addressing caregiver safety, particularly during moments of crisis. Participants' narratives revealed the urgent need for accessible and immediate support systems, such as crisis response teams and strategies, de-escalation training, and safety planning resources tailored to caregivers.

The findings from Theme 3: Constant Vigilance and Anxiety illuminated the persistent emotional and psychological toll of caregiving, as participants grappled with chronic states of alertness and fear. This theme shifted focus from the physical dimensions of caregiving challenges to the internalized, ongoing mental strain participants endured,

primarily driven by uncertainty, threats of harm, and concerns about their adult child's well-being. The three subthemes — Fear and Anxiety Due to Uncertainty, Fear of Immediate Physical Harm, and Fear for Child's Safety and Well-being — collectively underscored the profound and varied anxieties participants faced, emphasizing the pervasive impact of caregiving on their mental health and quality of life.

Fear and Anxiety Due to Uncertainty captured the pervasive worry participants felt over their adult child's unpredictable behaviours, mental state, or whereabouts. The unpredictability disrupted daily life, leaving participants in a constant state of alertness. Participants often imagined worst-case scenarios, such as police involvement or receiving bad news, underscoring the anticipatory nature of their anxiety. This state of hypervigilance reflected a chronic stress response, where participants, unable to predict or control outcomes, remained in a heightened state of arousal. In caregivers supporting individuals with mental disorders, it has been found that caregivers often face significant psychological distress stemming from unpredictable behaviours and crises (Shah et al., 2010). This shared psychological distress experienced by both groups of caregivers seemed to be compounded by caregivers' perceived lack of control and their responsibility to manage these crises, often without sufficient support or resources. As such, the constant need for vigilance, combined with managing behavioural disturbances, heightens their anxiety and increases their vulnerability to mental health issues. Participant's description of bracing for the worst during adult child's "bad days" exemplified the emotional toll of this uncertainty, further complicated by the responsibility of ensuring the safety of other family members. These experiences highlighted the need for structured support systems that can help participants manage uncertainty, such as communication protocols, tracking mechanisms, or crisis plans tailored to individuals with unpredictable behaviours.

Fear of Immediate Physical Harm focused on the participants' heightened fear of potential violence or accidents caused by their adult children during episodes of anger or agitation. This fear often stemmed from the perceived physical danger posed by their adult child, exacerbated by their increasing physical size and strength. Christine's account of her child threatening violence with a knife underscored the terror participants faced in anticipating harm to themselves or others. Similarly, Ahmad's fear of his son's sudden transformation into someone "stronger, more dangerous" reflected the traumatic nature of these moments. Unlike the subtheme on physical aggression in earlier findings, this subtheme emphasized the anticipatory anxiety surrounding harm rather than the harm itself, showing how the possibility of violence perpetuated a state of emotional distress. This constant anticipation of danger aligned with theories of trauma and hyperarousal (Krupnik, 2021), where participants' fear responses remained activated even in the absence of immediate threats. These findings suggested the importance of equipping caregivers with tools for de-escalation and self-protection, as well as providing accessible emergency support to mitigate the ongoing psychological strain of living with this fear.

Fear for Child's Safety and Well-being reflected participants' deep concerns about their adult child's vulnerability, particularly during mental health crises or episodes of self-harm and disappearance. This fear often transcended immediate crises, encompassing long-term worries about their adult child's mental health, safety from exploitation, and ability to meet basic needs. These fears often left participants feeling helpless, as they struggled to reconcile their efforts to protect and support their adult child with the harsh reality of their adult child's vulnerability. The enduring fear of loss or harm speaks to the existential weight of caregiving, where the stakes are not just high but deeply personal.

The findings from Theme 4: Responding, Anticipating, and Adapting to Traumatic Events highlighted the critical coping mechanisms and interventions employed by

participants. Immediate Crisis Management and Emotional Strain emphasized the urgency and intensity of participants' responses during high-stress situations, such as medical emergencies and aggressive episodes. Participants described the instinctive and rapid actions they took to ensure safety, ranging from calling an ambulance to de-escalating volatile situations. For instance, Rohan's emphasis on observing subtle behavioural cues and administering medication to prevent escalation reflected the tactical decision-making involved in crisis management. These immediate actions, while necessary, came with profound emotional strain. Christine's confession of staying calm outwardly while feeling terrified inside revealed the psychological endurance caregivers must sustain, often leading to exhaustion and internalized stress. The balancing act of staying composed while navigating volatile situations demonstrated participants' remarkable resilience but also exposed them to chronic stress and potential burnout.

The subtheme of Communication, Negotiation, and Positive Reinforcement explored the importance of tailored communication strategies in managing challenging behaviours. Participants emphasized using simple, clear communication, timing interactions effectively, and maintaining calm during negotiations. Participant's reliance on "simple and clear communication" and strategic use of timing underscored participants deep understanding of their adult child's needs. These approaches reflected participants' ability to adapt their communication to reduce triggers and promote cooperation, often using tone and brevity to minimize conflict. Positive reinforcement emerged as a complementary strategy, fostering trust and encouraging desired behaviours. By offering consistent encouragement, reassurance, and gentle feedback, participants were able to create supportive environments that bolstered their adult child's confidence. These strategies aligned with principles of behavioural reinforcement (Manente et al., 2010) emphasizing the need for structured and positive approaches (Sutton, 2021) in caregiving. However, participants also acknowledged that

communication and negotiation efforts did not always yield success, underscoring the emotional challenges of managing unpredictable behaviours. This highlighted the importance of training caregivers in evidence-based behavioural techniques, such as Applied Behaviour Analysis (Eckes et al., 2023) or motivational interviewing (Smeerdijk et al., 2015), to enhance their ability to navigate complex interactions effectively.

The process of Adaptation and Continuous Learning was central to participants' ability to refine their approaches and sustain their caregiving roles. Participants shared how they adjusted their responses, lowered their expectations, and developed strategies to align with their adult child's needs. Melissa's use of multiple-choice questions to decipher her son's concerns and Alice's practice of walking away when angry illustrated the iterative nature of caregiving. These examples highlighted participants' ability to integrate practical insights gained through experience into their daily practices. This subtheme reflected the dynamic nature of caregiving, where participants must constantly adjust their strategies in response to evolving challenges. The narratives demonstrated a form of adaptive resilience, where participants embraced flexibility and emotional regulation to maintain their effectiveness as caregivers. Peter's reflection on adjusting his expectations to remain practical highlighted the importance of realistic goal-setting and self-compassion in sustaining long-term caregiving efforts. From a conceptual perspective, these findings aligned with models of posttraumatic growth (Tedeschi & Calhoun, 2004), where participants developed new skills, insights, and coping mechanisms through their experiences. However, this growth is contingent on adequate support systems that allow caregivers the space to reflect, learn, and recover.

The findings from this theme emphasized the intersection of coping strategies, emotional strain, and resilience in caregiving for individuals with NDD. The subthemes collectively demonstrated that while participants possessed remarkable capacities to respond, anticipate, and adapt to traumatic events, the emotional toll was significant. Immediate crisis

management demanded a constant state of alertness, communication strategies required careful calibration, and adaptation involved an ongoing process of learning and adjusting.

The findings from Theme 5: Parental Duty and Commitment emphasized the enduring sense of responsibility, love, and perseverance exhibited by participants in the face of profound challenges and traumatic experiences. This theme revealed how participants derived meaning, motivation, and resilience from their roles, even as they navigated the significant physical, emotional, and social tolls of caregiving. The four subthemes — Acceptance and Resilience, Sense of Duty and Responsibility, Commitment and Hope, and Justification and Rationalization — collectively reflected the interplay of values, beliefs, and coping mechanisms that sustained participants through their demanding journeys.

The subtheme of Acceptance and Resilience revealed that participants demonstrated a profound ability to frame their caregiving challenges through a lens of acceptance, recognizing their adult child's behaviours as manifestations of their conditions rather than wilful defiance. This perspective allowed participants to manage frustration and helplessness by depersonalizing their adult child's actions. The participants' ability to attribute their adult child's behaviours to their conditions rather than personal faults helped reduce feelings of blame and guilt, fostering resilience. These finding echoes previous research emphasizing the importance of cognitive reframing in managing caregiver stress (Benson, 2014; Lindo et al., 2016). This acceptance fortified resilience, enabling participants to endure repeated traumatic events and continue providing care with empathy and patience. These findings aligned with concept of posttraumatic growth (Tedeschi & Calhoun, 2004), which suggest that acceptance of difficult realities can foster resilience and reduce emotional distress. By reframing caregiving challenges as opportunities for growth and understanding, participants mitigated the negative emotional impacts of their roles (Benson, 2014; Lindo et al., 2016). However, this acceptance often came at the cost of participants' mental health, as they internalized the

weight of their responsibilities. Supporting caregivers in balancing acceptance with self-care is crucial to sustaining their resilience.

In the subtheme of Sense of Duty and Responsibility, a deeply ingrained sense of parental duty permeated participants' narratives, shaping their unwavering commitment to their adult child's well-being. Participants expressed this duty as a moral and emotional imperative, compelling them to prioritize their adult child's needs above their own. This sense of duty was consistent with the role theory, which posits that individuals' behaviours are influenced by the expectations of their social roles (Biddle, 2013). Furthermore, this sense of duty appeared to intertwine participants' identities closely with their caregiving roles, making caregiving an integral part of their self-concept. While this dedication is admirable, it can also lead to neglect of participants' personal needs, resulting in burnout and diminished well-being. The findings highlighted the importance of interventions that validate caregivers' sense of duty while encouraging them to seek support and share responsibilities, promoting a healthier balance between caregiving and self-preservation.

Commitment and Hope highlighted participants' steadfast dedication to their adult children, which was often intertwined with a sense of hope that acted as a powerful driving force throughout their caregiving journey. Despite the physical and emotional toll, participants expressed hope for better circumstances, even in the face of aging and diminishing strength. This finding aligns with the theory of hope, which emphasizes the role of goal-directed thinking in maintaining motivation and psychological well-being (Snyder et al., 2002). This combination of commitment and hope sustained their perseverance, enabling them to navigate uncertainties and plan for their children's futures. The findings highlighted the duality of hope as both a source of strength and a potential source of stress. While hope can inspire caregivers to endure hardships and maintain optimism, it could also create pressure to achieve outcomes that may not be fully within their control. Interventions aimed at

fostering realistic hope and providing practical tools for future planning could help caregivers navigate this tension.

The subtheme of Justification and Rationalization highlighted how participants navigated societal pressures and internal doubts regarding their caregiving decisions. Participants often felt compelled to defend their choices, particularly when faced with external judgments that suggested abandoning their children. This process of rationalization seemed to have served as a coping mechanism, helping participants reconcile their actions with their values and societal expectations. It reflected the psychological construct of cognitive dissonance reduction, where individuals seek to align their behaviours with their beliefs to maintain emotional equilibrium and reduce psychological discomfort (Harmon-Jones & Mills, 2019). However, the need to justify caregiving decisions could also exacerbated feelings of isolation and vulnerability, as participants struggled to balance external pressures with their internal sense of duty. Supporting caregivers in building confidence and autonomy in their decisions, while challenging stigmatizing societal attitudes, may reduce the emotional burden of justification.

The theme of Parental Duty and Commitment underscored the profound impact of caregiving roles on participants' identities, relationships, and emotional well-being. While their unwavering dedication and resilience are commendable, the findings also highlighted the significant costs of such commitment, including emotional strain, burnout, and self-sacrifice. These findings aligned with broader caregiving literature that emphasized the dual nature of caregiving as both deeply fulfilling (Corman 2009; Bayat, 2007; Bekhet et al., 2012; Iacob et al., 2020) and profoundly taxing (Seymour et al., 2013; Hill & Ross, 2009). This theme illustrated the enduring strength of participants, rooted in love, responsibility, and hope. By acknowledging and addressing the challenges they face, it is possible to create a more supportive environment that enables caregivers to fulfill their roles with greater well-being

and sustainability. Their resilience, shaped by acceptance and a deep sense of duty, offered a powerful testament to the human capacity for enduring care and compassion in the face of trauma.

4.5 Summary and Conclusion

In conclusion, the findings of this study revealed the multifaceted influences of cultural, familial, community, and individual factors on the caregiving experience, particularly regarding the development of PTSS among participants. The discussion examined these findings, exploring their implications for caregiving practices and suggesting directions for future research and interventions. The profound impact of cultural practices and values, the shared responsibility within families, and the supportive role of communities highlighted the necessity of a holistic approach to caregiving. Cultural and religious contexts provided these participants with resilience and coping strategies, while familial support systems emphasized the importance of shared responsibility and emotional backing. Moreover, the participants' journey, marked by emotional turmoil and constant vigilance, emphasized the need for immediate psychological support and long-term mental health resources.

The challenges of managing aggressive behaviours and the importance of effective communication strategies further illustrated the complexity of caregiving. The study also revealed the critical need for targeted interventions and support systems to assist participants in managing these challenges. Recognizing and addressing these diverse influences are essential for developing effective support mechanisms, enhancing caregiver resilience, and ultimately improving the well-being of both participants and their care recipients. Future research should continue to explore these dimensions, aiming to create integrated and sustainable caregiving practices that acknowledge and support the diverse experiences of participants.

4.6 Limitations

While this study provided valuable insights into the experiences of caregivers of individuals with NDD, it is important to acknowledge certain limitations that may affect the generalizability and scope of the findings. One limitation to consider is the potential for researcher bias. Despite rigorous efforts to maintain objectivity, including reflexivity, debriefing and consultations with research supervisors, the perspectives and interpretations of the researcher may have influenced the data collection and analysis processes. Specifically, there is a risk of confirmation bias, as the researcher's prior clinical experience and familiarity with caregiver challenges may have unintentionally shaped the way data were interpreted, leading to an emphasis on themes that aligned with pre-existing expectations. Efforts were made to mitigate this through personal reflections and supervisor feedback to ensure that findings were grounded in participants' narratives.

The homogeneity of the sample, in terms of demographic characteristics such as age, gender, socioeconomic status, and cultural background, may limit the transferability of the findings to more diverse populations. Including a wider range of caregiver participants in future studies could enhance the representativeness of the results. Self-selection bias is another factor, as participants who chose to partake in the study may have had specific motivations or characteristics that influenced their involvement, potentially skewing the results. It's possible that those who did not participate might have different perspectives not captured in this study. Additionally, the reliance on retrospective reporting of experiences can introduce recall bias, as participants may have difficulty accurately remembering and articulating past events and feelings.

Cultural and individual differences in trauma response likely impacted various aspects of this study, from the way interviews were conducted to the interpretation of findings.

Participants' cultural backgrounds and personal experiences may have shaped their perspectives on caregiving, as well as how they interpreted and reacted to trauma. For instance, cultural beliefs surrounding caregiving obligations, mental health, and trauma disclosure could have influenced how participants conveyed their experiences. Some may have underplayed or reframed their trauma responses to align with cultural norms that prioritize family duty or view emotional distress as a personal or family burden. Recognizing this influence, it would be crucial that the interview approach and analysis maintained cultural sensitivity to capture the depth of each participant's lived experience without imposing external assumptions.

During interviews, cultural and personal differences would likely require an adaptable approach, where researchers could adjust language, tone, or prompts based on the participant's comfort level. Interviewers may need to be particularly attentive to nonverbal cues, cultural expressions of distress, and differences in discussing trauma. Some participants may have found certain terms, like "trauma" or "PTSD," to be stigmatized or discomforting; thus, interviewers could employ more accessible language, allowing participants to describe their experiences in ways that felt natural and culturally appropriate. By prioritizing rapport and understanding over strictly following an interview guide, researchers could create a safe space that encouraged more candid sharing.

In the analysis of the interview data, recognizing cultural and individual differences was equally important. Cultural beliefs or values may have subtly influenced how participants perceived caregiver responsibilities and trauma, potentially leading to distinct coping strategies and stress manifestations. Overlooking these subtleties could result in misinterpretations, like attributing resilience solely to individual strength rather than cultural support systems or familial obligations. Therefore, the analysis phase will require attentiveness to context, allowing themes to emerge organically while ensuring that culturally

specific responses were interpreted with appropriate depth and respect. It is important for researchers to remain aware of personal cultural lenses and avoid overlaying personal interpretations onto participants' unique perspectives when conducting reflexive thematic analysis.

Furthermore, the potential for fear of judgment or repercussions added another layer of complexity. Participants may have hesitated to disclose their most distressing experiences, possibly fearing negative repercussions from the researcher. This reticence could contribute to underreporting of traumatic symptoms, which might otherwise reveal key aspects of their experience. To counter this, interviewers would need to carefully build trust, reassure participants of confidentiality, and approach trauma-related questions sensitively, emphasizing the study's non-judgmental stance. During analysis, researchers would need to consider the potential underreporting of trauma symptoms and remain cautious about making broad generalizations, particularly in acknowledging the possibility that some distressing experiences went unspoken.

Despite these limitations, the study offers meaningful contributions to the understanding of caregivers' experiences. By recognizing these factors, future research can build on these findings, addressing the limitations and enhancing the generalizability and reliability of insights in the field of caregiver studies.

Chapter 5

Overall Discussion and Conclusions

This comprehensive research explored the intricate and multifaceted experiences of primary family caregivers of individuals with NDD. The research was divided into two studies: a quantitative study and a qualitative study, each aiming to shed light on different aspects in the exploration of PTSS in primary family caregivers of individuals with NDD and of the caregiving experience. The quantitative study examined the occurrence and impact of trauma symptoms, aggression, coping strategies, cognitive processes, and overall well-being among participants. The qualitative study delved deeper into the lived experiences of participants, exploring the nuanced and personal dimensions of their traumatic experience, and the caregiving within the cultural context of Singapore.

5.1 Review of Quantitative Study

The quantitative study provided a detailed examination of the psychological impact of caregiving for individuals with NDD. It highlighted the significant challenges faced by participants, including physical aggression and violence, which affected a substantial portion of the caregiver population. The study's key findings revealed that 11.1% of participants met the DSM-diagnostic criteria for PTSD, indicating a heightened risk of developing trauma-related symptoms in this caregiver population due to their exposure to aggressive and violent behaviours. Correlation analyses demonstrated that trauma symptoms were significantly associated with increased aggression, rumination, cognitive processing, and disengagement coping strategies. These factors also contributed to diminished psychological and general well-being. Event rumination was identified as a critical factor in the development of trauma symptoms, explaining a significant portion of the variance.

Disengagement coping strategies were found to significantly predict trauma symptoms, exacerbating the impact of aggressive behaviours. However, an interesting nuance found in quantitative study was that while disengagement coping increased trauma symptoms, it did not mediate the relationship between aggression and trauma symptoms. This suggests that while aggression directly impacts participants' trauma, disengagement coping worsens the situation but does not explain the entire pathway. This points to the need for interventions targeting aggressive behaviours in care recipients, as these were a direct source of participant trauma. The findings emphasized the importance of providing participants with skills and strategies to handle aggression, which could reduce both trauma and perceived caregiver burden.

Mediation analyses revealed that intrusive cognition mediated the relationship between aggression and trauma symptoms, while caregiver burden moderated the impact of aggression on trauma symptoms. This study contributed to the understanding of how cognitive and emotional processes influence the development of trauma symptoms among participants, underscoring the importance of addressing cognitive processes such as rumination and coping strategies in interventions aimed at supporting caregivers.

5.2 Review of Qualitative Study

The qualitative study built on the quantitative findings by exploring the lived experiences of participants within the multicultural context of Singapore, providing depth and context to the statistical associations observed in the quantitative study. For instance, while the quantitative study identified a significant relationship between trauma symptoms and disengagement coping strategies, the qualitative study examined how cultural beliefs, family dynamics, and community support influenced caregiving practices and the psychological well-being of participants.

Key findings from this study indicated that caregiving practices were significantly influenced by cultural backgrounds, religious beliefs, and societal expectations. Cultural values such as filial piety and family duty play a crucial role in shaping caregiving experiences. This cultural lens seems to explain why some participants may have relied on disengagement coping strategies despite their negative impact, as these strategies may have aligned with cultural expectations of resilience and self-sacrifice. Findings also highlighted that family dynamics and community support systems were essential in managing caregiving responsibilities and reducing feelings of isolation among participants.

While the quantitative study highlighted the role of aggression in triggering trauma symptoms, the qualitative study revealed the impact of these events on participants, as the emotional turmoil, constant vigilance, and anxiety that participants endured due to the unpredictable nature of aggressive behaviours. These lived experiences provided a richer understanding of how aggression impacts participants' mental health, as the qualitative narratives illustrated the daily struggles and deep emotional challenges that were not fully captured by quantitative measures alone.

The study's findings also illustrated the profound impact that trauma had on participants, not only shaping their caregiving roles but also significantly influencing how they provided care. Each theme within the findings revealed distinct layers of emotional, practical, and ethical complexities that have evolved from the traumatic experiences these participants encountered in their roles. Collectively, themes such as Emotional Turmoil, Living with Volatility and Aggression, Constant Vigilance and Anxiety, Responding and Adapting to Traumatic Events, and Parental Duty and Commitment offered insights into the toll of trauma on participants' mental health, caregiving practices, and the progression of their caregiving journey.

In context of emotional impact and psychological toll, findings showed that trauma affected participants' emotional well-being, creating a pervasive sense of distress and helplessness that underscored the caregiving experience. Acute emotional trauma, as discussed in the findings of Chapter 4, highlighted the intense and immediate psychological reactions participants experienced when confronted with their adult child's sudden violent or self-destructive behaviour. This emotional impact, compounded over time, led to sustained psychological strain, where feelings of persistent helplessness and frustration dominated. Findings showed that participants often felt inadequate despite their best efforts, a sentiment that amplified their emotional burden and contributed to feelings of self-doubt. These persistent emotional challenges likely affected participants' sense of agency in their roles, making it harder for them to feel confident in managing their loved one's behaviours effectively.

Living with unpredictable and aggressive behaviours, a primary source of participants' trauma, further complicated caregiving practices. Participants found their homes becoming unsafe spaces due to the unpredictability of their children's aggressive outbursts, leading them to adopt protective measures and crisis management strategies. The need to be on high alert at all times seemed to have limited participants' ability to plan or enjoy daily routines, imposing restrictions that affected not only the participant but also the entire family unit. Constant vigilance and fear of physical harm required participants to adapt their environment to ensure safety, which often meant reinforcing boundaries, removing potential triggers, and finding ways to reduce risk in both public and private settings. This sustained state of vigilance could have effectively redefined the caregiving journey, necessitating a shift from typical caregiving activities to continuous, crisis-driven management.

In response to the emotional and practical challenges of caregiving, participants developed a series of coping mechanisms and adaptive strategies. The findings revealed a

progression from reactive to anticipatory coping, where participants implemented strategies such as immediate crisis management, emotional self-regulation, and, eventually, more structured routines of communication and positive reinforcement. These adaptive techniques illustrated how the caregiving journey became a learning process, with participants gradually finding approaches that fostered stability and mitigated some of the emotional toll. Nevertheless, the traumatic nature of the caregiving role—compounded by the ongoing need to de-escalate aggression and regulate their own emotional responses—demonstrated that these coping mechanisms often serve as short-term solutions, unable to fully resolve the root causes of stress and trauma.

The findings also highlighted how cultural values and a strong sense of parental duty influenced participants' decision-making and persistence. Participants' narratives revealed that, despite facing trauma, many felt a deep commitment to their roles, driven by cultural expectations and personal beliefs about duty and responsibility. This cultural dimension often prevented them from seeking external help or considering institutional care options, reinforcing their belief in the importance of family-based care. While this commitment to caregiving demonstrated resilience, it could also mean that participants may be less likely to pursue formal support services, potentially exacerbating their emotional distress and isolating them from available resources. The societal and cultural norms surrounding caregiving could have therefore contributed to both the pressure and sense of purpose in the caregiving journey.

Finally, the enduring sense of duty and commitment, paired with the need for constant adaptation, suggested that trauma had fundamentally reshaped not only individual caregiving practices but also the entire caregiving journey. As participants confronted the progression of their loved one's needs over time, they might have found themselves rationalizing their sacrifices and justifying their choices, even when these choices led to personal and familial

strain. The study highlighted that participants may prioritize their adult child's needs over their own, a choice that both sustained and limited their resilience. Many participants expressed concerns about aging and the physical toll of caregiving, raising questions about the sustainability of their roles and the need for future planning. This indicates that, while trauma reinforced participants' dedication, it also underscored the vulnerability of their caregiving journey, making it clear that as caregivers age, the need for systemic support becomes even more critical.

In sum, the impact of trauma on caregiving is multifaceted, affecting both immediate caregiving practices and the broader caregiving trajectory. The emotional turmoil, practical challenges, adaptive coping, cultural values, and ongoing commitment to their roles reflect a complex interplay of factors that underscore the need for support systems tailored to caregivers facing traumatic stress. Recognizing and addressing these layers could help mitigate some of the trauma-related impacts on caregivers, offering them the resources, validation, and guidance needed to sustain their caregiving journeys with greater resilience and security.

5.3 Convergence and Divergence of Findings

Both studies highlighted the profound impact of aggressive behaviours on trauma symptoms in primary family caregivers of adults with NDD. The quantitative study revealed that while physical aggression was not a significant predictor in the regression model, it was a notable caregiving event associated with trauma symptoms. This finding was confirmed by the qualitative study, where participants frequently described aggressive behaviours as highly distressing and emotionally taxing. Participants' narratives revealed that managing aggression was not just a single incident but an ongoing stressor that caused sustained psychological strain. The emotional burden associated with these behaviours often led to feelings of

helplessness and fear, adding to the trauma experienced. Both studies revealed that managing aggressive behaviours was a significant predictor of both trauma symptoms and caregiver burden. This complementary nature of the findings suggested that while the quantitative data provided measurable associations, the qualitative insights captured the cultural and emotional complexities of caregiving.

A key divergence between the studies lies in the influence of cultural beliefs and values on trauma symptoms. The quantitative analysis examined cultural beliefs as a moderating factor but found no significant effect on trauma symptoms. However, the qualitative study offered a more nuanced perspective, showing that cultural values, such as filial piety, spiritual commitment, and the stigma surrounding mental health, played an essential role in shaping participants' experiences. Findings also revealed that participants' sense of duty and spiritual commitment, largely shaped by cultural and family dynamics, impacted their emotional well-being, a theme less evident in the quantitative analysis. This sense of obligation, while providing a source of strength, also increased emotional strain as participants felt they had to fulfil these roles regardless of their emotional or physical limitations.

While cultural beliefs may not have directly impacted trauma symptoms quantitatively, they influenced how participants perceived and emotionally navigated their caregiving roles. These cultural dynamics, explored in-depth in the qualitative study, suggest that participants often suppressed their own needs to meet societal and familial expectations, which could contribute to hidden emotional struggles that might not be immediately apparent in quantitative measures.

The qualitative study was instrumental in uncovering the profound impact of trauma on the caregiving journey and caregiving practices, offering a depth of insight that was not achievable through the quantitative approach. Through themes like Emotional Turmoil,

Constant Vigilance, and Parental Duty, participants' narratives illuminated the intricate layers of psychological strain, fear, and resilience that caregivers experience. This qualitative approach enabled an in-depth exploration of acute emotional traumas, such as intense distress during crises, and the long-term challenges of helplessness, which quantitatively structured data could not capture. For instance, the study surfaced the overwhelming sense of vulnerability and unpredictability that participants faced, often resulting in adaptive but highly individualized coping mechanisms and continuous vigilance. Furthermore, the study delved into how cultural and societal expectations shaped participants' commitment and sense of duty, revealing motivations behind persistent caregiving roles even amid personal sacrifice. By capturing participants' voices and contextualizing their lived experiences, the qualitative study offered a nuanced understanding of trauma's pervasive role in shaping caregiving dynamics, practices, and resilience strategies in ways a quantitative study could not.

5.3.1 *Summary*

The findings from both quantitative and qualitative studies provide an integrated understanding of the psychological, cultural, and contextual challenges in caregiving for individuals with NDD. Together, these studies highlight the deep psychological toll on participants. The quantitative study found trauma symptoms significantly associated with factors like aggression, rumination, and disengagement coping, with rumination identified as a key predictor of trauma. These insights reveal how cognitive processes and coping strategies critically shape participants' psychological well-being. The qualitative study adds depth by exploring how trauma, cultural values, family dynamics, and community support shape participants and the caregiving approach. The qualitative findings further illuminate the hidden emotional challenges of caregiving, such as constant vigilance, anxiety, and persistent feelings of helplessness. These experiences reveal the cumulative trauma faced by

participants, often left unspoken due to lack of awareness or limited opportunity to articulate these burdens within mental health services.

This research advances understanding of trauma in caregiving, revealing it as a cumulative and embedded aspect of the caregiving journey, marked by chronic stress, vigilance, and psychological strain. The findings call for culturally sensitive interventions that not only address trauma symptoms but also support caregivers' resilience. Additionally, these insights highlight the need for policies and community resources that recognize the cultural and societal factors contributing to caregiver burden, helping caregivers balance their responsibilities with self-care. While the study represents the experiences of a small group of participants, their insights are invaluable for informing caregiver support. Holistic and responsive services for both caregivers and care recipients are essential, as neglecting either group's needs can have far-reaching effects on mental health and caregiving outcomes.

Lastly, the findings clearly demonstrated that trauma significantly influenced not only the way participants approached their roles but also shaped the broader trajectory of their caregiving journey. This research provided an in-depth view of the emotional and psychological toll that trauma exacts on participants, affecting their resilience, sense of agency, and overall well-being. This insight highlights the complex dynamics of caregiving within a traumatic context, revealing how trauma weaves into everyday caregiving practices, decision-making, and long-term coping strategies. The study highlights that trauma not only could affect caregivers' immediate emotional responses but could also have lasting effects on their capacity for sustained caregiving, resilience, and adaptability.

5.4 Conceptual Framework: Understanding Trauma in Caregivers

Findings from this mixed-method study highlight the need for a multifaceted approach to understanding trauma in caregivers of individuals with NDD. The chronic and relational nature of caregiving experiences necessitates consideration beyond individual cognitive processes. While Ehlers and Clark's (2000) cognitive model provides valuable insights into individual cognitive mechanisms, integrating a framework that addresses broader situational and relational dynamics enriches the understanding of trauma's impact on caregivers. This comprehensive approach allows for a deeper exploration of trauma's complexity, accounting not only for cognitive factors but also for social and contextual influences on trauma responses. Carlson and Dalenberg's (2000) conceptual framework highlights the critical role of an individual's emotional and sociocultural context in shaping their responses to traumatic experiences, making it relevant for understanding trauma in caregivers of individuals with NDD. By incorporating this framework alongside Ehlers and Clark's (2000) cognitive model, this offers an integrated approach to exploring trauma. This perspective enables a more comprehensive understanding of how the interplay between cognitive, emotional, relational, and sociocultural factors impacts caregivers' trauma responses. This section synthesizes findings from the current research within these conceptual frameworks, highlighting the complexity and multifaceted nature of trauma in caregiving. It bridges cognitive processes with broader situational and relational dynamics, providing a nuanced understanding of how caregiving challenges shape traumatic experiences. This integrated approach could contribute to a deeper exploration of caregiver trauma, potentially offering new avenues to better understand and address its complexities.

Understanding trauma in caregivers of individuals with NDD requires a nuanced and integrated perspective that draws from Ehlers and Clark's (2000) cognitive model and Carlson and Dalenberg's (2000) situational-relational framework. Both models address the core PTSD

symptom clusters—intrusions, hyperarousal, and avoidance—while Carlson and Dalenberg further introduce three defining elements of a traumatic experience: lack of controllability, negative valence, and suddenness. These elements offer additional insights into the situational and relational dynamics of trauma and interact with each symptom cluster in meaningful ways.

Intrusions, such as vivid recollections of traumatic caregiving incidents, are interpreted differently by the two models. Ehlers and Clark explain intrusions as arising from disturbances in autobiographical memory and negative appraisals of traumatic events. For instance, emotional turmoil experienced by participants, such as acute distress during crises or persistent feelings of helplessness, may reflect disturbances in autobiographical memory and negative appraisals of traumatic events, as posited by the model (Ehlers & Clark, 2008). These appraisals, when centered on a sense of failure or inadequacy, may perpetuate a sense of current threat, amplifying the emotional toll of caregiving (Ehlers & Clark, 2008). Participants in this study described distressing intrusive memories tied to specific crises, such as suicidal attempts or violent aggression, reinforced by associative learning and perceptual priming. These cognitive processes maintain a persistent sense of threat, trapping caregivers in cycles of psychological distress. In contrast, Carlson and Dalenberg highlight the situational triggers behind intrusions. For example, sudden crises or unpredictable aggressive behaviours often became the focal points of intrusive recollections, replaying repeatedly in participants' minds. The suddenness of these events—such as abrupt medical emergencies or aggressive outbursts—intensifies intrusive symptoms by creating sharp, unprocessed memories that are repeatedly reactivated. While Ehlers and Clark emphasize cognitive disruptions, Carlson and Dalenberg focus on how the suddenness of these events intensifies intrusive symptoms, illustrating how the abrupt and unpredictable nature of caregiving crises leaves lasting psychological imprints.

Hyperarousal, marked by heightened vigilance and chronic anxiety, also aligns with the perspectives of both models. Ehlers and Clark attribute hyperarousal to persistent cognitive perceptions of current threat, where caregivers remain in a state of readiness to manage crises, fuelled by the unpredictable behaviours of individuals with NDD. Participants described heightened states of anxiety, and persistent worry, reinforcing this ongoing sense of danger. Participants often reported being on high alert, bracing for potential harm or crises, as illustrated by Christine's fear of aggression during public outings. This ongoing state of heightened arousal reflects the enduring stress and psychological toll of caregiving for individuals with neurodevelopmental disorders (Carlson & Dalenberg, 2000). Carlson and Dalenberg, meanwhile, emphasize the role of lack of controllability in hyperarousal. The inability to predict or prevent challenging behaviours and crises amplifies the feeling of being perpetually on edge. For example, Peter described sleepless nights consumed by worry over their child's safety and well-being. This lack of controllability—whether in managing sudden aggression or navigating complex healthcare systems—sustains caregivers' heightened vigilance and reinforces their sense of helplessness. While Ehlers and Clark emphasize the cognitive mechanisms behind hyperarousal, Carlson and Dalenberg draw attention to the relational and situational contexts in which hyperarousal persists, particularly the caregiver's powerlessness to control outcomes. Together, these perspectives show how both internal appraisals and external relational dynamics contribute to sustained hyperarousal in caregivers.

Avoidance, another central PTSD symptom, is also viewed through distinct lenses by the two models. Ehlers and Clark conceptualize avoidance as a cognitive safety-seeking strategy aimed at alleviating immediate distress but ultimately preventing trauma integration and reappraisal. These behaviours, while temporarily alleviating distress, align with safety-seeking strategies that maintain PTSD by preventing the integration and reappraisal of trauma (Ehlers & Clark, 2008; Ehlers & Clark, 2000). Participants reported behavioural avoidance,

such as steering clear of conflict-prone discussions, and cognitive avoidance, such as faith-based rationalizations of caregiving struggles. Behavioural avoidance was evident in strategies such as Rohan's practice of limiting verbal interaction to prevent triggering his son, or Christine's decision to walk away when angered, both of which highlight efforts to minimize exposure to potential triggers. Additionally, participants displayed adaptive strategies, such as anticipatory planning and refined communication techniques, which sometimes mitigated the impact of trauma. However, these strategies, when rooted in hypervigilance, may inadvertently maintain the sense of current threat (Ehlers & Clark, 2000). In contrast, Carlson and Dalenberg emphasize the role of negative valence—the emotionally distressing nature of significant caregiving events—as a driver of avoidance. Situational avoidance behaviours, such as limiting verbal interactions to avoid triggering aggression or physically removing oneself from escalating situations, were frequently observed. The negative valence of caregiving experiences, marked by ongoing distress, emotional exhaustion, and fear of failure, sustains avoidance behaviours. While Ehlers and Clark highlight the internal cognitive mechanisms that drive avoidance, Carlson and Dalenberg emphasize the situational and relational stressors that make avoidance a necessary, albeit maladaptive, coping strategy.

In addition to these PTSD symptom clusters, Carlson and Dalenberg's three defining elements of trauma—lack of controllability, negative valence, and suddenness—provide a valuable lens for understanding the chronic and relational nature of caregiver trauma. Lack of controllability refers to the profound sense of powerlessness caregivers experience when they are unable to prevent or predict challenging behaviours or crises. This helplessness often reinforces hyperarousal and avoidance symptoms. Negative valence highlights the persistent emotional distress associated with caregiving, where participants report grief, frustration, and anxiety stemming from both daily caregiving challenges and acute traumatic events.

Suddenness underscores the psychological impact of abrupt and unpredictable caregiving crises, such as aggressive outbursts or medical emergencies, which frequently act as triggers for both intrusive memories and heightened hypervigilance. These three elements collectively underscore the complexity of caregiver trauma, demonstrating how situational, relational, and cognitive factors interact to sustain PTSD symptoms.

Cultural factors further intersect with these trauma responses, adding layers of complexity. Cultural norms, such as filial piety and self-sacrifice, may intensify negative appraisals of caregiving failures, reinforcing feelings of guilt and helplessness. These norms may shape not only participants' perceptions of their roles but also their coping strategies, such as disengagement coping, as highlighted in this study. This perspective emphasizes that addressing PTSS in caregivers requires interventions that not only target cognitive distortions but also incorporate cultural sensitivity and acknowledge the broader social and contextual influences on trauma (Ehlers & Clark, 2000; Ehlers et al., 2005).

While Ehlers and Clark's (2000) model focuses on individual cognitive mechanisms—such as negative appraisals, intrusive memories, and safety-seeking behaviours—Carlson and Dalenberg (2000) adopt a broader perspective that encompasses situational unpredictability, relational dynamics, and environmental stressors. Carlson and Dalenberg's (2000) model emphasizes how these stressors are shaped by lack of controllability, negative valence, and suddenness, offering a more contextual understanding of the external factors that sustain trauma responses in caregivers. Both perspectives intersect with socio-cultural dynamics, where norms such as filial piety and self-sacrifice intensify feelings of guilt, helplessness, and responsibility. These socio-cultural pressures often shape how caregivers appraise their experiences, cope with distress, and seek support. Addressing caregiver trauma, therefore, requires interventions that integrate cognitive approaches with an awareness of situational, relational, and cultural influences. Strategies such as trauma processing, emotional regulation,

and safe exposure offer pathways to address intrusive memories, hyperarousal, and avoidance while also promoting resilience. This integrated perspective emphasizes the importance of trauma-informed and culturally sensitive support systems to address the multifaceted nature of caregiver trauma and enhance caregiver well-being.

5.4.1 *Secondary Emotional and Psychological Responses*

The chronic and cyclical nature of PTSD symptoms—intrusions, hyperarousal, and avoidance—as experienced by caregivers of individuals with NDD, not only disrupts their emotional and cognitive functioning but also creates a ripple effect on their broader psychological well-being. Over time, the persistent threat perception, emotional exhaustion, and coping mechanisms associated with these primary PTSD symptoms can give rise to secondary emotional and psychological responses, such as depression, guilt, low self-esteem, social isolation, and physical health consequences. These outcomes are best understood through the situational and relational dynamics emphasized in Carlson and Dalenberg's (2000) framework, which highlights how ongoing environmental stressors and relational patterns intensify emotional exhaustion and vulnerability. The following section explores these secondary emotional and psychological responses, emphasizing their interconnectedness with the caregiving context and the relational challenges caregivers navigate daily.

The framework proposed by Carlson and Dalenberg (2000) identifies several common secondary responses to traumatic experiences, which can manifest in various ways among caregivers of individuals with NDD. Depression is one such response, characterized by feelings of sadness, hopelessness, and a loss of interest in previously enjoyable activities, as caregivers cope with the emotional toll of their responsibilities. Another response, aggression, may surface as irritability or frustration, sometimes leading caregivers to express aggressive behaviours toward themselves or others as a way to handle overwhelming stress. The impact

of chronic stress from caregiving and managing repeated behavioural and aggressive outbursts can also result in physical illnesses and a weakened immune response (Miodrag, N., & Hodapp, 2011).

Caregivers may additionally experience low self-esteem as a secondary and associated response to trauma, struggling with feelings of inadequacy or guilt as they question their ability to provide adequate care. Additionally, identity confusion can occur when the caregiving role becomes all-encompassing, leading to a loss of personal identity and difficulty balancing other life aspects. Interpersonal relationships may suffer due to caregiving demands and challenges, as it can strain connections with family and friends, sometimes resulting in social isolation. Finally, feelings of guilt and shame might often arise, as caregivers may feel guilty about perceived caregiving shortcomings or ashamed of their own frustration and resentment.

These secondary responses are particularly relevant for caregivers of individuals with NDD for several reasons. The chronic stress environment of long-term caregiving associated with neurodevelopmental disorders creates cumulative trauma, making caregivers more vulnerable to the outlined responses. The emotional burden of caregiving can lead to depression and low self-esteem, with caregivers feeling overwhelmed by daily challenges. Additionally, the unique nature of caregiving may foster social isolation, as caregivers may struggle to relate to others who do not fully understand their situation. This isolation may amplify feelings of guilt and shame. The impact on relationships may be significant, with the stress of caregiving straining relationships with partners, family, and friends, leading to further isolation and emotional distress (Sarman & Tuncay, 2024).

Common secondary responses to traumatic experiences, can impact the caregiving journey for individuals caring for those with neurodevelopmental disorders. These responses often manifest as a direct consequence of the chronic stress and emotional burden associated

with caregiving, leading to a cycle of distress that can hinder both the caregiver's well-being and the quality of care provided. For instance, caregivers experiencing psychological distress may find it challenging to engage fully with their loved ones, resulting in diminished emotional availability and responsiveness. This disengagement can exacerbate feelings of guilt and shame, further entrenching the caregiver in a negative emotional state. Similarly, aggression and irritability can strain relationships within the family, creating an environment of tension and conflict that may affect the individual with NDD, who may already be sensitive to changes in their surroundings. This interplay of secondary responses not only impacts the caregiver's mental health but also shapes their experience of trauma, as the ongoing stressors may lead to a heightened sense of helplessness and loss of control. Consequently, the caregiving journey becomes a complex interplay of emotional challenges, where the caregiver's trauma responses can hinder their ability to cope effectively.

Recognizing these secondary responses emphasizes the need for support systems tailored to caregivers, and is crucial for fostering resilience in caregivers, enabling them to navigate their caregiving roles with greater emotional stability and support. Mental health professionals can offer interventions that address these specific responses, aiding caregivers in developing coping strategies and accessing resources to alleviate trauma's impact. This understanding fosters a holistic approach to trauma, which allows caregivers to gain self-compassion and seek help when needed.

5.5 Theoretical Contributions: Advancing Trauma Theory in Caregiving Contexts

This research contributes to trauma theory by providing a nuanced understanding of the effects of trauma within the caregiving context, particularly for caregivers of individuals with NDD. By integrating Ehlers and Clark's cognitive model (2000) and Carlson and Dalenberg's trauma framework (2000), the findings offer a comprehensive perspective on

caregiver trauma as both a cognitive and relational phenomenon influenced by chronic stress and socio-cultural factors.

The quantitative component revealed a heightened risk of PTSD among participants, with 11.1% meeting diagnostic criteria, and highlighted key factors such as physical aggression, rumination, disengagement coping, and caregiver burden. These findings highlight the chronic and relational nature of caregiver trauma, which aligns closely with Carlson and Dalenberg's emphasis on the intensity, duration, and interpersonal characteristics of traumatic stressors. Meanwhile, Ehlers and Clark's cognitive model illuminates the role of maladaptive appraisals and intrusive cognitions, demonstrating how negative cognitive processing can exacerbate distress in caregivers.

The qualitative study enriched these findings by uncovering cultural and societal dynamics that compound caregiver trauma. Themes such as "Emotional Turmoil," "Living with Volatility and Aggression," and "Parental Duty and Commitment" revealed how the chronic exposure to aggression and unpredictable caregiving demands erodes participants' sense of safety and well-being. These insights highlight how trauma in caregiving extends beyond the cognitive domain, emphasizing the relational and situational dimensions of stress, as captured by Carlson and Dalenberg's framework. At the same time, Ehlers and Clark's model provides a valuable lens to understand how participants' cognitive appraisals of their experiences shape their emotional responses and trauma symptoms.

By synthesizing these two models, this research proposes an expanded theoretical framework that positions caregiver trauma as a cumulative and context-specific phenomenon. Carlson and Dalenberg's framework accounts for the chronicity and relational embeddedness of caregiver trauma, offering a holistic perspective on how repeated, interpersonal stressors contribute to PTSS. Conversely, Ehlers and Clark's model explains the cognitive mechanisms, such as intrusive memories and rumination, that perpetuate trauma in caregivers.

Together, these models seem to offer complementary insights, potentially capturing both the situational dynamics and cognitive processes that underpin caregiver trauma.

This proposed integrated approach highlights the need for trauma-informed interventions that address not only the cognitive aspects of trauma but also the systemic and relational stressors caregivers face. For example, interventions could focus on equipping caregivers with effective strategies to manage aggressive behaviours, navigate socio-cultural expectations, and foster resilience in the face of chronic caregiving demands. The findings underscore the importance of culturally sensitive approaches, recognizing how values like filial piety and self-sacrifice in Singaporean caregivers may exacerbate disengagement coping and hinder emotional processing.

Ultimately, this research redefines trauma in the caregiving context as a dynamic interplay of cognitive, relational, and socio-cultural factors. It is suggested that by bridging Ehlers and Clark's and Carlson and Dalenberg's models, it helps to lay the groundwork for developing more holistic, trauma-informed frameworks and interventions tailored to the unique challenges of caregivers of individuals with NDD. This contribution advances trauma theory by emphasizing the layered nature of caregiver trauma and advocating for a broader understanding of its impact on caregivers' mental health and caregiving practices.

5.6 Implications for the Caregiving Journey and Practices

The findings from of this study have significant implications for the caregiving journey and practices of parents of individuals with NDD. Chapter 3 quantitatively illustrated how participant trauma was shaped by coping strategies, caregiver burden, and exposure to challenging behaviours. The findings highlighted the occurrence of PTSS among participants, revealing the mediating effects of rumination and disengagement coping strategies, as well as the moderating role of caregiver burden. These findings imply that as parents age, extended

exposure to caregiving stressors and behavioural challenges could intensify mental health impacts, particularly PTSS, underscoring a need for adaptive coping support as caregivers age alongside their children.

While the study found that 11.1% of caregivers met the DSM-5 diagnostic criteria for PTSD based on self-reported symptoms, it is important to recognize the stark gap between symptom prevalence and actual clinical diagnosis. In practice, few caregivers receive a formal PTSD diagnosis. This discrepancy may stem from several factors, including the normalization of trauma symptoms as part of caregiving, caregivers' reluctance to seek help due to stigma or cultural expectations of endurance, and the lack of trauma-informed screening within healthcare services. Additionally, mental health professionals may underrecognize trauma in caregivers, attributing symptoms to general stress or depression. These contextual and systemic barriers contribute to the underdiagnosis of PTSD, despite the presence of clinically significant distress. This finding underscores the need for improved clinical recognition of trauma in caregivers and for routine trauma-informed screening and intervention in mental health settings.

Qualitative exploration further enriched this perspective by contextualizing the emotional and psychological toll that caregiving takes over time. Participants reported experiencing continuous vigilance and anxiety in response to aggressive behaviours and emotional turmoil, highlighting a dynamic caregiving journey shaped by trauma and resilience. As participants age, the cumulative effects of managing volatility and emotional challenges can redefine caregiving roles, shifting from providing direct care to developing strategies for long-term coping and adaptation. For instance, participants’ sense of duty, supported by cultural values and family expectations, influences their commitment to caregiving and drives their resilience, even as they face increasing limitations due to aging.

Together, interventions should account for both the long-term impact of trauma and the aging process of caregivers. Developing culturally sensitive, trauma-informed approaches that incorporate family dynamics and provide avenues for respite, practical support, and community integration would enhance caregiver resilience. This integrative approach, informed by both quantitative data and lived experiences, emphasizes that supporting aging caregivers of individuals with NDD requires a framework that adapts to the evolving physical, psychological, and emotional needs of caregivers throughout their journey.

5.7 Implications for Trauma Interventions and Cultural Sensitivity

The study's findings suggest that trauma interventions may benefit from being culturally sensitive and tailored to the specific sociocultural contexts of caregivers. The extension of the Carlson and Dalenberg (2000) framework to include socio-cultural context has significant implications for clinical practice. It indicates that interventions should not only address individual trauma symptoms but also consider the broader cultural and societal factors that influence trauma. This refinement of the framework supports the development of more effective, culturally-informed therapeutic approaches that can better meet the needs of diverse caregiver populations.

By situating trauma within the specific cultural contexts of caregivers, this study contributes to a wider understanding of trauma in caregiving. It challenges the universality of existing trauma models and argues for a more contextually grounded approach to trauma theory. The findings underscore the necessity of incorporating cultural sensitivity into trauma research and practice, particularly in the field of caregiving, where cultural factors are deeply intertwined with the caregiving experience.

In summary, this study contributes to the understanding of trauma in caregivers by incorporating cultural considerations into the existing conceptual framework. It encourages

existing trauma theories to expand beyond individualistic and universal models, promoting a more comprehensive approach that considers the important role of sociocultural factors when supporting caregivers of individuals with NDD. This approach may provide a more accurate and holistic understanding of trauma in caregivers, potentially offering valuable insights for developing culturally sensitive interventions that could more effectively support caregivers across diverse cultural contexts.

5.8 Research Limitations

Despite the valuable insights gained from the quantitative and qualitative studies, several limitations must be acknowledged, which highlight the complexities involved in researching caregivers of individuals with neurodevelopmental disorders. First, the relatively small sample size in the quantitative study limits the generalizability of its findings. Although the sample size for the qualitative study was appropriate for the chosen research method, its transferability is constrained by the recruitment of participants from a single tertiary mental health hospital in Singapore. Additionally, all participants were caregivers of individuals receiving care from adult mental health services, which may not fully capture the experiences of caregivers in community settings or those outside the mental health service framework.

The recruitment process for this research presented unexpected and frustrating challenges. Despite extending the recruitment period, the response rate remained lower than anticipated, which was both surprising and frustrating given the relevance of the research topic. However, as recruitment progressed, it became clear that many potential participants were reluctant or unable to enrol in the study. This prompted me to reflect more deeply on the underlying reasons for their reluctance, which ultimately provided valuable insights into the research context.

One possible explanation for the low participation rate is the caregivers' familiarity with and understanding of research itself. It is plausible that some caregivers may not fully grasp the purpose of research, its methodologies, or the potential impact that findings can have on policy, practice, and ultimately, their own experiences. This lack of familiarity could lead to a perception that participation in research is either unnecessary or unbeneficial, especially if the immediate value of the study is not clear to them. This could have led to a lack of motivation to engage with the research process.

Furthermore, the findings of this study seemed to suggest that caregivers might carry a considerable burden. Some might be overwhelmed by the demands of their caregiving roles, possibly leaving them with limited time, space, or mental capacity to engage in activities that did not directly alleviate their immediate stressors. Participating in research, which might be perceived as an additional responsibility, may have felt like an unaffordable luxury when their primary focus was on managing day-to-day challenges. This insight could highlight the importance of considering the practical and emotional realities of caregivers when designing research studies that require their involvement.

Another critical point of reflection was the potential lack of confidence and trust in the utility of research findings. It seemed possible that caregivers might have harboured doubts about whether their participation would lead to meaningful change or if the research would simply be another academic exercise with little real-world impact. The uncertainty surrounding the outcomes of research and whether it would genuinely address their needs could have contributed to their reluctance to participate. This could suggest the importance of researchers clearly communicating the potential benefits of the study and how it aimed to effect tangible improvements in the lives of caregivers.

In addition to recruitment challenges, the cross-sectional design of the quantitative study restricts the ability to draw causal inferences about the relationships between trauma

symptoms, coping strategies, and other psychological factors. While the study identified significant associations, it cannot determine the directionality or causality of these relationships. Longitudinal studies are needed to better understand how these variables interact over time and the potential long-term impacts of caregiving on psychological well-being.

Furthermore, as discussed in Chapter 3, the measure used in the quantitative study to assess cultural reasons influencing caregiving in caregivers of individuals with NDD may not have fully captured the unique caregiving dynamics and challenges associated with this population. While the Cultural Justifications for Caregiving Scale (CJCS) was chosen for its relevance, its original design for caregivers of elderly relatives with dementia limits its applicability. Caregiving for individuals with NDD involves managing lifelong behavioural and emotional needs, societal stigma, and advocacy, which differ significantly from the progressive decline associated with dementia care. Modifications to the CJCS, such as removing the term "elderly," were insufficient to address these distinct challenges, as the scale primarily reflects traditional cultural expectations rather than the complex realities of caregiving for adults with NDD. Future research could expand the cultural dimensions assessed in caregiving measures by including items that go beyond cultural justifications to also capture cultural stigma, societal recognition of caregiving roles, and expectations related to lifelong caregiving for individuals with NDD. This broader approach would provide a more comprehensive understanding of the cultural influences shaping caregivers' experiences, highlighting both the supportive and challenging cultural factors they encounter.

Another limitation of this study is the lack of follow-up assessments with participants who exhibited posttraumatic stress symptoms. Although the primary aim of this research was to assess the occurrence of such symptoms within the caregiver population, incorporating follow-up assessments could have yielded valuable insights into the progression of these

symptoms over time. The exclusion of follow-up assessments was largely due to constraints in time, resources, and the study's focus on cross-sectional data. Future research would benefit from adopting longitudinal designs to more accurately trace the development of posttraumatic stress symptoms in caregivers and to evaluate the effectiveness of targeted interventions.

Cultural factors also play a significant role in shaping participants. experiences and their participation in research. Participants may have internalized societal stigma surrounding mental health issues, particularly when it involves their own family members. This stigma may lead to a reluctance to acknowledge or seek help for traumatic symptoms, as it could be perceived as a reflection of their inability to adequately care for their child. Consequently, participants might downplay or dismiss their experiences of trauma, leading to an underestimation of the prevalence and severity of traumatic symptoms within this population. Additionally, personal beliefs and cultural variations in how trauma and coping are understood could impact the consistency of the data, further complicating the research process.

Lastly, the qualitative study's focus on participants' experiences within the specific cultural context of Singapore might limit the applicability of the findings to other cultural settings. Cultural values and caregiving practices can vary significantly across different societies, and the unique sociocultural landscape of Singapore may not be representative of other regions. Comparative studies involving caregivers from diverse cultural backgrounds are necessary to explore the cultural nuances and generalize the findings more broadly. Nevertheless, the findings from this study offer critical preliminary data that highlight the need for ongoing research in this area.

These reflections have deepened my understanding of the barriers to research participation among caregivers. It is essential for future research to address these barriers by

improving outreach and education about the value of research, ensuring that participation is as convenient and low-burden as possible, and building trust by demonstrating the potential for real-world impact. By addressing these issues, researchers can better engage this vital population and ensure that their voices and experiences are adequately represented in studies that aim to support them.

5.9 Recommendations for Future Research

Building on the limitations identified, several recommendations for future research and directions can be proposed. First, future studies should aim to include larger and more diverse samples to enhance the generalizability of the findings. Recruiting caregivers from multiple healthcare settings, schools, communities, day activity centres, and various regions within and beyond Singapore can provide a more comprehensive understanding of the caregiving experience across different contexts. Including these diverse sources allows for the exploration of caregiving dynamics influenced by educational systems, community-based services, and structured care environments, offering a richer and more holistic perspective on caregivers' challenges and needs.

Second, employing longitudinal study designs can provide deeper insights into the dynamic nature of caregiving and its long-term psychological impacts. Longitudinal research can help identify causal relationships between trauma symptoms, coping strategies, and psychological well-being over time. This approach would also allow for the examination of how changes in caregiving circumstances and interventions influence caregivers' mental health trajectories.

Interestingly, the research also reveals that trauma is not a universal experience among caregivers. This variation suggests that certain caregivers may possess or develop protective factors that buffer against trauma. These protective factors could include effective coping

strategies, strong social support networks, adaptive beliefs about caregiving, or resilience traits fostered by cultural or familial values. Future research could seek to identify and understand these protective factors, as it can help professionals design preventive interventions that enhance these buffers across all caregivers, reducing trauma risk and supporting long-term mental well-being.

Lastly, expanding research to include comparative studies across different cultural contexts is crucial. Investigating how cultural values, social support systems, and healthcare policies influence caregiving practices and outcomes can inform the development of culturally sensitive interventions. Collaborative research involving international partners can facilitate cross-cultural comparisons and the sharing of best practices, ultimately contributing to more effective and globally applicable caregiver support strategies.

By addressing these recommendations, future research can build on the current study's findings to advance our understanding of the complexities of caregiving for individuals with neurodevelopmental disorders. This will aid in the development of targeted interventions and policies that support caregivers' well-being and enhance the quality of care provided to care recipients.

5.10 Practical Recommendations – Suggestions for Informing Local Practices and Support Framework

The findings from this research offer valuable insights that can inform local practices to support Asian caregivers of adults with neurodevelopmental disorders (NDD) in a tertiary mental health hospital setting. One of the key recommendations is to develop culturally sensitive training programs for healthcare providers. These programs should focus on cultural competence and sensitivity to the unique needs of Asian caregivers, emphasizing cultural values such as filial piety, family duty, and the stigma associated with mental health issues.

Additionally, the training should include modules on the psychological impact of caregiving, highlighting trauma symptoms, coping strategies, and the significance of event rumination.

The study's findings also revealed that caregivers often find themselves learning through experience as they navigate their caregiving journey, starting from the onset of the developmental phase and continuing throughout the lifespan of the individual with NDD. This suggests a potential gap in resources or a lack of coordinated support systems that could provide a structured framework to guide caregivers. While the positive attitude of learning and growth mindset demonstrated by caregivers is encouraging, the absence of accessible resources and clear pathways for acquiring knowledge and skills may limit the effectiveness of these attitudes.

This nuanced view of caregiving trauma—where some caregivers thrive despite challenges—also invites a more personalized approach to support and intervention. Rather than a one-size-fits-all model, therapists and support staff could work to assess individual caregiver profiles to understand their unique vulnerabilities and strengths. This approach allows for tailored interventions that reinforce existing resilience factors while addressing areas of potential trauma.

The findings from this study suggest that caregivers could benefit from multifaceted resources, encompassing awareness, education, and skills training to enhance both their caregiving practices and personal well-being, particularly in the context of managing significant and potentially traumatic caregiving events. The availability of resources focused on key areas identified through the research could be a critical aspect of fostering caregiver support and resilience. For instance, an awareness workshop on the impact of long-term caregiving for NDD Individuals could help caregivers understand the long-term psychological, emotional, and physical impacts of caregiving. This workshop would highlight the potential risks of chronic stress, burnout, and the development of PTSS, equipping

caregivers with the knowledge to recognize early signs of distress. Additionally, it would emphasize the importance of self-care and the need for systemic support to sustain caregivers over the long term.

An educational workshop on understanding aggression and behaviours in NDD individuals could deepen caregivers' understanding of the root causes of aggression and challenging behaviours commonly observed in individuals with NDD. By exploring the psychological and neurological factors that contribute to such behaviours, caregivers would be better equipped to approach these challenges with empathy and informed strategies. This workshop would also cover various behavioural interventions, stressing the importance of consistency and patience in behaviour management. A skills training workshop on managing aggression and challenging behaviours could provide caregivers with practical skills to effectively manage aggression and other challenging behaviours. This workshop would include hands-on demonstrations and role-playing exercises to teach caregivers de-escalation techniques, behavioural reinforcement strategies, and safety planning. The skills training is designed to empower caregivers to respond confidently and calmly in high-stress situations, thereby reducing the risk of harm to both the caregiver and the individual with NDD.

In addition to the workshops focused on awareness, education, and managing challenging behaviours, a skills training workshop on caregiver well-being: mindfulness practices and emotion regulation could serve as an upstream and ongoing service effort to foster emotional resilience and potentially prevent the development of traumatic stress and other mental health concerns. Recognizing the critical importance of caregiver well-being, this workshop would teach mindfulness practices and emotion regulation techniques specifically tailored for caregivers. Participants would learn how to incorporate mindfulness into their daily routines to reduce stress and build emotional resilience. The workshop would also cover strategies for managing difficult emotions, such as anger and frustration, which are

common in the caregiving context. By equipping caregivers with these skills, the workshop aims to promote sustained well-being, prevent burnout, and enhance the overall caregiving experience.

Integrating these workshops—focused on awareness, education, skill development, and caregiver well-being—could significantly enhance the quality of care provided to individuals with NDD and support the long-term well-being of caregivers. Future research should evaluate the effectiveness of these workshops in reducing caregiver stress and improving caregiving outcomes, with a view to refining and expanding the program to reach a broader caregiver population. This comprehensive approach to caregiver support would ensure that caregivers are not only better prepared to manage the challenges they face but also equipped to maintain their own mental health and well-being.

Implementing integrated care models that combine mental health services with culturally tailored support programs is crucial. Such models would ensure that caregivers receive holistic care addressing both psychological and cultural needs. It would be helpful if existing multidisciplinary teams working for the individual with neurodevelopmental disorder incorporate a dedicated aspect of the service focusing specifically on caregivers. This could include offering caregiver-specific interventions, psychoeducation, and emotional support while simultaneously addressing the care and treatment needs of individuals with neurodevelopmental disorders. By integrating caregiver-focused services, these teams can ensure a more holistic approach that supports both the individual and their caregivers, acknowledging the interconnected nature of their well-being.

Establishing multidisciplinary teams, including psychologists, social workers, cultural liaisons, and peer support specialists, would provide comprehensive support to caregivers. Moreover, promoting family and community involvement in the caregiving process is essential. Developing support groups and community-based programs can offer caregivers

platforms to share their experiences and receive peer support, while workshops and seminars can educate families on effective coping strategies and the importance of maintaining their well-being.

To enhance psychological support services, it is recommended to offer targeted counselling and therapy designed specifically for caregivers experiencing trauma symptoms. Ensuring that these services are accessible and culturally appropriate is vital. Introducing regular screening for PTSD and other trauma-related symptoms among caregivers, followed by timely interventions, can also significantly improve caregivers' mental health outcomes.

5.11 Practical Recommendations – Creating Awareness Among Policymakers and Community Agencies

Creating awareness among policymakers and community agencies about the prevalence of PTSD and trauma symptoms among caregivers is critical. Advocacy and awareness campaigns can be launched using various media channels to disseminate information. Collaborating with caregiver associations and mental health organizations to organize public awareness events, such as conferences, workshops, and community talks, can further amplify the message. Additionally, advocating for the inclusion of caregiver support in mental health policies is necessary. Highlighting research findings to policymakers and recommending the development of policies that mandate regular mental health assessments and support services for caregivers can ensure these practices are integrated into the standard care protocols of tertiary mental health hospitals.

Collaboration with community agencies is another key strategy. Partnering with these agencies to develop and implement support programs for caregivers, such as resource centres offering information, counselling, and practical assistance, can provide much-needed support.

Encouraging community agencies to train their staff on recognizing and addressing the signs of PTSD and other trauma symptoms in caregivers is also important. Developing educational materials, such as brochures, booklets, and online resources, and distributing them in hospitals, community centres, and through online platforms can raise awareness about the psychological impact of caregiving and available support services. Organizing training sessions for community leaders, religious leaders, and other influential figures to educate them about the challenges faced by caregivers and the importance of providing support can foster a more supportive community environment.

5.11.1 *Trauma-Informed Care Practices and Applications*

Trauma-informed care (TIC) is an approach that acknowledges the pervasive impact of trauma and integrates this understanding into all aspects of service delivery to promote healing and recovery. Applying trauma-informed care practices involves recognizing the signs and symptoms of trauma, understanding its potential impact on individuals, and responding in ways that avoid re-traumatization. This approach is grounded in principles such as safety, trustworthiness, peer support, collaboration, empowerment, and cultural sensitivity.

In a tertiary mental health hospital, implementing TIC means creating an environment where caregivers feel physically and emotionally safe, and where their experiences and needs are validated and respected. Staff training on the effects of trauma and effective communication strategies is essential to ensure that interactions are supportive and non-judgmental. Furthermore, incorporating TIC involves designing policies and procedures that prioritize the well-being and autonomy of caregivers, such as providing options for trauma-specific interventions, enhancing access to mental health resources, and fostering a culture of empathy and understanding. By embedding trauma-informed care into the organizational framework, healthcare providers can better support caregivers, helping them manage the

psychological impacts of caregiving and promoting resilience and long-term well-being. This holistic approach not only improves individual outcomes but also enhances the overall effectiveness of mental health services by fostering a more inclusive and compassionate care environment.

5.11.2 *Upstream and Downstream Service Provision*

In terms of upstream and downstream service provision, focusing on preventive measures is essential. Early intervention programs for caregivers, including stress management workshops, resilience training, and education on effective coping mechanisms, can help prevent the onset of severe trauma symptoms. Establishing a caregiver hotline or support line offering immediate assistance and counselling services can provide critical support in times of distress. For downstream interventions, developing long-term support systems for caregivers already experiencing significant trauma symptoms is necessary. This includes ongoing counselling, support groups, and respite care services. Implementing follow-up programs to monitor caregivers' mental health and provide continuous support can ensure they receive the necessary assistance over the long term.

By implementing these suggestions, tertiary mental health hospitals, policymakers, and community agencies can create a supportive environment for caregivers of adults with NDD. This integrated approach addresses the psychological, cultural, and practical challenges faced by caregivers, ultimately enhancing their well-being and the quality of care they provide.

5.12 Conclusion

This research deepens our understanding of the multifaceted challenges and emotional toll experienced by caregivers of individuals with NDD, particularly within the unique cultural context of Singapore. By integrating quantitative and qualitative methodologies, this study reveals not only the psychological impact of caregiving—such as trauma symptoms and the prevalence of PTSD—but also how cultural values and social expectations shape and complicate the trauma and caregiving experiences. The convergence of psychological and cultural dimensions in caregiving signals the need for interventions that are both trauma-informed and culturally attuned. The qualitative study's themes of vigilance, anxiety, and emotional turmoil underscore a persistent need for practical and emotional support systems that acknowledge the relational nature of caregiving trauma.

The findings from this research highlight the critical need for professionals and therapists working with families of individuals with NDD to recognize the potential for trauma among caregivers. Acknowledging the psychological strain and trauma risk inherent in caregiving allows for the timely mobilization of targeted support systems and interventions to address caregivers' mental health and well-being. These supports are not just reactive but can be implemented proactively to equip caregivers with resilience-building skills and coping mechanisms, ultimately enhancing the quality of care they provide.

The implications of this research extend to trauma-informed care practices within tertiary mental health settings, advocating for caregiver support services that accommodate both the psychological and cultural aspects of caregiving. By creating environments that prioritize caregiver safety, validation, and empowerment, healthcare providers can foster resilience among caregivers, ultimately improving care quality for individuals with NDD. Furthermore, this research emphasizes the importance of both upstream and downstream services, advocating for early intervention programs to prevent trauma symptoms and ongoing

support systems to sustain caregivers over time. Such an approach can equip caregivers with adaptive coping skills and emotional resilience, providing them with a sustainable foundation for long-term caregiving. Ultimately, this study offers a comprehensive framework that highlights the necessity of tailored support systems, bridging psychological insights with cultural sensitivity to bolster caregiver well-being and enhance the care provided to individuals with NDD.

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Appendix A

PICo Worksheet and Search Strategy Proposal

1. Define your question using PICo by identifying: Population, Interest, and Context:

   Question:
   - What is known about the prevalence, causes and other factors associated with traumatic stress symptoms among caregivers of individuals with psychiatric, neurodevelopmental, or neurocognitive disorders?

   Population:
   - Participants of the study involve caregivers who provide care to individuals with neurodevelopmental, psychiatric or neurocognitive disorders.

   Concept / Interest:
   - The article explores / investigates / examine posttraumatic stress symptoms, trauma symptoms, or PTSD, in these caregivers.
   - The article reports qualitative or quantitative primary data about posttraumatic stress symptoms (PTSS), trauma symptoms, and PTSD in these caregivers

   Context:
   - Caregivers must be providing caregiving to individuals with neurocognitive, psychiatric or neurodevelopmental disorders.

2. Type of study – methodology

   Clinical queries:
   qualitative and quantitative studies (Medline, CINAHL)

3. Type of study – data collection

   List types of data collection instruments:
   Questionnaires, interviews

4. Proposed search strategy for respective database:

   PsychInfo

   1st term:
   - PTSD → 5 terms (posttraumatic stress disorder, posttraumatic stress, stress reactions, traumatic experiences, traumatic neurosis)

   (MAINSUBJECT.EXACT("Traumatic Experiences") OR
   MAINSUBJECT.EXACT("Stress Reactions") OR
   MAINSUBJECT.EXACT("Posttraumatic Stress") OR
   MAINSUBJECT.EXACT("Traumatic Neurosis") OR
   MAINSUBJECT.EXACT.EXPLODE("Posttraumatic Stress Disorder"))

2nd term:
- Caregiver → 5 terms (caregiver, caregiver burden, caregiving, child care, elder care)
- Parent → "explode" → 6 terms

MAINSUBJECT.EXACT("Foster Parents") OR
MAINSUBJECT.EXACT("Caregiver Burden") OR
MAINSUBJECT.EXACT("Caregivers") OR
MAINSUBJECT.EXACT("Caregiving") OR
MAINSUBJECT.EXACT("Adoptive Parents") OR
MAINSUBJECT.EXACT("Homosexual Parents") OR
MAINSUBJECT.EXACT("Grandparents") OR
MAINSUBJECT.EXACT("Child Care") OR
MAINSUBJECT.EXACT.EXPLODE("Parents") OR
MAINSUBJECT.EXACT("Elder Care")

SCOPUS

1st term:
- (TITLE-ABS-
  KEY (caregiv* OR parent OR parents OR mother* OR father*)

2nd term:
- AND TITLE-ABS-KEY (ptsd OR "Posttraumatic Stress" OR "Posttraumatic Growth" OR "Trauma Related Disorders")

3rd term:
- TITLE-ABS-
  KEY (depression* OR anxiety OR autis* OR asperger* OR "intellectual disability" OR "learning disability" OR "mental retardation" OR "developmental disability" OR "attention deficit" OR adhd OR psychosis OR schizophrenia OR dementia OR bipolar OR "obsessive-compulsive" OR ocd OR "personality disorder" OR "borderline" OR "Mental disorder"))

CINAHL

1st term:
- AND TITLE-ABS-KEY (ptsd OR "Posttraumatic Stress" OR "Posttraumatic Growth" OR "Trauma Related Disorders")

2nd term:
- (TITLE-ABS-
  KEY (caregiv* OR parent OR parents OR mother* OR father*)

OVID PubMed

1st search:
- Stress Disorders, Post-Traumatic/

2nd search:
- parenting/ or grandparents/ or exp parents/

3rd search:
- Caregivers/

4th search:
- (caregiv* or parent or parents or mother* or father *).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

5th search:
- (ptsd or “"Posttraumatic Stress" or "Posttraumatic Growth" or "Trauma Related Disorders" or "Trauma Neurosis ").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

6th search:
- 1st search + 5th search (with OR)

7th search:
- 2nd search + 3rd search + 4 search (with OR)

8th search:
- 6th search + 7th search (with AND)

5. List any limits that may apply to your search:

Age: no age limit
Year(s) of publication: 2005-2020
Language(s): English

6. List the databases for that searches will be conducted in:

1. CINAHL
2. SCOPUS
3. PsychInfo
4. OVID PubMed
5. GREY LITERATURE (ProQuest Dissertation, Thesis Global)

Appendix B

Caregiver PTSS Abstract Screening Tool

To Screen In Article **A "yes" or "unsure" to all of the following:**	**To Screen Out Article** **A "no" to any of the following:**
1. Title and abstract is written in the English language.	
2. Population - Participants of the study involve caregivers who provide care to individuals with neurodevelopmental, psychiatric or neurocognitive disorders. - **Note** - Caregivers include informal caregivers, that includes parents and family members; exclude caregivers that are professionals / paid caregivers	
3. Concept / Interest - The article explores / investigates / examine posttraumatic stress symptoms, trauma symptoms, or PTSD, in these caregivers. - The article reports qualitative or quantitative primary data about posttraumatic stress symptoms (PTSS), trauma symptoms, and PTSD in these caregivers - **Note** - This excludes articles that review secondary data from other research related to PTSS, trauma symptoms or PTSD or post-traumatic growth in caregivers	
4. Context (to include in Full text screening tool) - Caregivers must be providing caregiving to individuals with neurocognitive, psychiatric or neurodevelopmental disorders. - **Note** - This excludes providing caregiving to individuals with medical illnesses, or premature infants.	

Guide on Screening Terms in Articles:

Likely to be Relevant	Unlikely to be Relevant
- Caregivers of patients / children / adults with neurodevelopmental, psychiatric and neurocognitive disorders - PTSS / PTSD / Trauma symptoms / traumatic experiences - Aggressive behaviours - Challenging behaviours - Behaviour problems - Violence / violent behaviours - Aggression - Neurodevelopmental disorders - Developmental disabilities - Intellectual disability - Autism - Psychosis - Schizophrenia - Personality disorder - Dementia	Participants - Patients / children / adults with PTSD / trauma - Patients / children / adults with chronic / acute medical illness - Patients / children / adults with cancer - Patients / children / adults with Motor vehicle accident Context - Physical / sexual abuse - Partner violence Types of articles - Commentaries or opinion articles that do not include primary or secondary data