The calm in their storm: Caregiver phenomenology of sensory modulation to co-regulate emotion in the care dyad.

A thesis presented in partial fulfilment of requirements for the degree of

Master of Science

In

Psychology

At Massey University, Manawatu, New Zealand

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2023

Abstract

Family caregivers have become a significant unpaid workforce in Aotearoa New Zealand, in terms of both numbers and economic contribution. Despite this, their own well-being is frequently overlooked and furthermore has the potential to diminish through the act of providing care. One of the most difficult aspects of caregiving is considered to be the management of maladaptive emotional and behavioural symptoms, and research suggests sensory reactivity may be an antecedent to these symptoms. Emotion regulation is believed to be bidirectional with extrinsic emotion regulation in children supported by parents intrinsically regulating and modelling their own emotion and responses. Parent caregivers are vulnerable to burnout which can make this more difficult. Qualitative methods were used to understand the phenomenology of sensory reactivity/management in intrinsic and extrinsic emotion regulation by 7 family caregivers. The data was analysed according to the components of the Process Model of Emotion Regulation (PMoER) (Gross, 2013) using Braun and Clarke's (2006) Thematic Analysis. The study found the participants were acutely aware of sensory reactivity in the care-recipient, and this was interwoven with the regulation strategies underpinned by the components of the PMoER. They predominantly utilised their own research and experimentation to down regulate maladaptive responses in the care recipient and receive little formal support to inform these strategies. Furthermore, they are often instrumentalised in sensory modulation by their intuitive knowledge of the care-recipient and their physical presence. Participants found care recipients displayed fewer maladaptive emotional and behavioural symptoms in predictable, manageable environments such as the home. This contributes to social isolation, reduced ability for the caregiver to engage in respite, and for the care-recipient to participate in developmentally appropriate activities. This study draws on the experiences of a small sample, captured at a specific moment in a dynamic experience. It draws attention to issues that are worthy of closer attention to sustain the well-being of caregivers who provide a significant contribution to both their family members and the healthcare system.

Key Words: Caregiver Well-being, Emotion Regulation, Emotion Co-regulation, Sensory Modulation, Burnout

Dedication

To my supervisor, Richard Fletcher, I began this research with an abundance of enthusiasm for this topic. Thank you for your guidance and direction in channelling this enthusiasm into research.

To the participants, who made this research possible. Thank you for sharing your precious time, your invaluable insights and your personal experiences with so much honesty.

To Chris, Griffin and Tobin, so grateful for my team. Thank you for helping me to create the space and time to be able to return to study. Without your endless encouragement and support I would never have been able to achieve this goal. Time to get out from behind the screens!

Lastly, but in no way least to Mum. You continue to inspire me with the way you unconditionally and selflessly dedicated yourself to family. We miss you.

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Over the last fifty years in Aotearoa New Zealand, care for individuals with a broad spectrum of conditions has been transferred from institutions towards care in the community. This has encompassed a change from care provided by formally trained healthcare providers, toward untrained, unpaid carers, who are often family members (Jorgensen et al., 2010; Welfare Expert Advisory Group, 2019). Caregiving arises from a relationship with an individual who needs more support than what would be expected within the normal context of the relationship, due to disability, a health condition, illness, or injury, (Gérain & Zech, 2021; Goodhead & McDonald, 2007; Synergia, 2022). It is estimated that currently 14% of adult New Zealanders identify as being a caregiver, therefore, at a minimum approximately 20% of the population operate in a care recipient-caregiver dyad, however this could potentially be much higher due to underreporting (Heyes & Grimmond, 2022).

Caregivers have been found to have high rates of mental distress, financial stress and low life satisfaction when compared with the general population which can lead to emotional exhaustion and burnout (Gérain & Zech, 2021; Goodhead & McDonald, 2007; Heyes & Grimmond, 2022; Maslach & Jackson, 1981; Synergia, 2022). Behavioural and emotional concerns in particular have been identified as a risk factor for caregiver burnout with adverse impacts on the daily functioning, quality of life, and long-term outcomes for both individuals in the care dyad (Gérain & Zech, 2019; Miller et al., 2018; Samson et al., 2015). Hutchison et al. (2016) found that child behaviour problems resulting from poor self-regulatory abilities were significantly attributable to parenting stress, more so than other features of child disabilities. Furthermore, parenting stress and child behaviour regulation were highly interrelated and bidirectional. Caregivers can be particularly vulnerable to stress when the perception of support is inadequate when compared with the demands of their role (Gérain & Zech, 2018; Hutchison et al., 2016; Martin et al., 2019; Mikolajczak & Roskam, 2018; Sullivan-Bolyai et al., 2003).

Sensory stimuli from the environment around us, and the way in which it is perceived has an impact on behaviour and cognition particularly for individuals with certain conditions such as autism spectrum disorder (ASD) (Tavassoli et al., 2018; Watling & Hauer, 2015). Adams et al. (2015) describe sensory processing as the organisation and interpretation of sensory stimuli from the body and surrounding environment, and atypical sensory processing manifests as abnormal behavioural reactions in response to sensory stimulation. This is notable as it is suggested that sensory function may overlap with adaptive function because adverse behavioural reactions to sensory stimuli have been hypothesised to interfere with the ability to perform age-appropriate functional skills (Adams et al., 2015; Cheng & Boggett-Carsjens, 2005; Critz et al., 2015; Fletcher et al., 2019; Gourley et al., 2013; Tavassoli et al., 2018; Watling & Hauer, 2015).

Sensory modulation is the ability to regulate the degree, intensity, and nature of a response to sensory input and affects the way an individual reacts to the world (Critz et al., 2015). Similarly, emotions vary in frequency, intensity and duration and are conceptualised as a series of physiological, behavioural, and experiential responses that occur as a result of an individual's evaluation of a situation (Brindle et al., 2015; Gross, 2013). If an individual becomes overwhelmed by sensory stimuli this could impact their ability to use emotion regulation strategies to meet situational demands (Brindle et al., 2015; Watling & Hauer, 2015). Behaviours associated with sensory issues can contribute to stress for both the caregiver and the care-recipient as they can hinder household routines, limit participation in community activities or social events and impede the development of positive relationships (Walbam, 2022). The ability to participate in developmentally appropriate activities helps individuals, particularly children, develop social awareness and the necessary cognitive and physical skills (Cosbey et al., 2010).

The number of family caregivers in Aotearoa New Zealand is increasing with social acceptance of community care. Family caregivers have become an important part of the healthcare system, however the role is demanding and often not well supported. Emotion regulation is a particularly challenging aspect within the care dyad and can impede daily routines and social participation. Sensory reactivity can be a contributing factor eliciting emotional responses. The New Zealand government has specifically recognised that supporting caregivers by providing education combined with psychological support can help to reduce the risk of caregiver burden and depression, which is especially helpful for those dealing with challenging behaviours (Welfare Expert Advisory Group, 2019). Increased understanding of some of the factors that challenge emotional and behavioural regulation may be an important aspect of this support.

Deinstitutionalisation and Dedifferentiation

During the 1960s there was a fundamental shift away from long term institutionalisation favouring a model of empowerment, with individuals encouraged to actively participate in their own care and treatment (Brunton, 2003). The ideological and fiscal motivation for this preceded the move towards care to be delivered in the community, as society became more accepting of mental distress and disability (Brunton, 2003). Deinstitutionalisation in healthcare refers to the transfer of care from hospitals to the community, encompassing ideals of normalisation, social inclusion, and participation in broader society of people with disabilities (Bredewold et al., 2018; Brunton, 2003; Mansell, 2006). Dedifferentiation describes a policy shift in the way disability is regarded that has been occurring since the 1990s (Clegg, 2020). Both deinstitutionalisation and dedifferentiation emerged from a civil rights paradigm and continues to shape health and social care services, favouring the least restrictive environments possible and participation in mainstream activities (Bredewold et al., 2018; Clegg, 2020). Although the purported intention is that individuals will have better outcomes in their own home with family, there is a marked economic benefit for the government, or healthcare provider (Brunton, 2003; Mansell, 2006. While this is a contributing factor, the former benefit can only be realised when community care is properly set up and managed (Bredewold et al., 2018; Brunton, 2003; Mansell, 2006). With disability being highly heterogenous it can be difficult to respond to such a vast array of needs, and community care in New Zealand has a history of being poorly structured and lacking coordination (Bredewold et al., 2018; Clegg, 2020). Living within society requires certain skills such as self-care, independent functioning, some future responsibility, self-direction, and social skills. A key aspect of deinstitutionalisation is a reliable support network, such as family, to support activities of daily living (ADLs) and community integration (Bredewold et al., 2018). As such, informal family caregivers have become an integral component of the healthcare system to achieve the aforementioned goals. The movement towards care in the community was socially motivated to benefit the care-recipient and fiscally motivated to benefit the government. Although care-recipients may be highly reliant on caregivers, there is little evidence that caregivers have been given much consideration for their own needs or support.

Caregiving in Aotearoa New Zealand

"In New Zealand carers are individuals, family, whānau and āiga providing care for someone close to them who needs additional assistance with everyday living because of a disability, health condition, illness or injury" (Ministry of Health, 2023, para. 1). The number of informal carers in New Zealand has been increasing as the government proceeds with deinstitutionalisation (Jorgenson et al., 2010; Maidment, 2016). There are currently around 490,000 informal carers in New Zealand (Heyes & Grimmond, 2022; Jorgensen et al., 2010; Maidment, 2016; Ministry of Social Development, 2019), although Heyes and Grimmond (2022) suggest this could be at least 50% higher. It can be difficult to capture an accurate picture as the terms used to describe caregivers are very diverse and can relate to both formal and informal carers (Gérain & Zech, 2021). However, some caregivers may be looking after more than one person, and some people do not regard themselves as a caregiver due to the familial relationship, which contributes to uncertainty in caregiver estimates (Goodhead & McDonald, 2007; Heyes & Grimmond, 2022; Synergia, 2022). The Ministry of Social Development (2019) highlighted culturally bound variations in what people perceive as caregiving, despite the increased demands of illness and disability beyond what would normally be expected in a relationship. Informal caregivers provide a significant economic value to the healthcare system, estimated to be well over $17.6 billion, or 5.4% of GDP, which would be exceedingly difficult to replicate in other ways (Heyes & Grimmond, 2022; Maidment, 2016; Ministry of Social Development, 2019). In New Zealand there are 7.9 unpaid carers for every practising nurse and 9.6 unpaid carers for every health care assistant (Heyes & Grimmond, 2022). Unlike countries such as the United Kingdom (UK), caregivers in New Zealand currently receive no legislative protection, although this may be subject to change in the future (Welfare Expert Advisory Group, 2019). The valuable contribution of caregivers is beginning to be formally recognised, in 2021 the Australian Capital Territory (ACT) created state law with the Carers Recognition Act (Community Services ACT Government, n.d.). In 2008 the New Zealand government produced the Carers' Strategy Action Plan in conjunction with the New Zealand Carers Alliance (Maidment, 2016). The intention behind this plan was to recognise the effects of deinstitutionalisation on caregivers, and the importance of safeguarding their long-term well-being. This speaks to the widespread recognition that being an informal caregiver puts a person at risk of poorer mental and physical health (Bredewold et al., 2018; Gérain & Zech, 2019; Heyes & Grimmond, 2022; Jorgenson et al., 2010; Maidment, 2016). At this time, the New Zealand Government's *Carers' Strategy Action Plan 2019-2023*, now known as *Mahi Aroha*, has been expanded to five objectives; to provide information, protect the health and wellbeing of carers, enable carers to take a break, provide financial support for carers and provide training and pathways to employment for carers (Ministry of Social Development, 2019). The previous iterations of this action plan have been criticised for having little accountability due to a lack of outcome measures and providing no substantial change to the caregiver burden (Ministry of Social Development, 2019). It is important to consider that caregivers and their communities can be as diverse as the people they support. For this reason, there can be notable variation amongst caregivers regarding both material and personal resources to locate, understand and navigate access to support (Welfare Expert Advisory Group, 2019). It has been highlighted that with the government continuing towards the disestablishment of institutionalisation to have more people with disabilities or chronic illness living at home, greater resources will be needed to provide sufficient support (Jorgenson et al., 2010). Although informal caregivers are often unpaid family members, they are beginning to receive recognition for their valuable contribution to the healthcare sector. This includes the importance of their role in supporting the care-recipient, and level of self-sacrifice required to do this.

Caregiver Burden

Caregiving can be extremely demanding, with informal care covering a wide range of activities relating to personal care, household chores, finances, help with mobility, attendance at appointments, compliance with treatment regimes, assistance with rehabilitation and emotional support (Goodhead & McDonald, 2007; Ministry of Social Development, 2019; Welfare Expert Advisory Group, 2019). Sustaining the provision of healthcare by both formal and informal care providers can cause significant compromises to well-being over time and result in high levels of depression and adverse effects on lifestyle, health, and finances (Maslach, 2018; Maslach & Jackson, 1981). Both formal and informal caregivers often work in a culture of one-way caring in which they need to demonstrate empathy, compassion, and patience, without the expectation of reciprocity of care in return from the care-recipient (Posluns & Gall, 2020). However, it is difficult to find the right balance in addressing the interests of the caregiver and care-recipient (Gérain & Zech, 2021; Jorgensen et al., 2010; Maidment, 2016; Melo et al., 2011; Ministry of Social Development, 2019; Welfare Expert Advisory Group, 2019). The interminable demands of providing support for daily living tasks, often combined with behavioural problems, leaves caregivers with insufficient time and energy to attend to their own health needs, leading to physical and mental decline (Acton, 2002; Yueh-Feng Lu & Wykle, 2007). As a result of the caregiving burden, many family caregivers become “hidden patients” with their own health issues (Lupton, 2013; Yueh-Feng Lu & Wykle, 2007). Caregiver efficacy and coping skills are integral in both maintaining their own well-being, but also to utilise emotional and behavioural interventions for the care-recipient with positive outcomes (Adams et al., 2015; Heath et al., 2015). One of the most difficult aspects of caregiving has been found to be the management of emotional dysregulation, contributing to challenging behaviours (Anderson et al., 2019; Yueh-Feng Lu & Guerriero Austrom, 2005). Sensory stimuli especially can be unpredictable and difficult to filter, leading to a heightened emotional response. This has been found to lead to high levels of stress for the caregiver, as well as increased social isolation, as caregivers may avoid having to manage behaviour outside the home. This may contribute to the care-recipient being excluded from opportunities that provide both development and carer respite (Ministry of Health, 2017; Welfare Expert Advisory Group, 2019). As part of providing care for the individual with the condition, it is also important that caregivers are provided with strategies to respond to maladaptive behaviour. Economic necessity has contributed to an environment with informal caregiving arrangements by untrained and poorly supported caregivers becoming increasingly common for families and healthcare services (Heyes & Grimmond, 2022). Research such as that of Gourley et al. (2013), Li et al. (2022) and Walbam (2022) continue to advocate for caregiver education to ameliorate maladaptive sensory regulation, thereby reducing behavioural problems and caregiver stress. Walbam (2022), in particular addressed the considerable time and effort by caregivers to make accommodations for things such as sensory stimuli to reduce emotional and behavioural symptoms, and thereby their own stress. Care-recipients can be extremely reliant on caregivers for community integration however the daily demands of this situation can make it difficult for caregivers to attend to their own needs and well-being. The lack of balance in this situation can directly to contribute to stress for the caregiver and within the care dyad (Mikolajczak & Roskam, 2018).

Caregiver Self-Care

Research related to the health of family caregivers has been conducted within a stress-illness framework focusing on the negative effects of caregiving, whilst less research has considered caregiver well-being from health-promotion paradigms (Acton, 2002). Self-care can be described as engagement in behaviours that maintain and promote physical and emotional well-being to lessen or prevent the stress, anxiety, or emotional reaction when working with a care-recipient (Acton, 2002; Mills, 2016; Oliveria et al., 2019; Posluns & Gall, 2020). Posluns and Gall (2020) classified self-care into the areas of awareness, balance, flexibility, physical health, social support, or spirituality. This can include such actions as staying in bed, dietary changes, taking medication, engaging in prayer, or consulting a professional to address a particular symptom, but significantly, also includes "taking no action" which may be due to lack of energy or fear of stigma (Yueh-Feng Lu and Wykle, 2007). Mills (2016) also found that self-care requires self-reflection and awareness to ensure caregivers are able to identify relevant stressors and supports. It is notable that in many studies caregivers were unable to state any specific actions they took to promote their own health, and the more demanding the care the less likely they are to take care of their own health, particularly when the care-recipient exhibited problem behaviours (Acton, 2002; Yueh-Feng Lu & Wykle, 2007). Yueh-Feng Lu and Wykle (2007) also found that small but frequent stressors are a regular occurrence and ongoing source of frustration. Furthermore, caregivers frequently live with the care-recipient and are attending to care duties throughout the day and night. This can leave little time for engaging in self-care, partly explaining why nearly one third of caregivers said they "take no action". Caregivers have been found to not only engage in fewer health-promoting self-care behaviours than non-caregivers, they have also been found to have more barriers to health promotion (Acton, 2002; Anderson et al., 2019), and are twice as likely to experience clinical and non-clinical levels of depression, fatigue, and frustration relating to high stress and poor health than non-caregivers (Feast et al., 2016; Fletcher et al., 2019; Yueh-Feng Lu and Wykle, 2007). The expectations for family caregiving very often represents cultural values, although the sacrifices required for caregiving can conflict with neoliberal westernised social values, particularly a focus on the nuclear rather than extended family and economic contribution (Funk et al., 2013). Women are far more likely to assume caregiving duties and more frequently become enmeshed between providing care both to young children, and aging parents overlooking their own needs due to time or energy constraints or the belief that this would be selfish (Feast et al., 2016; Heyes & Grimmond, 2022; Oliveira et al., 2019; Posluns & Gall, 2020). Although some research has found that altruism associated with caregiving can be protective from the negative effects of caregiving, this can also adversely affect self-care due to caregivers prioritising care-recipients well-being over their own (Anderson et al., 2019; Yueh-Feng Lu and Wykle, 2007). For this reason, Mills (2016) suggested that demonstrating self-care should be reframed, not as a luxury but a necessity, and compassion should be seen as not just kindness but the combination of cognition, affect, intention, and motivation for the alleviation of suffering. Mills (2016) therefore finds that self-neglect is incompatible with sustaining long-term caregiving arrangements. This is further supported by Acton (2002) who found that caregivers who are able to engage in self-care have reduced stress and improved well-being. Additionally, a significant mediating variable in caregiver well-being has been found to be the quality of the relationship between the caregiver and care recipient, and for this reason needs to be formally addressed for the benefit of both individuals. The above research demonstrates that although family caregivers have been an important part of the healthcare sector for over 50 years, concerns remain with regard to properly supporting care arrangements for individuals within the community. This is a contributor to stress within the care dyad which can exacerbate emotion regulation and increase the prevalence of these symptoms occurring.

Support Seeking

Perceived health status and psychological distress can also be important predictors of self-care behaviour on account of the way people interpret and prescribe meaning to their symptoms and whether they seek support (Yueh-Feng Lu & Guerriero Austrom, 2005). Anderson et al. (2019) have found that more frequently, caregivers who do engage in self-care, tend to try, and manage their symptoms on their own without professional interventions, and programmes and services to alleviate caregiver stress remain underutilised. Although there is little information on actual self-care methods, searching for information relating to health and wellness is the third most common use of the internet, compensating for a paucity of formal support (Lupton et al., 2013). Chronic stress can however increase the factors that compromise well-being and may contribute or precipitate mood disorders that may make it more difficult to engage in self-care such as exercise or other problem solving (Feast et al., 2016; Oliveira et al., 2019). Caregiver stress is highly correlated with behavioural issues of the care recipient and one of the primary reasons for caregivers seeking support (Anderson et al., 2019; Yueh-Feng Lu & Guerriero Austrom, 2005). This stress variable is also found in Acton's (2002) research, as the reaction to behaviour problems exhibited by the care-recipient can evoke feelings of distress, anger, or resentment. Many caregivers have reported they have reached crisis points due to either physical or mental wellbeing which has jeopardised the sustainability of the caregiving arrangement, as formal support does not meet their needs (Fletcher et al., 2019; Oliveira et al., 2019). Oliveira et al. (2019) found that the main activities caregivers need to engage in for self-care are respite, education, and awareness, with this being provided early in the caregiving process rather than when a crisis occurs. Self-care activities can therefore be used not only for themselves but also the person receiving care (Yueh-Feng Lu and Guerriero Austrom, 2005). Organisation and planning are described as another example of a self-care activity to alleviate stress by reducing the chaos in their everyday lives (Anderson et al., 2019). As the healthcare system increasingly depends on informal caregivers, maintaining caregiver well-being for the sustainability of these home-based caregiving arrangements will become a priority (Yueh-Feng Lu and Wykle, 2007).

Burnout

Burnout syndrome emerged from the research of Maslach and Jackson (1981) with healthcare professionals, who spent a considerable amount of time intensely engaged with people in the provision of care. It is now recognised as both an important social and individual concern with the primary concerns being both a decline in attitude towards the care recipient and a decline in personal health and wellbeing including loss of sleep, substance use and family problems (Maslach 2018). This syndrome describes a psychological shift primarily affecting three factors, emotional exhaustion (loss of energy, depletion, debilitation, fatigue), depersonalisation (detachment, negative or inappropriate attitudes toward clients, loss of idealism, irritability), and personal accomplishment (decline in achievement/competence, low morale, withdrawal, inability to cope) (Maslach, 2018; Maslach & Jackson, 1981). However, the phenomenon of burnout is related to a specific experience of exhaustion occurring in prolonged situations of imbalance, where the burden of perceived stress exceeds emotional resources (Hubert & Aujoulat, 2018; Maslach, 2018; Maslach & Jackson, 1981; Posluns & Gall, 2020). Although Maslach (2018) describes burnout syndrome as an individual stress experience, she also insists it be considered alongside the other two criteria as it is intrinsically linked with interpersonal relationships and has the potential to negatively impact the person’s concept of both self and others. Since Maslach and Jackson’s (1981) initial research with healthcare professionals, it has now been used with consideration to a variety of groups, including parents and caregivers, with a focus on dyadic care being integral to research on the phenomenon of burnout (Gérain & Zech, 2019; Hubert & Aujoulat, 2018; Maslach, 2018; Posluns & Gall, 2020).

Parental Burnout

Parental burnout is a specific syndrome developing from an imbalance of chronic parenting stress and reduced parental resources (Gérain & Zech, 2019; Hubert & Aujoulat, 2018; Mikolajczak

& Roskam, 2018; Mikolajczak, Gross, & Roskam, 2019; Mikolajczak & Roskam, 2020). As is the case with the original burnout syndrome it is characterised by intense exhaustion, and is described in relation to four main criteria, exhaustion in the parental role, emotional distancing/detachment from their children to manage energy, loss of pleasure/fulfilment in parenting, and a loss of connection with the parent they were/want to be (Gérain & Zech, 2019; Mikolajczak & Roskam, 2020). The adverse effects and increase in conflict can be noted in other relationships including that of the parent-child, the couple relationship, and other supporters (Gérain & Zech, 2019). It has been found to be more strongly associated with escape ideation, child neglect, and parental violence, with as much as a third of neglect and violence towards children attributable to this situation (Hubert & Aujoulat, 2018; Mikolajczak, Gross, & Roskam, 2019; Mikolajczak & Roskam, 2020). Gérain and Zech (2019; 2021) have found that informal caregivers who are required to sustain a level of care beyond the demands of typical parenting are particularly at risk of burnout and reported more emotional exhaustion, depersonalisation and reduced personal accomplishment. However, Mikolajczak & Roskam (2018) and Hutchison et al. (2016) suggest that it is not so much having children with additional needs which makes caregivers vulnerable to burnout, rather, it is the lack of balance between the risks and resources. Much consideration in research has been given to the risk to resource dynamic, including by both Gérain & Zech (2019) and Mikolajczak & Roskam (2018). Gérain & Zech (2019) found there are numerous objectives to consider when accounting for the multitude of stressors, alongside the subjective evaluation of mediating factors drawn from qualitative research including coping strategies, personality, and contextual factors such as sociodemographic, cultural, and ethnic determinants that also contribute to the caregiving experience. If the factors causing stress outweigh opportunities for well-being, over time it has the potential to result in caregiver burnout, which will also impact negatively on the care-recipient. Due to the importance of the care dyad in achieving the goals of social inclusion it is essential that support and empowerment of both the caregiver and care-recipient is appropriately addressed.

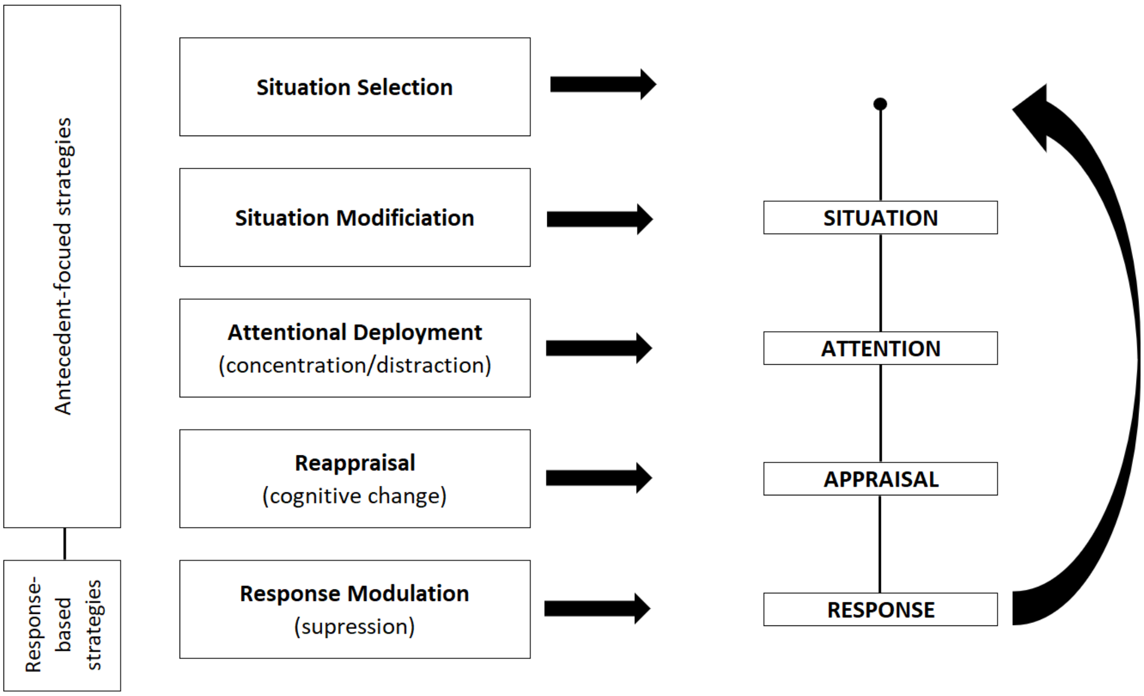
Emotion Regulation

The negative effects on development and relationships have been found to be circular and intertwined. Social competence develops through participation, which is compromised in the neurodiverse due to poor emotional regulation leading to disinhibited behaviour and withdrawal (Burley et al. 2022; Cheung & Siu, 2009; Cosbey et al., 2010; Galiana-Simal et al.,2020; Koziol et al., 2011; Hutchison et al., 2016; O'Connor et al., 2021; Pfeiffer et al., 2018; Reynolds & Lane, 2008; Schaaf et al., 2010; Wood et al., 2019). Descriptions of maladaptive emotional and behavioural responses encompass a broad range of socially inappropriate symptomology sometimes described as disinhibition (Burley et al., 2022; Carnevale et al., 2002; Filipčíková et al., 2021; Fletcher et al. (2019); Green & Ben-Sasson, 2010; Honan et al., 2016; Knutson et al., 2015; Mariano et al., 2019; O'Connor et al., 2021; Verberne et al., 2019; Warriner & Velikonja, 2006). Both Adams et al. (2015) and Filipčíková et al. (2021), found that disinhibition appears to capture symptomology relating to impairment in the cognitive domain of executive function, including working memory, emotional dysregulation, and inability to engage in goal-directed behaviour such as delaying gratification. For this reason, it has also been referred to as both frontal lobe syndrome and dysexecutive syndrome, but more recently theories have begun to consider that a lack of inhibitory control and self-awareness might also be prevalent. Burley et al. (2022) expands on this and have found that disinhibition is associated with a wide range of psychopathologic conditions, health behaviours, and public health concerns. It is therefore understandable that executive dysfunctions, including disinhibition, are found to be independent predictors of caregiver burden, with long-term negative emotional effects (Adams et al., 2015; Arciniegas & Wortzel, 2014; Filipčíková et al., 2021). Both Wood et al. (2019) and Burley et al. (2022) describe disinhibited behaviours as an uncomfortable and stressful experience for the both the individual and their caregiver. The ability to self-regulate, as well as plan, organise, initiate, and adapt behaviour is a fundamental component of executive function (Adams et al., 2015; Hutchison et al., 2016), and poor emotional regulation and disinhibited behaviour is a feature of a number of conditions including neurodegenerative, neurodevelopmental, and acquired brain injuries (ABI). A lack of awareness and understanding can contribute to miscommunication and unhelpful responses which leads to a dynamic which can exacerbate behaviours and increase stress for both parties (Arciniegas & Wortzel, 2018; Burley at al., 2022; Critz et al., 2015; Filipčíková et al., 2021; Gourley et al., 2013; Hutchison, 2016; Martin et al., 2019; Melo et al., 2011; Walbam, 2022; Wood et al., 2019). Gross (2013, 2015) describes how emotions can direct attention towards salient environmental stimuli, and enhance sensory intake, decision making, behavioural responses, social interactions, and episodic memory. Emotion can set in motion a multifaceted response, either consciously or unconsciously, causing an individual to both feel and react with facial changes, body language, and actions, (or lack thereof) (Gross, 2015). Emotion regulation encompasses the duration, intensity and frequency of a response which can be helpful for a certain situation, or harmful if it is inappropriate (Gross, 2015). Self-regulation is an important developmental skill associated with numerous positive outcomes including academic achievement, higher incomes, interpersonal relationships, and happiness, whereas self-regulation deficits are found in a number of personal and social problems and psychological disorders (Gross, 2015; Gulsrud et al., 2010; Sanders & Mazzucchelli, 2013). Self-regulation also requires a certain level of cognitive ability to moderate reactivity and behavioural adjustment (Zhang et al., 2020). Supportive parental emotion socialisation practices have been shown to promote children's self-regulation capability and reduce risk for externalising symptoms (Eisenberg et al., 1998; Gulsrud et al., 2010; Sanders & Mazzucchelli, 2013; Zhang et al., 2020). In the model of emotion socialisation, Eisenberg at al. (1998), suggested that specific emotion-related parenting practices have been used to promote children's neurophysiological regulation of arousal through multiple channels to avoid defensive arousal. However, this model requires a level of cognitive capabilities for engagement, with the emotional scaffolding provided by parents. Both extrinsic (supporting someone else) and intrinsic (self-regulation) processes, utilising cognitive, behavioural, and affective processes to plan and anticipate both intrinsic and extrinsic strategies, are fundamental to parenting and caregiving (Gulsrud et al., 2010).

The Process Model of Emotion Regulation

Gross (2013, 2015) describes emotion regulation as having three core features or stages of emotion regulation. The first is identification or outcome of what people want to achieve, the second is selection of a strategy used to achieve the outcome, and the third is consequence of using the chosen strategy to achieve the outcome. Regulation difficulties can occur at each of these stages as evaluation at each point depends on the available cognitive and physiological resources with regard to the strength of the emotional response. Further to this Gross developed the Process Model of Emotion Regulation (PMoER) seen in figure 1 (Gross, 2013; Gross 2015) which presents five points at which individuals can regulate their emotions, situation selection, situation modification, attentional deployment, reappraisal, and response modulation (Gross, 2013). *Situation selection* involves an action to increase/decrease the occurrence of a situation that gives rise to certain emotions, such as avoiding someone who causes a negative emotion such as anger. *Situation modification* relates to intentionally modifying a situation so as to improve the possibility of a positive emotional outcome. *Attentional deployment* refers to the deliberate directing of attention towards/away from emotion eliciting stimuli through either concentration or distraction. *Reappraisal* or cognitive change is the consideration of how an individual chooses to frame the situation to which they are attempting to respond. *Response modulation* occurs after an emotional response has been initiated, and an attempt is made to alter the response either experientially, behaviourally, or physiologically to decrease the negative affect and/or increase positive affect. The process model of emotion regulation has been applied by Witten et al. (2022) to understand how carers and care recipients are utilising strategies to manage anger following ABI. They found this model was able to capture and compare the application of multiple strategies being applied to emotion regulation simultaneously. Similarly, Samson et al. (2015) studied the individual component of reappraisal and also found it was suitable for comparing multiple strategies particularly in disorders such as ASD. They identified as a limitation of their research that they had not attempted to link their research to the core attributes of ASD, such as sensory sensitivity, and how this may relate to emotion regulation. One of the findings from Fletcher et al. (2019) was that sensory difficulties, including environmental triggers, specific locations, and behaviour management strategies, received near constant mention in identifying barriers to social participation due to the level of emotion dysregulation that was invoked by these outings.

Figure 1 Process Model of Emotion Regulation



Note. Based on “Emotion Regulation: Conceptual Foundations” by J.J. Gross and R.A. Thompson, 2007, in J.J. Gross (Ed.), Handbook of Emotion Regulation, p 10, Guildford Press.

Emotion Co-regulation

Research shows that behavioural and emotional problems are more common for parents and caregivers of children with neurodevelopmental conditions than children meeting typical milestones (Gulsrud et al., 2010; Mikolajczak, Gross, & Roskam, 2019; Miller et al., 2018; Zhang et al., 2020). Miller et al, (2018) suggest the specific nature of these concerns is less well understood despite the significant impact on the health and wellbeing of both the individual and their family. Their research found significant stress stemmed from issues relating to emotional and behavioural responses that precluded them from socio-normative activities that contribute to development. This is very similar to the research of Gulsrud et al., 2010, who found children with ASD in particular, are considered by their parents to be more temperamentally difficult, slower to adapt, less persistent, less able to focus and shift attention, and more easily distracted when compared to typically matched peers. These maladaptive behaviours significantly predict maternal stress as they increase the need for support and decrease opportunities for respite. Furthermore, the externalising symptoms which become apparent due to dysregulated arousal when facing emotional challenges can be extremely disruptive. These may come at the cost of interfering with opportunities for development due to maladaptive sociocultural participation (Gulsrud et al., 2010; Miller et al., 2018; Zhang et al., 2020). In early childhood, children require support from caregivers to regulate emotion and behaviour through modelling and scaffolding which provides the foundation for developing independent self-regulation (Gulsrud et al., 2010; Sanders & Mazzucchelli, 2013; Zhang et al., 2020). Gulsrud et al. (2010) suggest this process appears to be delayed in neurodevelopmental children. They found that mothers of young children with ASD are quite skilled in their interactions with their children utilising active strategies (redirection, prompting, physical behaviour) and vocal strategies (vocal soothing and reassurance) to redirect attention away from the source of the child's distress, to reengage the child in activity. It is therefore asserted that caregivers are important agents of change who should be a focus of intervention efforts further supporting the dyadic nature of child and maternal behaviours (Gulsrud et al., 2010). Similarly, Miller et al. (2018) suggest that interventions need to be considered less from the perspective of the diagnosis-to-treatment pathway aimed at halting or reversing the pathogenic pathway and more at managing symptoms and optimising function for individuals with complex characteristics and needs within their lived environment.

Sensory Processing

Sensory processing was first described by Dr A. Jean Ayres in 1965, later developing Sensory Integration Theory (SIT), to identify children who have atypical behavioural responses, and challenges integrating input from the various sensory stimuli in their environment (Adams et al., 2015; Cheng & Boggett-Carsjens, 2005; Critz et al., 2015; Galiana-Simal et al., 2020; Jorquera-Cabrera et al., 2017; Kilroy et al., 2019; Koziol et al., 2011; Reynolds & Lane, 2008; Schaaf et al., 2010; Schoen et al., 2014; Tavassoli et al., 2018; Wood et al., 2019). Kilroy et al. (2019), Lane (2019), and Watling and Hauer (2015) summarise that Ayres had described the dynamic process of registration, modulation, and motivation by which the nervous system integrates sensory information and forms adaptive responses. Ayres hypothesised that registration was the detection of sensory sensations within the central nervous system (CNS), occurring in both the limbic and vestibular systems, which are responsible both for bringing stimuli into awareness and for determining how meaningful it is. Modulation is the ability to regulate physiological responses to the stimuli and along with motivation, the ability to either inhibit a response, or adapt appropriately. Ayres proposed that impairment of registration, modulation, and motivation of sensory stimuli affected an individual’s ability to participate in purposeful and constructive activities and was the antecedent of behaviours, referred to as sensory features, such as hand flapping, spinning, withdrawal, rocking, ear covering, and intense staring (Watling & Hauer, 2015). Research into maladaptive sensory processing uses many different descriptors including sensory processing disorder (SPD), sensory integration disorder (SID), sensory modulation disorder (SMD), and sensory processing challenges. Much of the research concurs there is confusion as to how these disorders are conceptualised and little consensus on best practice approaches to assessment and intervention (DuBois et al., 2017; Koziol et al., 2011; Watling & Hauer, 2015). There is, however, a considerable level of consensus among researchers that sensory challenges can interfere with participation in daily activities, affecting social, cognitive, and sensorimotor development in children, whereas in adults it appears to be related to increased stress and ill-health (Boterberg & Warreyn, 2016; Cheung & Siu, 2009; Cosbey et al., 2010; Critz et al., 2015; Li et al., 2022; Schaaf et al., 2010; Walbam, 2022).

Sensory Processing Disorder and Sensory Processing Sensitivity

The most prominent model of sensory processing is by Dunn (2001) who suggests individuals could be classified according to their neurological threshold and behavioural responses to incoming stimuli based on neuronal thresholds and the subsequent effect on the nervous system (Cheng & Boggett-Carsjens, 2005; Reynolds & Lane, 2008). Sensory modulation disorder can be subclassified into three types, over-responsivity (a negative or exaggerated response), sensory under-responsivity (lack of response) and sensory craving (seeking increased intensity, duration, or frequency). Over-responsivity appears to be the most common form of sensory dysregulation. It is suggested over-responsivity accounts for up to 80% of cases, but the subtypes do also coexist (Critz et al., 2015; Galiana-Simal et al., 2020; Green & Ben-Sasson, 2010; Jorquera-Cabrera et al., 2017; Reynolds & Lane, 2008; Watling & Hauer, 2015). Sensory processing sensitivity (SPS) is considered to be a slightly different construct, albeit with a considerable number of overlapping features. Whereas sensory processing disorder is hypothesised to be based in neurobiology, sensory processing sensitivity (SPS) is believed to be a personality trait (Brindle et al., 2015; Boterberg & Warreyn, 2016; Walbam, 2022). SPS was proposed by Aron and Aron (1997) to describe a trait distinctly related to how people process sensory input from both the external environment and internal (i.e., emotions) and are typically highly sensitive, have a low sensory threshold, and more prone to become mentally overwhelmed by internal and external demands (Boterberg & Warreyn, 2016; Brindle et al., 2015). Much like Ayres' SIT, Aron and Aron (1997) hypothesised SPS occurred due to an increased sensitivity of the CNS due to a deeper cognitive processing of physical, social and emotional stimuli (Boterberg & Warreyn, 2016). However, as Boterberg & Warreyn (2016) and Schoen et al. (2014) explain, there is still a lack of fundamental, empirical, and independent scientific evidence for the temperamental concept of sensory processing as a standalone disorder. These responsive patterns can result in adverse behaviours due to reduced inhibitory control and disorganisation and responses can include avoidance, defensiveness, distractibility, and anxiety. Individuals with over-responsivity are believed to be easily overstimulated because they have a lower perceptual threshold and are unable to neurocognitively filter stimuli, thereby effectively receiving an assault on the senses (Boterberg & Warreyn, 2016; Jorquera-Cabrera et al., 2017). Although sensory stimuli are known to cause maladaptive responses in numerous conditions, it has been reified in the diagnostic criteria of very few. It is predominantly found in the Diagnostic and Statistical Manual of Mental Disorders (*DSM-5*) in the core criteria of neurodevelopmental disorders; autism spectrum disorder (ASD) which describes reactivity to, or unusual interest in sensory stimuli, and attention hyperactivity disorder (ADHD) in which it contributes to distraction (American Psychiatric Association, 2013). The *DSM-5* criteria now include over and under reactivity to sensory input as well as sensory craving, as adverse responses to sensory stimuli (Green & Ben-Sasson, 2010; Tavassoli et al., 2018). These challenges may fluctuate daily, but can contribute to individuals being mislabelled, mismanaged, and misunderstood (Critz et al., 2015). Although sensory reactivity is a new *DSM-5* criterion for ASD, sensory reactivity has however been noted in a number of conditions beyond ASD (Tavassoli et al., 2018).

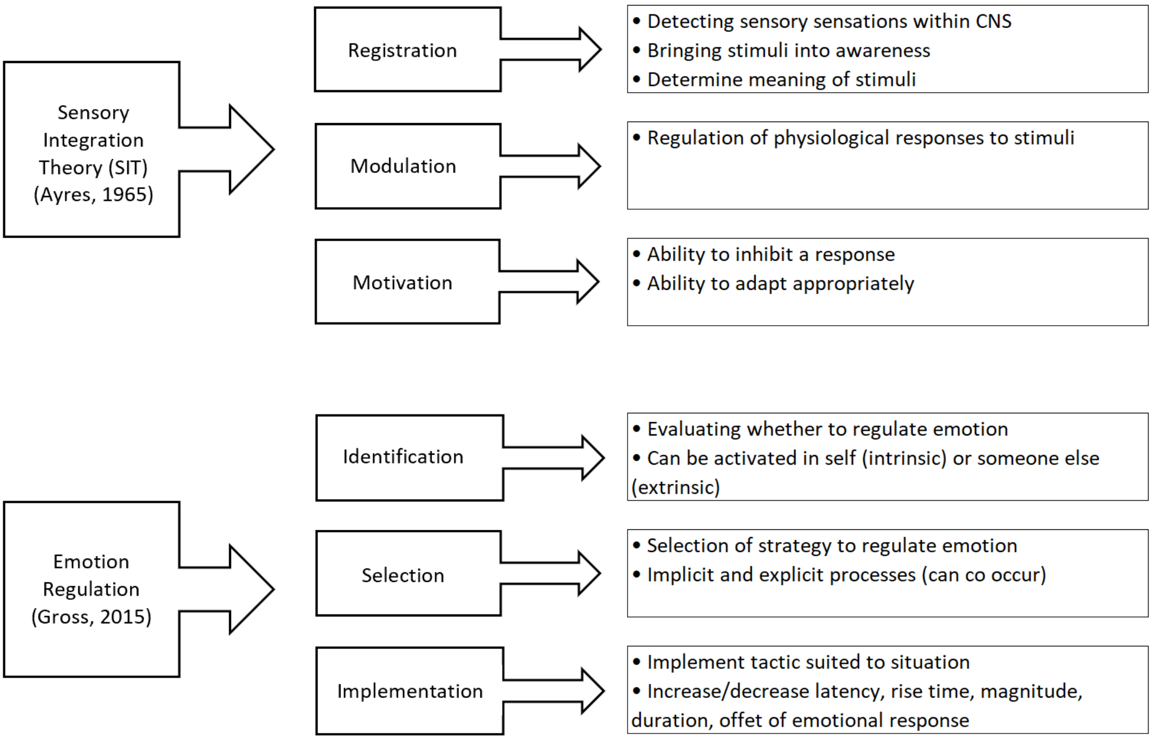
Neurobiology of Sensory Processing

Cheng & Boggett-Carsjens, (2005) and Scanlan & Novak (2015) suggest that sensory modification is designed to assist individuals to regulate physiological and emotional arousal, however they also highlight a lack of research evaluating the effectiveness of this approach. Wallis et al. (2018) describe sensory modulation as a neurological process to assist the regulation of sensory input within the CNS to be able to produce a response that is appropriate to the environmental demands. Scanlan and Novak (2015) noted that sensory interventions have moved away from SIT with a focus on improving sensory processing, to assisting with the self-management of emotional regulation, a finding that was supported by the intervention study of Wallis et al. (2018). Both Corbett et al. (2009) and Green and Ben-Sasson (2010) focused on cortisol as a biomarker to consider the relationship between stress induced as a result of sensory sensitivity in children with ASD. However, Green and Ben-Sasson (2010) considered increased activity in the amygdala contributing to anxiety due to hypervigilance of sensory input and the subsequent physiological response due to rising cortisol levels. Whereas Corbett et al. (2009), described the role of the hypothalamic pituitary adrenal (HPA) axis as an indicator of increased levels of arousal and stress, and that HPA responsivity is highly dependent on specific factors such as control, predictability, and feedback, which can be linked to behavioural inhibition and temperament. Corbett et al. (2009) also suggests that parenting style can affect the factors that regulate activity of the HPA axis, an important implication due to the significant amount of research finding caregivers of children with neurodevelopmental conditions are frequently found to have higher stress levels than those of typically developing children. They found that sensory sensitivity was associated with cortisol levels which fluctuated throughout the day as did sensitivity. Furthermore, the HPA axis is connected to the CNS, driving sensory responses which relates back to Ayres' SIT. The HPA has also been implicated in emotion regulation, as changes in experience and behaviour are associated with autonomic and neuroendocrine responses that both anticipate emotion-related behaviours and follow them, often as a consequence of the motor activity associated with the emotional response (Gross, 2015). Parental burnout has also been found to cause a strong dysregulation in the HPA axis of the caregiver and can have significant consequences for child development (Mikolajczak & Roskam, 2020).

Summary

Providing care to family members has the potential to be a life affirming experience for both members of the care dyad. Research suggests this relationship is undermined by the stress experienced by caregivers due to insufficient support to enhance and protect their own well-being, whilst responding to the care-recipient’s needs. Maladaptive emotional and behavioural responses are considered to be among the most difficult symptoms for caregivers to manage. The increased stress that occurs as a result further compromises the ability to positively co-regulate emotion with the care-recipient, as emotion regulation is bidirectional between both the caregiver and the care-recipient. Rodriguez & Kross (2023) suggest that sensory experiences are notably absent from the most prominent models of emotion regulation including the Process Model of Emotion Regulation (Gross, 2013). They highlight that sensory experiences are well established as both inducing and regulating emotional responses, such as listening to music to ease anxiety, holding someone’s hand for comfort, or eating sweet food to increase feelings of pleasure. Furthermore Brindle et al., (2015) found evidence to suggest that individuals affected by SPS are susceptible to increased negative affect. As seen in figure 2, there are parallels in the way sensory integration and emotion regulation is represented. As such it is possible that these theories could be more closely aligned in the development of interventions targeted at emotional and behavioural symptoms to better support both individuals in care dyads.

Figure 2 Comparison of Sensory Integration Theory (SIT) and Emotion Regulation



The Current Study

This study aims to consider the extent to which caregivers feel they utilise sensory modulation to regulate emotion within the care dyad. As Tavassoli et al. (2018) have found, both healthcare professionals and parents have reported that children with sensory processing difficulties often have difficulty in the behavioural and emotional domains particularly with regard to emotion regulation. Although most people are able to utilise self-regulation and sensory strategies without being aware of it, reducing the symptoms of emotional dysregulation often requires the cooperation of a caregiver applying emotional and behavioural management strategies (Cheng & Boggett-Carsjens, 2005; O’Connor et al., 2021; Verberne et al., 2019). These techniques frequently include addressing sensory components to address the mismatch between a person and their environment (Arciniegas & Wortzel, 2018; Wood et al., 2019). As such caregiver education regarding how people tolerate and integrate sensory input could improve the care-recipient’s ability to adapt to daily environments if the caregiver can interpret the individuals signals and implement specific strategies to support the development of self-regulation skills (Cosbey et al., 2010; Critz et al., 2015). Furthermore, it is important to consider the effects of long-term caregiving arrangements and any consequences relating to the wellbeing of the caregiver which may contribute to emotional and behavioural challenges. Given that research implicates emotional regulation as a developmental process within dyadic care arrangements, usually a parent/child, it is important to understand negative implications when overburdened caregivers are no longer able to contribute positively to this development. Applying the Process Model of Emotion Regulation (Gross, 2013; Gross 2015) would be a suitable way to examine the extent to which informal caregivers apply interventions used for sensory modulation for the purposes of reducing symptoms of emotion dysregulation to reduce the burden of caregiving.

Research Design and Methods

Qualitative research data is the consideration of information and experiences which Coyle (2007) describes as a "collection and analysis of non-numerical data through a psychological lens" (p. 11). Although qualitative research can be criticised for being imprecise or lacking scientific rigour, subjectivity is an essential part of the process (Brinkmann, 2014). The strength of qualitative research is in capturing the complexity and nuanced experience of being human, as thinking, feeling and acting is difficult to reduce to a set of variables (Brinkmann, 2014, Coyle, 2007). The search for meaning therefore is the primary reason for utilising qualitative methods as they are particularly suitable for capturing the phenomenological situation of a particular group with shared characteristics (Hermanowicz, 2002). Phenomenology is a description of the lived world, providing situated knowledge and an understanding of what informs a person's interactions in their daily lives (Kvale, 2002). In particular it focus' on the subjective experience of the research participant, and it is essential this is framed with context to understand the findings (Coyle, 2007; Harper, 2011). There are different positions on what level of interpretation the researcher should make when reporting research findings. Harper (2011) suggests phenomenology requires interpretation of the subjective experience into meaning by placing the account into a broader social, cultural, and theoretical context with the researcher providing the interpretation of the participant's experience. By contrast van Manen (2017) finds that phenomenology should allow experience to be revealed without judgement or trying to determine meaning. Phenomenology is considered to be a less structured approach to research, as there may be variation within data sets depending on how the participants respond, as well as the researchers attempt to extract responses (Knox & Burkard, 2009). There are many different methods to elucidate this experience from research participants including using prompts such as photos, focus groups, or interviews to generate data. Interviews were selected as the method of data collection for this research study as the purpose was to understand each individual participants experience as part of a care dyad at a particular moment in time. This experience is constantly evolving, especially as it is positioned directly in relation to another person – the care-recipient. Although the interview is captured at a moment in time the information conveyed provides insight around social experiences, norms, ideas, and values (Rapley, 2014). These experiences can then be compared between participants to determine the similarities and differences within the caregiving experience.

Procedures

Kvale (2002) describes the qualitative research interview as a conversation with a purpose, and the relationship between the researcher and participant as an integral component to be considered in the research outcomes. This is because there is a power differential in an interview conversation compared with a regular conversation, whereby the researcher guides the conversation according to the phenomena of interest and interprets and assigns meaning. The participants motivation for being interviewed may also be relevant in interpreting the data, particularly when evaluating the participants authenticity in communicating their beliefs and values (Knox & Burkard, 2009). Although Kvale (2002) speaks of the power imbalance in interviews, the less formal nature of the semi-structured interview allows the participant to maintain ultimate control over their responses deciding the information they will choose to reveal and prioritising that which they feel is relevant (Harper, 2011). The interview relationship is considered essential for eliciting quality data, with the researcher needing to ensure the interview is not mechanistic, but rather that it flows like a meaningful conversation, in addition to listening for the data and probing for detail within the responses (Hermanowicz, 2002; Knox & Burkard, 2009; Rapley, 2014). For the purposes of gathering information on the phenomenological experience of interest, there are several aspects of the interview procedure which should be given due consideration which include, developing rapport, interview setting, and the interview schedule. The interview procedure should include an introduction to the research and allow time to ask scene setting questions that are not recorded and do not form part of the final transcription (Rapley, 2014). Different interview settings offer different advantages, whereas in-person interviews allow the researcher to register non-verbal information and develop rapport, remote interviews allow accessibility and greater anonymity (Knox & Burkard, 2009). Semi-structured interviews use open-ended questions developed around the central focus of the research to enable comparison as a guide but provide sufficient flexibility that the researcher can follow up on issues as needed with prompts to ascertain greater understanding where needed. (Hermanowicz, 2002; Knox & Burkard, 2009; Rapley, 2012). The interview schedule contributes to credibility to ensure that repeated interviews follow a similar pattern to enable comparison, with the addition of warm-up questions to allow the recipient to adjust to the nature of the interview experience. The interview schedule for this study was developed with the intention of understanding in the first instance what caregiving meant to the participant and how it shaped their life and their relationship with the care-recipient. Secondly, to understand how, if at all, participants were affected by maladaptive emotional and behavioural symptoms and if they assign these in any way to sensory reactivity. The questions did not signpost the caregivers to consider sensory reactivity, rather they allowed the participant to determine the relevance to make connections with the emotional and behavioural responses. This research required a small sample of participants for a single semi-structured interview, in an individual format, to be conducted either in-person or remotely and audio recorded for transcription. It is difficult to ascertain at the outset of the research how many interviews it will be necessary to conduct. As Brinkmann (2014) suggests, when the intention of the research is to understand other people's experience, placing a predetermined number, or calculability, will restrain the potential of the research. Malterud et al. (2016) suggest an approximate sample size is proposed during planning and evaluated throughout the research process to ensure it is adequate. Criteria used to evaluate the information power of the sample size includes the aim of the study, sample specificity, use of established theory, quality of dialogue, and analysis strategy. Fewer participants are required when the sample holds a sufficient amount of data to meet the criteria.

Ethics

Ethical considerations for this research were peer reviewed and evaluated in accordance with the Massey University Code of Ethical Conduct for Research, Teaching and Evaluation Involving Human Participants. A low-risk notification was subsequently made to the Massey Human Ethics Committee. Principles of the Te Tiriti o Waitangi, namely partnership, participation, and protection were also taken into consideration.

Recruitment for participation and supporting documentation such as the research advertisement were considered to ensure the project was represented in such a way that did not bias or turn potential participants away.

Supporting documentation included a participant information sheet and consent form. The participant information sheet provided a description of the research study. As there was a possibility the interview could touch on difficult subjects, the interview process allowed time to debrief and information relating to a source of support was also provided. Informed consent was obtained by discussing the consent form prior to the interview beginning, at which point they were offered the opportunity to ask questions. The consent form also included an explanation of the participant's right to withdraw their data until a specific date.

The audio recordings were transcribed by the researcher and during the transcription process all identifying information such as names and places were anonymised. Once the transcription was complete the data and audio recordings were held on a password protected external storage device. Participants were informed this would be held by Massey University for five years.

Recruitment

For this study it was planned that 6-10 participants would be required. These participants were recruited through both social media and snowball sampling. A research advertisement (see Appendix A) was provided to Carers NZ who adapted this into a social media post. Carers NZ acts as the national peak body providing information, advice, learning and support for carers in Aotearoa New Zealand (Ministry of Health, 2022). Potential participants could scan a QR code within this post to take them to the participant information sheet (see Appendix B) which included a link to a 12-question pre-screening questionnaire (PSQ) (see Appendix C). The PSQ was for the purposes of gathering sociodemographic data and to determine eligibility criteria. The eligibility criteria required that interview participants provided care without payment, to a care-recipient with a formal diagnosis, a minimum of 3 days a week. Formal diagnosis was used to determine the role of caregiving, but the diagnosis did not impact on eligibility to participate. 11 people completed the PSQ which took an average of 1 minute to complete. Of these 7 provided contact information and 4 proceeded with an interview. A further 3 were recruited through snowball sampling. An interview was then arranged at a suitable time and location, which took place in person (n = 4) and online (n =3), with all interviews completed over a six-week period. The interview followed a predetermined set of 21 questions (see Appendix E), however due to the semi-structured nature of the interview there were variations between participants, the average interview time was 52 minutes. Before the interview, participants were given an opportunity to ask questions about the research and the researcher, and a consent form (see Appendix D) was discussed and signed. After the interview, participants were given an opportunity to debrief. Participants were provided with a $40 grocery voucher as appreciation for their time and willingness to be interviewed.

Participants

7 participants completed an interview and basic demographic characteristics are shown in table 1. All the participants were residing outside of the major cities of Aotearoa New Zealand. All the participants self-identified as a primary caregiver, providing personal, social, and emotional support and assistance with ADLs to a care recipient with a formal diagnosis who they lived with. 6 of the participants were providing care to biological children and 1 was providing care to a whāngai child.

Table 1 Sociodemographic Characteristics of Participants

Participant	Sex	Age Bracket	Ethnicity	Care Recipient (CR)	CRs Diagnosis
1	Female	46-55	NZ European/Pākeha	Child	ASD
2	Female	26-35	Māori	Child	ASD, ADHD, Coeliac's Disease
3	Female	46-55	NZ European/Pākeha	Child	Not Disclosed
4	Female	46-55	NZ European/Pākeha	Child	Down Syndrome, ASD
5	Female	46-55	NZ European/Pākeha	Child	ASD, ADHD, Gender Dysphoria
6	Female	46-55	NZ European/Pākeha	Child	ASD, Dyslexia
7	Female	36-45	Māori	Whāngai Child	ASD, ADHD, ID, FAS

Note. ASD Autism Spectrum Disorder, ADHD Attention Deficit Hyperactivity Disorder, ID Intellectual Disorder, FAS Foetal Alcohol Syndrome.

Method of Analysis

Qualitative research is ideal for capturing rich, descriptive details of an experience that is unique to an individual. However, there is a tension in qualitative research regarding methodolatry and ensuring the research question remains the priority (Chamberlain, 2000; Coyle, 2007; Parker, 2004). Methodolatry describes the prioritising of methods over other considerations that may compromise the benefits of utilising a qualitative method (Chamberlain, 2000). Although qualitative research allows for greater flexibility in data collection than quantitative research, it is important to manage the data according to methodological criteria and to be able to describe this process. Braun and Clarke's (2006) six phases of Thematic Analysis is well suited to small samples and novice researchers and this was employed with slight variation due to the incorporation of a conceptual model. In the first phase the audio recorded interviews were transcribed using a simplified version of Jeffersonian transcription notation. This allowed for familiarisation and for the researcher to find the discursive patterns, adding depth by providing an understanding not just of what is said, but how it is said. This was important as it adds contextual detail to the phenomenology of the participant's situation. Once the first two interviews were transcribed, they were returned to the participants, and they were given an opportunity to comment if they wish. One participant commented that the interview had captured their experience accurately and felt it had been somewhat therapeutic to talk about it and how far they had come. The other participant also felt it had accurately captured a difficult time in their lives. This feedback suggests that interviews capture the phenomenology of an individual's particular situation at a given point in time. The second phase of analysis was to code the data identifying the research variable of sensory modulation to map onto the research question. Ordinarily, the third phase of analysis would be to begin generating themes. However, in this research project the themes (Situation Selection, Situation Modification, Attentional Deployment, Reappraisal, Response Modulation) were predetermined by the Process Model of Emotion Regulation (Gross, 2013). The fourth phase required a more latent level of interpretation as to how the data fit within these themes. This included consideration of the embodiment, spatiality, intersubjectivity and temporality of the phenomenological experience on which the participants reality is based (Lawthom & Tindall, 2012; Shaw, 2019). The fifth phase refined thematic analysis with consideration of credibility to the research phenomena. This was done for the individual participant and then compared between participants. The sixth phase summarised the analysis of each theme to answer the research question.

Reflexivity

Reflexivity has come to be recognised as an essential component of qualitative research (Berger, 2015). It is unavoidable that the researcher has their own experiences and beliefs informing their knowledge of the subject being researched, and it is important to acknowledge this (Berger, 2015; Chamberlain, 2014; Parker, 2004). Berger (2015) explains how researchers must be cognisant of "the role of the self in the creation of knowledge; carefully monitor the impact of their biases, beliefs, and personal experiences on their research; and maintain the balance between the personal and universal" (p. 220). I am a female NZ European/Pākeha and would be considered an insider researcher (Berger, 2015) having lived experience of being a family caregiver. O'Hagan (2014) writes "A lot of people didn't want Carrington to close. The public were suspicious and fearful. Families didn't want to take responsibility for their cast-offs or feared how their loved ones would cope." (pp. 177). I first read this in a compulsory text for a postgraduate psychology course and I recall feeling upset and angered both at the way families were portrayed, and the description "cast-offs". Family caregiving is very familiar to me and something I have grown up with, as following the closure of Carrington Hospital my grandmother came to live with us. We absolutely loved her, and she us, she spoilt us no end, she was never considered a cast-off. I feel the perspective of O'Hagan (2014) downplays the numerous variables family caregivers might have to account for. As young children we were largely shielded from some of the difficulties. One of my earliest memories of family caregiving is my mother on her hands and knees at a difficult moment mouthing the words “help me” trying to clean a mess. I remember her desperate expression and being confused, frozen, not knowing what help was needed, aged approximately 6. In later years I observed my mother, a caregiver again, this time with her sisters looking after their own mother, I don’t recall their brothers being involved. When my own mother became unwell, my father retired one day, and became a full-time caregiver the next. As a family we worked together because we had an implicit understanding of this expectation. I continue to be a family caregiver as my own children have diagnoses of ASD and ADHD. Family caregiving has therefore featured prominently in my life, although in a very poorly defined way as it had never been suggested that I was anything more than family and I had never considered it either. In some respects, it is only through the process of researching that I have come to more fully consider how it has shaped my relationships and my life and continues to do so. In addition to this I have professional experience of working with individuals within mental distress and disability and supporting family caregivers. As such I have a high degree of familiarity with both the phenomena of interest and the formal support networks available in Aotearoa New Zealand. It was essential that throughout the research, from developing the interview schedule to analysing the data, I was able to continually attend to my own subjectivity and how this may bias my interpretation of the data. There are some benefits to this position in being able to develop rapport and being attuned to nuanced details. I explained my experience as a family caregiver to participants during discussion prior to the interview. This was beneficial as it appeared to put the participants somewhat more at ease. I got the sense they were often in a position of having to convince people of their experience, whereas I am duly aware of the significant pressures faced by family caregivers. Participants realised there were aspects of institutions such as within education and healthcare in which we had a shared understanding of what they were and how they worked. This was evidenced in the interview in which they would say things such as “well you would know”. Participants consistently expressed a frustration with being perceived as altruistic for their caregiving role, and I recognised the loyalty and protective instincts that I was familiar with in my own family. In developing the interview schedule, it had occurred to me there was the possibility for this to be an emotional experience for the participants, I had not considered how I might be affected by observing this emotion so closely. At times participants touched on experiences I had suppressed and brought them to the surface again. However, every participant's experience is unique, and it is important to consider the differences as well as the similarities with my own experience.

Quality Criteria

Quality criteria for qualitative research can include credibility, transferability, dependability, and confirmability (Guba, 1981, as cited in Shenton, 2004). Credibility aims to ensure the research maintains congruence with the phenomena of interest and that the researcher is cognisant of familiarity with the subject, methods, bias, and ethics (Tracy, 2010; Shenton, 2004). The phenomena of interest should have a substantial description to provide context for interpretation of the findings and all the procedures should be thoroughly documented to maximise the potential of the transferability of the findings (Tracy, 2010; Shenton, 2004). Dependability is very closely linked to credibility and is maintained by the reflexivity of the researcher during the study (Tracy, 2010; Shenton, 2004). Confirmability speaks to the effort that is made to represent the experience of the participants by limiting as much as possible the bias of the researcher (Tracey, 2010; Shenton, 2004).

Analysis

In describing the Process Model of Emotion Regulation Gross (2013) details how emotions direct attention to salient environmental stimuli and contribute to decision making, behavioural responses, social interactions, and memory development. These emotions can be regulated to form differing responses using a variety of strategies as certain responses are found to have more sociocultural appropriateness than others. There is an important distinction to be made between intrinsic emotion regulation in which someone attempts to regulate their own emotions such as the caregiver, and extrinsic emotion regulation in which someone attempts to regulate someone else's emotions such as that of a care-recipient (CR). The Process Model of Emotion Regulation encapsulates five points at which an individual can regulate emotion based on the point at which the situation provokes a response. These five points are situated in a sequence of response regulation beginning with situation selection, situation modification, and attentional deployment which are antecedent based strategies, as well as reappraisal and response modulation which are response-based strategies.

Situation Selection

Gross (2013) describes situation selection as less cognitively demanding and a form of action to either increase/decrease the likelihood of being in a situation that gives rise to certain emotions. Situation selection is the first opportunity in the emotion regulation sequence that individuals have, to regulate their emotions. There is a level of uncertainty however, as to how an individual will respond in a given situation, and the contributing factors likely to occur that may trigger an emotional reaction. Participants described a process of making assessments of situation selection based on prior knowledge of the CR and their ability to manage, as well as their own resources. This aligns with the research of Fletcher et al. (2019) who found that behaviour triggers and needs influenced decisions regarding locations caregivers selected and avoided. Participants drew on very similar descriptions of the CRs emotion regulation particularly the word overstimulated, whilst their own experience was typified by exhaustion. Whilst at home caregivers had more oversight and control to ensure that incoming sensory stimuli was predictable and managed to reduce agitation. Outside the home they had little control, however, participants also had to consider their own ability to respond as the need arose. South and Rodgers (2017) suggest this overstimulation could be a result of brain activity that has been found to be especially heightened when multiple sensory modalities (auditory and tactile) appeared simultaneously, particularly in ASD samples.

"…I tend not to do things with her in the community…cos she just doesn't cope with it, the whole sensory challenge of being in that space with lots of people, we just kind of go off and do our own thing" – Participant 2

"…I actually need to be able to manage and engage, to be able to be present…that's actually why we get isolated cos I just needed a break" – Participant 3

"…she gets quite tired and anxious and just overstimulated by the whole world so yeah we spend a lot of time at home" – Participant 4

"…very hypervigilant and always yeah feeling like you're being on guard, my kids going to be in that situation, they're going to get overwhelmed, they're going to get overstimulated, do I protect them from that, or do I let them go into that and guide them through the discomfort?" – Participant 5

Participants described how they had become highly attuned to particular situations and the challenges they presented in terms of sensory stimulation for the CR. These could include spatial deprivation, lighting, noise, lack of predictability/familiarity, and the CRs maladaptive response often attracted negative attention from other people in the community. Fletcher et al. (2019) described how sensory-related responses also had the effect of reducing participation due to fears related to their child's safety, particularly running away, resisting parental supervision, growing physically larger and becoming more difficult to physically manage and these exact concerns were also sighted by the participants. Gulsrud et al. (2010) found that high levels of stress not only interfere with sensitive and responsive parenting, but that it is highly likely stress may also interfere with the maternal support of emotion regulation in the child. Stress was highlighted by all of the participants, in relation to the level of social isolation that came about due to the challenges of managing emotional and behavioural responses in public and the energy that required. Participants identified that public spaces not only contributed to more frequent instances that required emotion regulation, but that they also needed to be highly responsive and co-regulating with the CR. The CR was likely to become increasingly reactive, drawing attention. The caregiver then had to manage both the reactivity from the CR and the reactions from other people which contributed to a rise in their own tension. This was also found in the research of Brindle et al. (2015) in which individuals who are more prone to sensory overload may organise their lives around minimising sensory stimulation. For this reason, home became a safe space with much greater consideration given to the importance of outings.

> *"…he's got everything he needs…I think he just feels more comfortable in his own space…the outside world is full of irregularities, out of routineness, I guess the outside world is anything could happen out there, whereas inside the home everything is predictable…" – Participant 1*

> *"…I can't cope with everyone staring and he gets heightened because he can feel my tension so we just don't go out…you're just so strung out it's not even worth going anywhere, people tell you to relax well you can't relax…" – Participant 7*

The participants discussed how even running small errands or participating in what would be considered regular family outings such as attending a sibling's sport could become highly contentious due to the situational demand placed on the CR. The process of running an errand, which would otherwise be taken for granted by people not familiar to caregiving, becomes an enormous undertaking with everything from just convincing a CR to get in the car having the potential to cause stress through conflict. As Walbam (2022) describes, the cumulative effects can result in caregiver stress that can impede dyadic engagement and affect the CRs social responsivity and can add to the difficulty in trying to understand the cause to be able to respond accordingly. All the participants were highly cognisant of the effects of different environments on their children. As a result, it required a significant level of mental and sometimes physical energy to be able to manage and respond to both their own needs and those of their child. This aligns with the research of Gérain & Zech, (2019) who found that isolation can originate from the social environment, but that caregivers experiencing burnout are less likely to seek social contact. Furthermore, Fletcher et al. (2019) have found that community participation challenges identified by caregivers fell into four categories of sensory processing difficulties, environmental triggers, specific locations and behaviour challenge management strategies. As such burnout was related to having a reduced social life and the loss of friends and more globally the feeling of having to give up important things for themselves due to the CRs needs and lack of flexibility. Participants had found regular support networks were compromised due to the lack of understanding, and the lack of energy to create understanding. Their lives had become highly routinised with little room for deviation or spontaneity to develop social networks. For this reason, they found their social networks were predominantly with parents who were also in similar caregiving situations, as this is where they found the most awareness and understanding.

"…I've withdrawn from that because these Mums…they've got their own thing going but they don't get it…it's really hard because suddenly you're even more *unusual than the* unusual *parents so it's quite hard and quite isolating and you just to have to kind of suck it up cos you can't go oh poor me because it's just the way it is…certainly the level of caregiving I give makes me feel very disconnected from others" – Participant 4*

"…I kind of have a tendency to gravitate towards parents who might be going through similar things…my people that I feel more comfortable with are parents of kids who are a little bit different" – Participant 5

"…my world has got very small…I just don't have the energy, I don't have the time revolving everything around (child) and people don't get that…" – Participant 6

Gérain & Zech, (2019) put forth that caregivers continue to be individuals with personal cognitions, emotions and motives that should be given consideration when trying to understand caregiver burnout. Caregivers are frequently encouraged to take respite, however, all of the participants described how this was incongruent with the level of care they provided. The caregiving experience is highly nuanced, and the closeness of the relationship leads to a level of intuitive understanding in which they are highly attuned to the CRs needs. For this reason, it is very difficult for another person to temporarily assume their role, furthermore, removing the stability that was provided by the consistent caregiver could lead to a sustained period of emotional dysregulation until routine was re-established.

"…I wouldn't even know what I need to refresh myself anymore it's been so long, I wouldn't even have a clue where to start if I did have the time…doing something I want to do is just not worth it…it's not worth the fall out that lasts for days and days and days" – Participant 6

"…a lot of professionals are like you need a break…but the issue is those transitions aren't worth it…it will take at least three days for her to one sleep properly and two get back into some kind of routine…" – Participant 2

"…[day] was meant to be a day off on my own…so I could do things like watching tv and I don't know going for a walk, just I don't know sit still in absolute silence without any demands being made of me…it kind of annoys me because I go to my GP and say I'm quite stressed and…they go well you need to make a bit of time for yourself…it's easier just to go with the flow and not put myself into the equation at all" – Participant 4

"…everyone wants support from me…forgetting that I'm actually a person and needing that reset and break…it's just a hamster wheel for negative decline" – Participant 3

Gourley et al. (2013) found that parents of children with sensory processing deficits had significantly higher levels of parental stress than parents of children without sensory deficits.

Caregivers were aware that many situations would be too demanding and result in a negative reaction from the CR causing them to prioritise and put de-escalation measures in place describing this as “pick your battles” as caregivers needed to reduce the stress in the relationship and their lives. Hutchison et al. (2016) draws a link between the experiences of the child in the surrounding environment which are modified by the child’s behaviour, the changed child then in turn influences the surrounding environment through their evolved behaviour.

“…we have to pick and choose I have to pick and choose my battles and whether she’s in a frame of mind to do it, but we don’t just go out for the sake of it…” – Participant 2

“…we have avoided social situations because it’s just too overwhelming for him…he would be way out of his comfort zone, he wouldn’t know what would be expected of him so he would probably have a meltdown…everything we did was kind of tailored around what we knew he would be fine with…” – Participant 1

Samson et al. (2015) found that situations that are novel, difficult to anticipate and involve unexpected changes or are lacking in familiarity seem to induce strong negative emotions in individuals with ASD. This aligns with South & Rodgers (2017) who found that higher levels of sensory dysfunction seem to be found in people who are intolerant of uncertainty and have a difficult time with ambiguity, which appears to be a key mechanism underlying anxiety. This is concurrent with Green and Ben-Sasson (2010) who found evidence of an overlap between anxiety and sensory responsivity was particularly common in individuals with ASD, although the causal mechanism is not currently understood. Consideration of anxiety appeared to be a consistent underlying factor of the selection of social situations for both the intrinsic regulation of the caregiver and the extrinsic regulation of the CR.

Situation Modification

Situation modification refers to actions that modify a situation to change the emotional impact (Gross, 2013). Situation modification is considered modification of the physical environment as opposed to cognitive change to modify the internal environment. When a situation is modified, a new situation is created. Extensive use of pre-empting provocative stimuli to extinguish it before it occurred, routines and prompting was detailed by all of the participants. As the CRs generally lacked the ability, or had a delayed ability, to intuitively adopt skills needed for personal care and social integration, participants found themselves utilising these compensatory strategies. They also described how this was the part that was especially exhausting due to the effort and sustained focus that was necessary from them. They described a process of coaxing, cajoling, prompting, cueing and thinking ahead for the next step in the process, whilst also being vigilant for anything that may cause interference with completion of the current step. The participants found that reliability of these routines reduced the likelihood of dysregulated behaviour and "meltdowns". This was also seen in the research of Fletcher et al. (2019) who found that caregivers relied on preparation, planning and consistency to manage participation challenges related to sensory processing. Gulsrud et al. (2010) also described how extrinsic and intrinsic processes can be implemented for monitoring, evaluating, and modifying emotional reactions.

"…he's got his routines that he sticks to and if there's anything out of that routine it can certainly throw him a curveball and sometimes will end up in a meltdown…" – Participant 1

"…our home is filled with things to help the situation, like really structured, there's lots of routines, even the dog was got in mind with keeping the child calm…" – Participant 3

"…going to school is enough for him, I have to put the toothpaste on his toothbrush, I have to make his breakfast, I have to tell him verbally what the options are for breakfast <u>every single day</u> even though they haven't changed for 10 years, but he needs to hear it…" – Participant 6

However, despite the participants trying to ensure the removal of provocative stimuli there are certain things that are beyond their control. Many of the participants described interactions with family, peers and members of the community that would typically be unremarkable but caused significant discomfort to the CR due to their sensory reactivity. The participant once again found themselves acting as a guardian, or modulator, for the CR by trying to reduce or remove the cause of the sensory discomfort. Both Brindle et al. (2015) and Fletcher et al. (2019) have found individuals with sensory processing difficulties participate differently with peers and in the community, and that environmental supports, including sensory based strategies, can serve as a mediator to enhance participation and promote self-regulation.

"…he didn't deal with the noise, the closeness of people, having to sit still on a mat…I think (child) was probably very stressed he didn't fit into that routine…" – Participant 1

"…when she was little, I'd have old ladies come right up to her and go you're so cute and I would say please don't do that she will punch you in the face…luckily she never did punch any old ladies, but all the teachers at daycare got very beaten cos they would do the same…" – Participant 4

"…he's got quite a good understanding of his sensory issues…but at the moment his (sibling) is chewing too loudly and the way I say s-words is really annoying…evidently there are too many s-words…" – Participant 6

This included trying to pave the way for attendance at school. Participants described an extensive amount of time spent working with teachers and teacher aides to support the CR. This was by way of sharing their knowledge of the CR and their strategies, to feel physically more comfortable in the school environment thereby reducing maladaptive behavioural responses. Caregiver and family education is suggested to support regulation strategies, as better regulation will improve the ability of the child to function more effectively in the world and family functioning as a whole (Critz et al., 2015). However, the family exists within a community who also need to be supported to utilise these strategies.

"…sharing things with the schools was key as well…some of the schools would get a box of familiar things for him and put that in a corner and let him know that whenever he's feeling overwhelmed, he could go over to that box, find something familiar and that would help him calm down…" – Participant 1

"…her teacher aide is literally with her from the minute she arrives, I literally do a handover, I don't leave until she's got a teacher aide with her and then the teacher aide hands over to me at the end of the day, she's got adult supervision and support and connection…it's about relationship…it's quite intense" – Participant 4

"…there is extra stuff that you carry…visiting school before they start the next year…just to explain what behaviours your kids might have, how they might present versus what the teacher says on paper…" – Participant 5

Participants consistently referenced issues with both sleep and food, daily necessities of life that were an unavoidable struggle. It was very common that the CRs had dysregulated sleep patterns which unavoidably affected the participants own sleep patterns. This is also seen in the research of Martin et al. (2019) in which they found that sleep problems not only increased behavioural dysregulation but affected the parents' opportunities for any meaningful time to themselves and interrupted their own sleep. Some participants quite literally had an unending physical connection with the CR throughout the day and night. Their presence was needed by the CR for comfort and as such can undoubtedly be seen as a form of situation modification for extrinsic emotion regulation.

"…(child) didn't sleep through the night until he was about 11…it was like why does my child not sleep, what am I doing wrong…we tried white noise and we would leave an electric toothbrush at

the side of the bed…honestly we tried everything, I remember hours of (partner) holding him in his basket and rocking him…" – Participant 1

"…I sleep with her, because otherwise she gets up in the night…she literally cannot fall asleep, it's like she needs to hear my heartbeat going to sleep…" – Participant 4

"…he can't fall asleep unless I'm lying beside him…so we all share a bed which is very cosy…" – Participant 6

"…you don't really know that you could end up three months, six months, three years not having sleep…" – Participant 3

Situation modifications included evaluations of safety considerations for the CR as they tended to act extremely impulsively and was included in the near constant situational monitoring. Participants found themselves scanning for things which could be emotionally provocative, which may attract the CRs interest causing them to run off without warning. Two of the participants described having the doors of their house locked, and even bolted, at all times in an effort to reduce this situation, however despite their efforts it still occurred on occasion.

"…if he saw a butterfly on the other side of the road, he would have run over that road so for him it was a case of you had to hold his hand, you had to pre-empt that…" – Participant 1

"…we've got bolts on all of our doors with keys…cos if she goes outside one of us has to go with her…" – Participant 4

Caregivers themselves become part of the situation modification insofar as the CR is extremely reliant on their presence and often their sustained attention as well. They become aware of stimuli that cause significant distress and take steps to modify this situation for the CR, so as to reduce the dysregulated response which comes from the distress. Caregivers modify the situation by increasing the comfort levels of the CR as much as possible to reduce their anxiety which are difficult not just for the CR, but the caregiver and other members of the family also. This is a constant process they engage in throughout the day, every day. This supports the dynamic that Hutchison et al. (2016) found whereby the relationship between parenting stress, parenting style and child executive functioning for children with disabilities was highly interwoven and there was evidence of a bidirectional relationship in which parent and child characteristics interact over time and change one another.

Attentional Deployment

Gross (2013) describes attentional deployment as the way in which attention is directed to affect one's emotions, primarily when it is not possible to modify the situation. Attentional deployment is a cognitive strategy including both concentration and distraction, with distraction being less cognitively demanding and more effective than concentration (Witten et al., 2022). It can be used to move attention away from emotion-eliciting stimuli, or the situation entirely. Concentration is more cognitively demanding but used similarly, to focus attention on things that are less provocative.

Participants described actively concentrating throughout the day due to oversight of the CR. However, this was not limited to focusing on things that were less provocative, rather it was constant situational monitoring of the CRs emotional state or what could potentially affect their emotional state. This is congruent with the research of Gérain & Zech (2018) who found that ongoing preoccupations regarding their children placed constant tension on parents, which represents an ongoing stressor contributing to emotional exhaustion. Participants found they were attuned to the CR from the moment of waking, listening for signs that would give an indication of the CRs mood, as it was likely to set the mood for the participant also. During this time, they were often pulled in different directions trying to attend to their own needs to set themselves up for the day, and sometimes those of other family members.

"…when I'm getting up like I'm…listening to hear if they're in the shower already because then I know it's going to be a reasonably motivated day for them…if they're still in bed I know it's going to be difficult" – Participant 5

"…sometimes she does stay in bed and stays asleep and I sneak around and get a shower done and lunchboxes done…it's awesome, then we have the battle, not battle negotiation, but it can feel like a battle sometimes about making sure she's ready to leave at the time her sister needs to leave…all the way through you have to keep her in a good positive mood…" – Participant 4

Concentration also extended to consideration of the CRs emotion regulation and extensive hypervigilance. This included situational monitoring of stress inducing stimuli, changes in routine, completion of routines and maladaptive responses. Participants described an incessant state of pre-empting potential stressors in an effort to reduce or eliminate them. Green & Ben-Sasson (2010) have suggested that for anxious individuals' hypervigilance, or scanning for threat-based stimuli, leads to hyperarousal as part of an overall difficulty in regulating negative affectivity, known as threat-based emotion regulation. If children are hyper aroused and scanning the environment to look for threats, they are more likely to notice and react to environmental sensory stimuli. This supports the notion that there is a subgroup of children with ASD who are particularly prone to sensory over-reactivity and that these children show some symptoms similar to individuals with anxiety disorders, including difficulty with rapid disengagement and selective attention (Green & Ben-Sasson, 2010; South & Rodgers, 2017). Boterberg & Warreyn (2016) support this stating that individuals with sensory challenges are believed to be easily overstimulated by external stimuli because they have a lower perceptual threshold and process stimuli cognitively more intensely than most people.

"…you can't kind of let your guard down…I have to be constantly monitoring how things are going and where he's at…I could see a meltdown coming 15 minutes before it did…" – Participant 6

"…just the advance thinking of things…you're just trying to think of anything in advance of what could possibly go wrong and overcome that before it happens…" – Participant 1

"…very hypervigilant, always trying to look for what potential y'know, I can read her pretty well…" – Participant 2

As the participants were likely to be significantly affected by dysregulated emotion it was important for their own well-being to try to reduce potential reactivity as much as possible. This is very similar to Fletcher et al., (2019) who found that not only do caregivers learn to predict the triggers and antecedents, but they can also be ready with the strategies needed to help their child manage them. This connection to the CR lasted throughout the day, even when they were not physically with them, they remained connected mentally and emotionally to respond to the CRs emotion regulation needs, which was often distracting from their own tasks. Furthermore, significant others, such as educators, expected them to be available to support the CR with significantly more responsibility and accountability than perhaps a parent of a typically developing child might be. However, this meant there was really no point at which they were able to disconnect from their caregiving responsibilities and often lead to friction in these important relationships.

"…I was constantly getting called to come and get her from school, I got a phone call one morning asking had I actually dropped her off that day because she wasn't there…" – Participant 2

"…if I'm lucky they will go off to school and I won't get a call or an email and I won't have a meeting or need to have a meeting about a meeting but some days I might be arranging staff…just so I can step out and get some work done…" – Participant 3

"…if I've had the messages and haven't picked up straight away and there would be a lot of them…if I look at those after a period of time and I know I haven't seen them that worries me to a certain extent and especially at that time I'll be sitting at work trying to concentrate so yeah it is stressful…" – Participant 5

"…I've told them I'm not picking him up to take him home…they get paid for it, it's not naughty behaviour…they've been paid a massive grant for that" – Participant 7

Aside from using mental resources for extrinsic emotion regulation in the CR, concentration was the main attentional deployment strategy used by participants to manage their own emotions, particularly within the community. Concentration would be used by caregivers to maintain what they described as a "mask" to try to avoid engaging with people who were noticing them when the CR was drawing attention, and to focus on the task they were trying to complete such as grocery shopping or trying to engage in socio-normative outings. This was usually in response to the attention they received from the community which often felt negative, unwanted and like judgement. Participants felt there was a considerable lack of awareness and understanding relating to disability. The CRs disability may not be immediately obvious, and participant's felt there was a judgement the CR presented as being of an age at which they should have moved past the maladaptive behaviour. Participants often felt their parenting skills were being scrutinised, rather than members of the public having an understanding of the heterogenous presentation of disability, and what might present as demanding for the CR and therefore themselves. This is concurrent with research suggests it is the perception of support, or lack of, which significantly effects caregiving stress and supportive environments are essential in managing behavioural challenges (Gérain & Zech, 2018; Lu & Wykle, 2007)

"I don't think they would have a clue what effort goes into maintaining that stiff upper lip as you go outside…what effort goes into keeping (child) at an even keel…what goes in behind the scenes at all" – Participant 1

"…my therapist is like would you take off your damn mask…I struggle to do that because then I've got to walk out of this appointment and y'know put that mask back on…I just can't take it off because I have to be in <u>that frame of mind</u>" – Participant 2

“we’re always being watched…that’s not paranoia…I kind of just got used to that and put it aside…but if there’s harder days that increases” – Participant 3

“…the mask I wear to be her mum…is to make sure I’m child centric, I’m focused on her, I’m relieving her anxiety at all points, I am keeping her regulated so I have to be as self-regulated as possible so I can co-regulate with her to keep her steady, cos the steadier she is the happier she is and the less unpredictable and chaotic she is…” – Participant 4

“I actually want to get t-shirts that say like my superpower is autism, stuff like that, so people can see and stop staring at me, y’know there’s no awareness, and like I say they look normal they’re not in a wheelchair” – Participant 7

Distraction was often part of a pre-emptive plan for extrinsic emotion regulation to avoid a maladaptive response by having things such as treats, snacks, toys, or electronic devices available if it became necessary. This often came from prior awareness of situations that were challenging for the CR and had a high potential for emotion dysregulation. This has crossover with situation modification, but the primary intention was distraction from the situation causing the emotional response.

“…if we were to go somewhere or to try something new then it would probably be stressful for all of us, but we’d have plans in place…again pre-empting things…I’d always make sure we had an iPad or we had snacks that he’d like or something to distract him with…” – Participant 1

“it looks like we live out of our car, honestly…it has clothes, it has stuff to clean up y’know sensory toys, food, drink, y’know my car is just full of stuff, and it looks like we live in it to be fair” – Participant 2

“his [sibling] has swimming for half an hour so I have to make sure he’s got snacks, and the right type of snacks and that he’s got something to do…” – Participant 6

Overall participants described feeling exhausted from the constant monitoring, prompting, and micro-managing to support the CR, as a regular day could easily overwhelm their coping resources. As such, participants very much existed in the world of the CR, seeing it from their perspective and acting to regulate extrinsic emotional responses, often before they occurred.

Reappraisal

Gross (2013) describes reappraisal as a strategy to regulate emotion through cognitive change, in that an individual reconsiders the emotional significance of a situation, effectively modifying the internal environment. This can relate to both the way in which the individual evaluates the situation and their ability to cope with the demands generated from that situation. Managing the consequences of the combined caregiving/parenting role was dynamic and largely dependent on the effects of other stressors at a given time. Some participants described experiencing the loss of their own life expectations or diminished ability to enjoy parenting, as caregiving allowed for less time and energy to enjoy this role. There was also consideration of the length of time for which it would be necessary to sustain the level of support they provided to the CR. All the participants felt they would very likely be maintaining support for their lifetime, with some expecting little change in the level of support they provided. Others felt this may decrease or become less intense, however, the emotional support they provided to the CR may never change.

"...I am that mum that says I need to live a day longer than my child...sometimes I still grieve the child I didn't get given, that I thought I was going to get" – *Participant 4*

"...I'm honestly quite resentful, not about the care, but about the enormous impact on my life…I feel really disrespected as a person, as a parent…I've almost become a bit of a non-entity" – *Participant 3*

"…I'm kind of looking forward to the fact that there possibly will be, a little bit of spare time down the track…hopefully they will be independent, not 100% sure yet…I'm assuming they will become independent but I'm not sure to what extent yet" – Participant 5

Caregiving is a dynamic experience that gives rise to reappraisal of the emotional significance of situations that require attention both short-term and those that develop over a longer period of time. Of significance, was the intrinsic emotion regulation required as participants revaluated their expectations of parenting as they went through the process of diagnosis with the CR. All the participants felt there was a distinction between their role as parents and their role as a caregiver due to the intense nature of providing for care needs that were directly related to the CRs diagnosis and went beyond the typical demands of parenting to some extent. They found it was necessary to take on considerably more roles and in a greater capacity than regular parenting such as advocate, social facilitator, support administrator, employer, therapist, educator, attending to regular medical needs, among others. Hutchison et al. (2016) found there are many characteristics of children with disabilities that may cause stress for families (poor social skills, developmental delays, behavioural concerns), as well as contextual factors (limited social support, difficulty obtaining medical/educational resources) that contribute to parental stress. At times this might mean having to consider what role they were fulfilling at any given time, and their personal resilience to be able to do that.

"I remember a midwife telling me once you've given birth it's a constant journey away from you that your child is doing, that you need to support them in, and that's parenting, whereas caregiving…I still have a very similar relationship that I did when she was a year old…" – Participant 4

"…there is the parent, the medical caregiving, the advocate, the social community path maker, the PA and manager of their support, the finder of safe people and safe places, the trainer of those people …I just did this worksheet of how many hours of caregiving I am doing…I didn't even put

everything in and it was 400 hours a month over and above normal parenting… just being mum can kind of get lost" – Participant 3

"…in my mind I was always going to go back to work after I'd had the kids, but (child) and his extra needs kind of made me want to stay home and look after him because he just wouldn't of coped with anything else out of routine, I don't think like after school clubs or things would have worked for him… he has become a lot more independent…I don't think he will be ready to leave home for a long time, he will need teaching a lot more life skills that he doesn't pick up as intuitively" – Participant 1

"…that's kind of what caregiving looks like, it's keeping the peace, it's micromanaging everything from emotions to sensory stuff, to behaviour, to actually getting tasks done…my entire career is gone…my earning potential and all that stuff is just non-existent…I can't do a job that's mentally as taxing as I used to do" – Participant 6

"…I would be three years into my career, I gave that up, I don't go visiting [people]…a lot of meetings, a lot of appointments, a lot of paperwork…that's where you can get overwhelmed too" – Participant 7

"…if I'm not teaching her or doing work with her, y'know, I'm writing reports or filling out forms, I'm chasing up services and y'know putting out fires here, there and everywhere" – Participant 2

Many of the caregivers described adaption to caregiving as a time of confusion, where they felt isolated from their natural support networks such as families, friends, schools, and communities on account of the misunderstood and challenging behaviour of the CR. For some this was a time of uncertainty when they had less confidence to communicate with people about both their own needs and the CRs as they were still making sense of this themselves. For others they did not feel they lacked confidence, but that they were not heard.

"…when we'd go to a friend's house for a birthday party and (child) would behave very differently and I'd be stressed because I knew he behaved very differently…because he's quirky and he's just (child), but the other mum's they didn't quite understand, they just sort of look at him and say why is he doing that?" – Participant 1

"…you don't know why all the other traditional parenting techniques aren't quite working in the same way that they have for other parents…there's so much self-blame…" – Participant 5

"…I spent a million hours with every teacher who didn't believe me until there'd be some crisis point at school and then they'd be like ah now we know what you're talking about…" – Participant 6

"…it was important for me to, to be able to do that [represent experience/qualifications] as well, otherwise they saw me as just a mum…it's stupid that it should take that level of being an authority, rather than just a mum, but it's worked…" – Participant 4

Each caregiver's experience of moving through the process of diagnosis with the CR was unique. For some this relieved them of the self-blame they were experiencing and feelings of a lack of competence that impeded positive engagement with the CR. They were also able to communicate to significant supporters more easily about both their own and the CRs needs as they found the diagnosis began to validate their own experience and challenges. As Gourley et al. (2013) have found parental stress often accompanies poorly diagnosed behavioural difficulties and that identification of sensory deficits may provide a potential explanation for behavioural problems, increase understanding and highlight additional pathways for treatment and empathy for their child's experience and difficulties rather than being labelled oppositional or non-compliant.

"…the diagnosis gives you that comfort that it's not something you've done as a parent, there is actually a reason" – Participant 1

"…as a parent you have that different emotional connection…and a sense of guilt…wondering what you passed on to them genetically on top of what you might be doing environmentally that might contribute to their behaviours or feelings…" – Participant 5

All caregivers communicated how a diagnosis had given a pathway to research and resources, which was frequently self-led, but increased their understanding of the CR. This had allowed them to develop more understanding and patience of the maladaptive behaviour and see it as a form of communication as opposed to misbehaving, which was an important distinction. Samson et al. (2015) considered the degree to which co-regulatory support from parents was able to moderate the rate of externalising behaviour in children with ASD and found that parents provide important scaffolding to overcome reduced problem-solving abilities. Participants were acutely aware of their role in regulating the extrinsic emotion regulation of the CR. They outlined how internet and social media had become important tools to conduct their own research or to connect with other parents with relatable experiences. With that they also became defensive towards the judgement from others towards themselves, and protective of the CR.

"…I felt more protective of him, and I felt like I had to explain to other people why he was the way he was…you know they think he's just a spoiled kid…having a paddy…" – Participant 1

"…family members are like you're too easy on her…a lot of things involve control…so she's gonna do things that are impulsive and destructive, and I can't punish her, because I'm mostly punishing what she can't control…" – Participant 2

"…it's helped me advocate for her, it's helped me understand, it's helped me to not keep pushing her to be something she's not, it's helped me to have a better relationship with her because I'm experimenting with different techniques and encouraging others around her to use those techniques which are a bit the opposite of what we're raised to believe parenting is…" – Participant 4

"…whatever they're acting out, it's not personal…any behaviour that looks destructive…aggressive…it's coming from something…fear, or a discomfort…" – Participant 5

"…it must be horrible for him, we have anxiety as adults and we don't cope, imagine how he feels? He can't even tell us how he feels…I've just come to accept we do things on (child's) terms because he can't adapt to our world, we adapt to him" – Participant 7

Caregivers also utilised extrinsic strategies involving reappraisal with both the CR and to a lesser extent other significant people. In some situations, the participants were able to use the diagnosis to support the CR to better understand their own needs. They also found it was the foundation for establishing more supportive partnerships with other significant people such as family members and educators.

"…once we had a diagnosis [family] was a lot more understanding about triggers and things that could start *these things off and talking to them about it really helped…they became a lot more patient and a lot more explanatory with him"* – Participant 1

"…I used to be fierce, I had to be fierce…her teacher wouldn't talk to me unless she'd done something naughty…I kept saying to her…what was the antecedent…what led to that…that won't have come out of nowhere…" – Participant 4

"one of the things that's been useful about having a diagnosis…it helps him to understand his sensory things particularly…I always used to explain it that his filter is broken so he can't filter out things like other people do and that's why this bothers him, and you know when you're tired you feel it gets even more wobbly" – Participant 6

Due to developmental delays, participants found that transferring life skills including emotion regulation was not intuitive and took considerably longer. As such normal transitions, such as changing schools were described as being particularly challenging and they needed to prepare for extended periods of dysregulation from the CR as this required a cognitive shift for them to become familiar with, and adjust to new situations, people, and routines. Different forms of extrinsic reappraisal that might be utilised include staging, visual planning or contracting to create the appearance of a situation that was acceptable to the CR.

"…we used to talk about fake bedtime, she [sibling] has to look like she's going to bed as well, the dog has to come too…I have to put my pyjamas on, I have to get into bed with her…" – Participant 4

"…at the beginning of the day I'd run through this whole social visual story…just to give him what was coming up right from the start of the day, this is what is going to happen, and it would mostly work" – Participant 1

"…it's got to be high interest…opting into with choice of like music in the car, knowing what they've got to go back to which would be a favourite movie and something engaging, and then keeping it really short like go in go out" – Participant 3

Some participants were in a position in which they were beginning to support the CR into increased ownership of the emotion regulation strategies they had been implementing for them. This included having them take responsibility for some of the required preparation or trying to model resilience by talking through their own challenges with the CR.

"…I think he picks up on what we do…he has put a lot of effort into making his own routines now so we're teaching him…we've sort of tried to help him pre-empt things that could happen there's still a lot of work to be done but he's learning skills I think…" – Participant 1

"I'm trying to instil in (child) when it comes to being a bit more resilient, I make sure I'm honest about how I'm feeling…trying to model that…not to make them feel stink but it's just to try and give them an example of someone,, actually y'know people struggle with their day and it's hard and you do get anxious but there's ways of um or strategies of coping with it" – Participant 5

Overall participants described an experience in which they had to reconsider the experience of parenting and the role or roles they fulfilled in their child's life. Each participant had to try to make sense of not only their own expectations but reconcile these alongside the parenting expectations from their families and the community, and the caregiver expectations from the healthcare system. The lack of caregiver support was repeatedly mentioned as one of the most difficult aspects of caregiving as many felt there was no part of the care system that saw them or heard them.

"I think ideally as an endpoint is raising the awareness of everybody, parents, other parents, other people in the community of these additional needs…so that people can be a little bit more understanding and not so judgey when you're walking around with your meltdown child…" – Participant 1

"…you know what I probably care more about me…it gives me a sense of actually you don't understand me, or you're not hearing me or what I go through…" – Participant 5

"…I've completely felt like is anyone listening to me? Like does anyone care? Does anyone see the big picture?..." – Participant 7

"…there's kind of no room for me as a mum to be having a hard time because that's judged as I'm having a hard time about my child or who my child is, not around all the other things…there's such a lack of compassion because when I have been vulnerable it's often used against you, well mum's just not coping and that's why the child's like this" – Participant 3

Gourley et al. (2013) highlighted the circular nature of parental stress and maladaptive behaviour of children, which is often poorly diagnosed. Furthermore, they suggested healthcare professionals could work to increase parental understanding of sensory deficits as a pathway to increased understanding of their child. The participants in this study appeared to have a high level of knowledge, understanding and empathy for their children. The issues they highlighted were related in communicating their understanding to others, who they often felt were dismissive of them.

Gourley et al. (2013) make mention that training of mental health professionals will increase and improve with regard to sensory sensitivities.

Response Modulation

Gross (2013) describes response modulation as a group of strategies used much later in the emotion generating process. Response modulation is an attempt to influence experiential, behavioural or physiological components of the response which have already been initiated. This can include suppression, in an effort to inhibit the emotion-expressive behaviour. Participants described how their own resilience to respond to challenging situations and support the CR fluctuated depending on other stressors. However, they were aware of the need for their own support to be able to influence the CR as much as possible when the CR did not have the resources to self-regulate. Furthermore, participants had become very aware of the reciprocity of emotions between themselves and the CR which aligns with the research of both Gourley et al. (2019) and Gulsrud et al. (2010) who found that greater child externalising behaviours were associated with higher levels of maternal stress and the use of more active regulatory strategies, further supporting the dyadic nature of child and maternal behaviours.

> *"…my stress levels were probably higher than (child's) and I think they probably feed off each other" – Participant 1*

> *"…it's like a circle…the more worried I would get the less I could actually cope and support them…it's like putting your oxygen mask on first on the plane…actually putting myself first isn't selfish, I'm actually doing it for them…" – Participant 5*

Despite all the hypervigilance, routines, pre-empting and planning they had implemented, situations would arise for which participants would find themselves unprepared to deal with the CRs response. Fletcher et al. (2019) found that caregivers cited learning to read their child's behaviour and familiarity with community settings as methods to assist regulation. This was also observed by

Gulsrud et al. (2010), who found that mothers emotion regulation strategies included increased use of emotional and motivational scaffolding during distress episodes. This was predominantly as participants found CR adoption of social norms and learning was delayed and not intuitive, however there was no way to predict every situation that may cause difficulty.

> *"…sometimes it's hard to even recognise that it's missing…things that you can't pre-empt…that social etiquette was not quite there but it's like I can't pre-empt that, I don't know what's missing until it happens…" – Participant 1*

> *"… there are a lot of situations I have no control over which is what I struggle with, so I can't control the situation so I kind of have to suck it up and like I know what's gonna happen, I know what's coming and how I can try and deal with that or how I can deescalate this as much as I can" – Participant 2*

> *"…I was able to control all of the variables until he started kindy and yeah, that's when…he had his first kind of violent outburst, he didn't have any up until that time because I did manage everything, my life revolved around him…" – Participant 6*

> *"…he knows them [routines] and it makes him feels safe…[if the routines are disrupted] I know that I need to do a few other things…that I've got things covered, because I know what's gonna happen" – Participant 7*

Participants saying "what's gonna happen" was the dysregulated behaviour, typically described as a meltdown. Both Miller et al. (2018) and Samson et al. (2015) describe tantrums, outbursts, meltdowns, volatility, self-regulation difficulties, and sensory issues as being the most prominent features of behavioural dysregulation reported by families with children who have disabilities, particularly ASD. This could include causing harm to themselves, the caregiver or property which was immensely distressing. Trial and error, or experimentation was described by participants as how they found the most suitable response modulation techniques. The reason for this being they were often experimenting with strategies from their own research, as opposed to being guided with formal interventions provided by healthcare professionals. This was usually due to limited access to formalised support, which they felt was on account of there being nothing physically wrong with their children, therefore the healthcare system was less responsive.

"…we never went out there and looked for help from therapists, I guess we kind of thought we would just barrel on through on our own and try and get through it" – Participant 1

"…I had to do my own research into how I could help her, what things I could change to support her to make her life a little easier which would hopefully in turn make my day-to-day somewhat easier…" – Participant 2

"…when you've got a lot of diagnoses you gotta sift through various supports out there to understand what works and try them…" – Participant 3

"…I was like please, y'know I've done lots of research, but this is what's going on…and they told me about 10% of what I already know with their days and days of research…I was like <u>yeah I knew all this</u> *…that's my nature is to find out absolutely everything and work it out because I'm a problem solver…" – Participant 4*

"heh heh I'm slightly obsessive…it's almost like my kids are my project…I'm researching all sorts of stuff"– Participant 5

When they did have access to formalised support it was often not the help they had hoped for. This was either, as they had done such a considerable amount of research themselves, therefore they were already experimenting with the interventions that were offered. Alternatively, it required they adopt the role of therapist in the home in addition to the other myriad of roles they were already performing.

"…I discovered that (child) likes sensory, likes pressure, or um the pressure or weight…it soothes (child)…when I suggested that to the OT she said I was literally just going to say that…I kind of was grateful…but then I thought, I just actually researched that myself…we didn't get a heck of a lot of extra ideas from her…" – Participant 5

"…you're being the teacher and you're being the therapist for all the other therapies…you don't just go to an appointment…you have to come everyday, and do those things over and over again…" – Participant 2

"…you tend to just lose yourself because it's a constant battle…it's actually taken me until now to find someone who can actually tell me some of the strategies to use…so that means I'm still <u>doing it</u>*…it still requires more work from me…"* – Participant 3

Just as the caregivers utilised masking when they were in public, several of the participants described CRs developing an ability to use masking or emotion suppression as they got older. This gave way to a delayed reaction until they were in a setting where the CR felt more comfortable to release the withheld emotion, usually when they were reunited with the participant. This could be incredibly difficult and stressful for the participant to manage at home, as often they were not fully cognisant of the antecedent to this. Furthermore, there would be little understanding from significant others of how challenging a situation may have been for the CR due to the delayed reaction.

"…he could very easily just meltdown and not care what anybody else thought…now he's a lot more aware…he can hold it in until he gets home and has a meltdown…" – Participant 1

"…I wear the brunt of it…with the whole masking thing and holding it together and then we get home and it's like you're my safe person blurgh here it is…" – Participant 2

"…he masks really well, and people don't believe me…so I'm careful about who I talk to…because they just think I'm making it up…" – Participant 6

This could be seen as a form of emotion-expressive suppression. Several caregivers felt they had needed to reconsider who they could feel safe with in developing social/support networks as they had to choose when they felt like they could explain their situation to people, and when they felt this could not improve their situation, choosing to ignore the reaction from bystanders.

"…it does change you as a person, I didn't feel like I fit in…but you kind of harden up towards the views of other people…" – Participant 1

"…I internalised and felt everything he was going through…I've had to say to myself this isn't happening to me…it probably sounds selfish, but it was the only way I could deal with it…" – Participant 5

"…we just do what we have to do to survive, y'know, like I'm not trying to be a good parent I'm just trying to survive…I sort of already feel I'm doing everything that I can…" – Participant 6

"…caregivers are just so exhausted, or they get so bullied…the challenge to get the support is so, like it's often emotionally damaging, relationally damaging…" – Participant 3

"there are times where I've hidden in my car and cried…I've had to take myself out of the equation…I need to try and not explode myself because if I explode myself, I'm only heightening the situation and making it worse, and trying to be the calm in her storm is not always the easiest" – Participant 2

The participants highlighted essential differences between parenting and caregiving. They felt this distinction was not well understood by family, educators, healthcare professionals and the community. Furthermore, that the inherent nature of living with disability as a caregiver is also not well understood, and therefore not well supported. Although the circular nature of parental stress and emotional regulation in children has been well established in research, parent caregivers are subject to significantly more stressors, therefore this relationship is especially vulnerable to maladaptive emotional and behavioural responses. As Gourley et al (2013) have found the high stress levels reported by parents is a cause for concern and illuminates the importance of better detection and treatment of children's sensory processing difficulties as research illustrates the reciprocal and mutually amplifying nature of children's behaviour problems and parental stress.

Discussion

This study aimed to consider the extent to which caregivers feel that sensory modulation interacts with emotion regulation. The participants were all parent caregivers and 6 of the 7 participants disclosed the CR had a diagnosis of ASD, of which sensory symptoms have been reified in the *DSM-5* (American Psychiatric Association, 2013). The Process Model of Emotion Regulation (PMoER) (Gross, 2013) was used to understand the phenomenology of responding to maladaptive emotional and behavioural symptoms. The participants in this study were innately attuned to the effects of sensory stimuli on the CRs emotional and behavioural responses. This aligns with the findings of Walbam (2022) in which caregivers independently identified sensory sensitivity even before the CR had received a diagnosis. Similarly, the participants utilised some degree of accommodation for sensory reactivity at each point available for emotion regulation according to the PMoER (Gross, 2013).

This study suggests that caregivers rely primarily on the first point of the model which is *situation selection*, in making decisions surrounding situations to select or avoid. Sensory stimuli in the home environment were found to be more regular, predictable and had often been adapted to accommodate the CRs needs, as such there were fewer instances of dysregulation. Emotion co-regulation was required to be able to manage situations outside of a home environment in which care-recipients frequently became overstimulated which requires that participants have the energy to be able to appropriately engage. Further to this, the participants felt more comfortable co-regulating the CRs emotion in the home environment due to the level of perceived negative judgement from within the community. The participants were hypervigilant to potential provocation and attempted to manage this before the CR became affected. The result of this overstimulation was emotional and behavioural responses often depicted as temper tantrums or a meltdown which as Critz et al. (2015) and Samson et al. (2015) describe are often exaggerated because of the child's inability to regulate. Sensory stimuli including lighting, spatial deprivation in crowds, and unpredictable noises contribute to an increase in anxiety resulting in socially inappropriate or maladaptive responses. This is concurrent with research in which individuals with sensory sensitivities can become overwhelmed, reducing their ability to engage in emotion regulation and have increased problematic externalising behaviour (Brindle et al., 2015; Fletcher et al., 2019; Gourley et al., 2015; Green and Ben-Sasson, 2010; South & Rodgers, 2017).

The participants were instrumentalised in emotion regulation for the CR at each point of the PMoER (Gross, 2013). They expended physical, mental, and emotional energy through the use of routines, pre-empting, planning, prompting and hypervigilance for extrinsic emotion regulation in the CR. In doing so they modified both the physical and internal environments. This scaffolding minimised the demands of a given situation with ADLs often completed in concert, with the caregiver providing guidance and comfort. These compensatory strategies bridged the developmental delay in the care-recipients acquiring their own independence. This created consistency, reduced the need for tolerance of irregularity and mediated social interactions. This is repeatedly referenced in sensory related research including that of Critz et al. (2015) who found that an individual's ability to integrate and modulate sensory input can have a profound effect on their comfort in the world as they tend to respond inappropriately which may affect their ability to adapt to daily situations, regulate attention and mood, and function in a broad array of social interactions and learning. Due to the incessant demands of caregiving beyond typical parenting, participants felt their own exhaustion often impeded their ability to co-regulate. This was exacerbated by the CRs difficulties with sleep hygiene, and they frequently modified the situation with their physical presence through co-sleeping arrangements. This again affected their ability to attend to their own well-being as they were ceaselessly responding to the needs of the CR. The closeness of the care relationship meant that it was difficult for another person to assume their caregiving role, even temporarily, as their intimate knowledge of the CR was difficult to share or replicate, as was their steadying influence in daily routines. This directly contributed to increasing social isolation and the loss of support networks and respite opportunities for themselves and the care-recipient. These have been specifically identified as situations that need to be addressed for caregiver well-being within the Mahi Aroha strategy (Ministry of Social Development, 2019).

The participants described having received little formal support specifically for the management of challenging behaviour. Beyond diagnosis they found themselves conducting their own research by way of the internet and using a process of experimentation. They had an intimate perspective of the sensory challenges experienced by the CR due to their proximity to their environment. A significant stressor was the difficulty the CR had in communicating their own needs. The behaviour came to be seen as a manifestation of the CRs discomfort and was therefore seen as a form of communication in the place of verbal communication. Due to their innate level of understanding they were frequently asked to support significant others such as family members, educators, and healthcare professionals with relationship management. Once again, the demands placed on the participant to support the CR holistically accumulate, meaning they were afforded little time for their own needs. Walbam (2022) found that sensory processing deficits are associated with caregiver stress and caregiver stress has been associated with reduced responsivity. Walbam suggests to manage stress and improve relationships with their children, caregivers can learn to anticipate environmental and social factors that might impact interactions and make accommodations that are reflective of children's sensory needs. This sample would suggest that caregivers devote an appreciable amount of their time and energy to doing just this.

This study increases awareness and understanding of the multiplicity of roles that parent caregivers must fulfil on a daily basis. It thereby draws attention to and illuminates the level of support that may be required to achieve the potential of dedifferentiation as outlined by Clegg

(2020). The importance of the overall well-being of both individuals within a care dyad must be considered to sustain long-term caregiving arrangements.

Implications

Socially and governmentally, there is a priority to move towards greater dedifferentiation of disability (Clegg, 2020; Ministry of Social Development, 2019; Welfare Expert Advisory Group, 2019). The most recent iteration of Mahi Aroha (Social Development, 2019) specifically identifies the need to overcome social isolation and reduced opportunities for respite. Addressing the difficulties faced within care dyads relating to emotion regulation and sensory reactivity is potentially an avenue that needs to be considered in achieving these objectives. Fletcher et al. (2019) noted that environmental supports involving sensory needs can improve with public awareness, governmental support, and cultural shifts. With this it may be possible that caregivers of children with participation challenges will experience greater quality of life with less isolation, diminished stress, and reduced anxiety (Fletcher et al., 2019).

Each individual within the care dyad is affected by differing stressors which combined impact on emotion regulation. The CR may have a reduced ability to filter sensory stimuli and become overwhelmed, manifesting in maladaptive emotional and behavioural symptoms. The caregiver plays a key role in modulating the external and internal sensory environment by way of their intimate understanding of the CR. Modulation refers to the ability to adjust responses to sensory stimuli, which results in behaviours that are appropriate to those stimuli (Walbam, 2022). Sanders & Mazzucchelli (2013) are emphatic about parental ability to self-regulate which they see as a fundamental process for positive developmental and health outcomes in children. However, this does not take into account the demanding expenditure of physical, mental, and emotional energy in addition to the numerous roles parent caregivers must fulfil, which can lead to exhaustion and reduced capacity for both self and co-regulation. Gérain & Zech (2019) support this in that emotional competencies have been found to play a role in preventing burnout and identified as a promising target of intervention to reduce informal caregiver's psychological distress.

Despite the abundance of research into conceptualising and assessing sensory reactivity, this study suggests there is a paucity of interventions that are available to individuals with these challenges and their caregivers. This could potentially be due to limited access to healthcare professionals who can provide this support or because interventions have limited utility. Gourley et al. (2013) suggest that healthcare professionals need to be trained to identify and address sensory problems as they may be underlying behavioural difficulties. However Green and Ben-Sasson (2010) suggest there are differing disciplinary approaches to this situation with occupational therapists more likely to recommend a sensory-based intervention whereas psychologists were more likely to recommend family therapy. Interdisciplinary research may be essential to reconcile the link between sensory challenges and emotion dysregulation.

Limitations

Qualitative research has the ability to capture rich and detailed information. However, the interviews conducted for this study capture a moment in time in a dynamic experience and is potentially biased by the underlying affective state of the participant when they were being interviewed. Not all the participants were asked to provide feedback on their interview transcript which could potentially increase the credibility of the research through member validation (Shenton, 2004; Tracy, 2010).

Awareness of sensory sensitivity across a range of conditions within disability and mental health is increasing and for this reason the formal diagnosis of the care-recipient was included in the PSQ to provide a more thorough understanding of participant characteristics. Aside from one participant who did not disclose the care-recipients diagnosis to protect their privacy, all the participants provided care to a care-recipient with a diagnosis of ASD. It is possible that with sensory criteria being reified in the diagnostic criteria of ASD (American Psychiatric Association, 2013), these participants have a greater awareness of sensory symptoms than caregivers of other conditions. The transferability of this study to caregivers of other conditions could therefore be somewhat limited. Purposive sampling of caregivers attending to care-recipients with varying diagnoses may allow for greater confirmation of the relationship between sensory reactivity and emotion regulation and increase the transferability of the findings.

Although this was a convenience sample all the participants were women and the parent of the care-recipient. It is uncertain as to whether this follows caregiving trends in which women are twice as likely to assume a caregiving role than men (Heyes & Grimmond, 2022; Welfare Expert Advisory Group, 2019). Increased contextualisation of caregiving could be sought by including the perspectives of other family members where available.

As has been suggested the notion of caregiving does not always translate due to cultural expectations of supporting family members (Funk et al., 2013; Goodhead & McDonald, 2007; Heyes & Grimmond, 2022; Synergia, 2022). This study drew on the experiences of a small predominantly NZ European/Pākeha sample with limited ethnic diversity, which is not entirely representative of the population of Aotearoa New Zealand. It is important to understand how to include the perspectives of family and informal caregivers of varying cultural backgrounds.

Future Research

This study supports the notion of a convergence between sensory sensitivities and emotion regulation. Although there has been an abundance of research into sensory integration since Ayres described sensory processing (Dunn, 2001; Kilroy et al., 2019; Lane 2019; Watling & Hauer, 2015) there remains confusion as to how the disorders are conceptualised, along with best practice approaches to intervention. Additionally, as Rodriguez and Kross (2023) outline, the most frequently cited review papers on emotion regulation over the past 6 years have not considered sensation as a tool for emotion regulation. Research such as Brindle et al. (2015), Green and Ben-Sasson (2010) and South and Rodgers (2017) have elucidated the relationship between sensation and affectivity. This may be integral in developing interventions to manage emotional and behavioural symptoms.

The participants in this study highlighted many differences between parenting and caregiving. This distinction is important for healthcare professionals to consider when supporting families who have children with disabilities. It is possible that parent caregivers are a subgroup of caregivers, distinct from parents and or informal caregivers. Future research could consider differentiating between parents and parent caregivers, as this may have significant implications when healthcare professionals instrumentalise them in the delivery of interventions. Parent caregivers may be especially vulnerable to burnout due to the interminable demands and reduced opportunities for respite. Mikolajczak and Roskam (2020) have suggested that parental mental health is now considered as an important variable, and not only because of its relevance to child development.

Finally, the scope of sensation is vast and as such there are numerous possibilities for sensory interventions to contribute to emotion regulation. This scope should be explored with regard to the most relevant sensory interventions to best support individuals with regulation challenges. To date there appears to be few intervention studies aside from those which consider weighted blankets (Ekholm et al., 2020; Gee et al., 2016). However, these have limited utility in supporting individuals to manage situations such as social isolation as a result of overstimulation in community settings.

Conclusion

This study found that even with limited formalised support family caregivers are acutely aware of the effects of sensory stimuli in contributing to maladaptive emotional and behavioural responses. The caregivers in this sample were attuned to the sensitivities of the care-recipient and highly responsive to the challenges that sensory demands present. As such, they develop an intuitive understanding of their needs, and are connected mentally, physically, and emotionally, to the care-recipient. Caregivers are regularly conducting their own research and experimental approach to strategies for emotional regulation to minimise distress, which are frequently embedded in sensory modulation. It is somewhat of a paradox that the caregivers prioritised the care-recipients needs over their own. Caregivers are affected by the emotional discomfort of the care-recipient which can manifest in maladaptive and disruptive behaviour. They are therefore instrumentalised in the sensory modulation as they benefit from improved emotional regulation in the care-recipient. However, this requires the sacrifice of their own needs due to their stabilising influence. The Process Model of Emotion Regulation (Gross, 2013) presents five points at which emotion can be regulated. Due to the intensity of the demands within the care dyad, caregivers described frequently experiencing exhaustion. For this reason, they often relied on the first point of emotion regulation, situation selection, contributing to social isolation. The home environment was described as being predictable and highly routinised, thereby reducing the number of emotionally provocative variables they were required to attend to. The caregiver then is precluded from opportunities to develop support networks and have respite, and the care-recipient from opportunities to participate in socionormative developmental activities.

This study supports research that has found maladaptive emotional and behavioural responses are among the more difficult symptoms for caregivers to manage (Anderson et al., 2019; Yueh-Feng Lu & Guerriero Austrom, 2005), and are frequently caused by disordered reactivity to sensory stimuli, placing stress on the care dyad. The participants in this study highlighted differences between parenting and parents who are also caregivers. This is an important distinction, not only for applying research findings relating to parents, but also in identifying the value provided by informal and family caregivers within the delivery of healthcare.

This study adds to the research that finds family caregivers frequently experience a decline in their own well-being. As Gérain and Zech (2018), Hutchison et al. (2016) and Lu and Wykle (2007) suggest, this is not due to having a child with a disability in itself, but rather the interminable demands around that experience. This can place a significant tension on relationships with healthcare professionals, educators and within communities. Future research could consider the perspective of these significant others and how to facilitate, support and improve these relationships. Research on sensory sensitivity and the impact on emotional and behavioural regulation has been undertaken within a variety of different disciplines. Interdisciplinary research could improve the understanding and conceptualisation of this disorder as well as best practice approaches to assessment and intervention.

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Appendix A

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

ARE YOU AN INFORMAL OR FAMILY/WHĀNAU CAREGIVER?

Would you like to talk about your experience?

The number of family/whānau caregivers in Aotearoa New Zealand is increasing. It is important to hear from caregivers about how it effects their own well-being, how they manage stress, and where they get support.

If you would like to know more about this research project, please scan the QR code or email Angela for an information sheet.

ELIGIBILITY CRITERIA

- Over 18 years of age
- Do not receive payment for caregiving
- Live with the care recipient
- Provide care on a daily basis

You will receive a $40 grocery voucher for participating.

SCAN THE CODE OR CLICK ON THE LINK FOR MORE INFORMATION

Researcher: Angela Thompson
Angela.Thompson4@uni.massey.ac.nz

Supervisor: Dr Richard Fletcher
R.B.Fletcher@massey.ac.nz

This project has been evaluated by peer review and judged to be low risk. If you have any concerns, please contact:

Prof. Craig Johnson, Director Research
Ethics.humanethics@massey.ac.nz

Appendix B

MASSEY UNIVERSITY
TE KUNENGA KI PUREHUROA
UNIVERSITY OF NEW ZEALAND

PARTICIPANT INFORMATION FORM

Carer perceptions of sensory management as a health-promoting strategy to reduce stress in the provision of care.

What is the purpose of the project?

My name is Angela Thompson, I am a postgraduate student at Massey University supervised by Dr Richard Fletcher, Associate Professor – School of Psychology. This research study is being undertaken in partial fulfilment of the requirements for the degree of Master of Science. My project aims to explore how informal carers perceive sensory stimuli as something that may contribute to stress in the provision of care but can be managed to improve their experience of caregiving. As informal carers have insights of caregiving that health professionals may not, it is important that their experience is better understood.

Do I have to take part?

Approximately 6-10 informal/family/whānau caregivers are being sought to voluntarily share their experience. The following eligibility criteria applies:

- Are over 18 years of age
- Do not receive payment for caregiving
- Live with the care recipient
- Provide care on a daily basis

What will happen to me if I take part?

This research study involves a pre-screening questionnaire (approximately 2 minutes) followed by participation in an interview (approximately 45-60 minutes). The interview will be arranged at a time and location that is convenient for the participant. Following the interview participants may request to review their interview transcript and a copy of the research project when it has been completed. Participants are compensated for their time with a $40 grocery voucher.

What are the possible disadvantages and risks of taking part?

This research has been assessed as low risk. However, participants can stop the interview, or withdraw at any time, and will be encouraged to contact services who can provide support. If during the interview you disclose any information which indicates that either yourself or someone you know is at risk of harm, I will be required to inform my supervisor and I will inform you accordingly. If during the course of participating in this study you feel that you need to talk to someone for more support, the following service may be helpful:

1737 – Need to Talk? https://1737.org.nz

Will my taking part in this project be kept confidential?

The interview will be audio-recorded and then transcribed. The audio-recordings will be stored on an external digital storage device by Massey University for a period of five years in accordance with university requirements. During transcription all names and identifying details will be anonymised. Participants can withdraw their interview data until 1/7/23.

What happens immediately after the interview?

Following the interview there will be time to debrief and ask any questions the participant may have relating to the research project.

Who has reviewed the project?

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns please contact Professor Craig Johnson, Director Research Ethics. humanethics@massey.ac.nz

Contact for further information on the project?

Further information about this research can be requested from myself as the principal researcher Angela Thompson Angela.Thompson.4@uni.massey.ac.nz or my supervisor Dr Richard Fletcher R.B.Fletcher@massey.ac.nz

To proceed to the pre-screening questionnaire please scan the QR code or click on the link:

https://forms.office.com/r/MnumeCkMwf

Or email Angela.Thompson.4@uni.massey.ac.nz

Appendix C

1. Age:
   18-25 / 26-35 / 35-45 / 46-55 / 56-65 / 66+ / Prefer Not to Say

2. Gender:
   Male / Female

3. Ethnicity:
   Māori / NZ European – Pākeha / Pacifica / Indian / Chinese / Other / Prefer Not to Say

4. During the last 12 months have you provided care to someone with a long-term illness or disability?
   Yes / No

5. Do you receive payment for providing care?
   Yes / No

6. Does the recipient have a diagnosis?
   Yes / No

7. Please state the diagnosis:

8. Do you live with the care recipient?
   Yes / No

9. Is the person you care for:
   Son or Daughter / Mother or Father / Spouse or Partner / Grandchild / Other whānau member or friend

10. Please state the age of the care recipient:

11. How often on average do you provide care?
    Everyday / Several times per week / Once a week / Less Often

12. Please provide an email contact to arrange an interview:

Appendix D

MASSEY UNIVERSITY
TE KUNENGA KI PUREHUROA
UNIVERSITY OF NEW ZEALAND

PARTICIPANT CONSENT FORM

Carer perceptions of sensory management as a health-promoting strategy to reduce stress in the provision of care.

Principal Researcher: Angela Thompson

I have read, or had read to me, and understand the Participant Information Sheet. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from participating in the study at any time. I understand that if I do not consent to my interview content being used, I have one month from the date of recording to redact the data. I understand that consent includes agreeing to have my anonymised data used in the researcher's project.

	Initial Showing Consent
I confirm that I have read and understood the Information Sheet for this project and had the opportunity to ask questions.	
I understand that my participation is voluntary and that I can withdraw from the interview at any time during the interview without giving a reason.	
I understand that I am free to withdraw my data without any reason until 1/7/23	
I understand that the interview will be recorded, and the audio file will be securely stored and only listed to by the researcher signed below and their supervisor.	
I understand that my responses will be anonymised in the interview transcript and will be seen the research supervisor/markers/examiners of this thesis project.	
I understand that all personal data about me will be kept confidential.	

I agree to take part in the above research project.	

I, ____________________________ (**Participant’s** full name) hereby volunteer to participate in the above-named study.

Signed ________________________ **Date ________________________**

(Participant)

I, ____________________________ (**Researcher’s** full name) certify that the details of this research project have been fully explained and described in writing to the person named above.

Signed ________________________ **Date ________________________**

(Researcher)

Appendix E

Focus Area	**Questions/Prompts**
Warm Up Questions/ Participant Introduction	1. Could you tell me a little about who you care for and describe your relationship with them? a. How long have you been a caregiver? b. How long do you expect to be a caregiver? 2. How do you feel about being a caregiver? a. Positive/negative/both b. Life enhancing/challenging 3. Could you describe a typical day of caregiving? a. Time spent attending (*to care-recipient*)? b. Time spent planning/negotiating/doing? 4. How much time do you get for yourself?
Increasing Awareness	5. Do you think there is a difference between being a parent and being a caregiver? 6. How do you think other people see your role as a caregiver and your relationship with (*the care-recipient*)? 7. How connected do you feel to your community? a. Are you aware of the low sensory hours in public spaces like the supermarket? b. Do you use them? c. Are they helpful? 8. Do you get much formal support from therapists? 9. Do you do much research into things that might help either yourself or (*the care-recipient*)? a. Where do you get your information from? b. Do you discuss it with your support network/care recipient? 10. Have you made any changes to the way you negotiate with (*the care-recipient*) for their care needs?
Reducing Stress	11. What kind of support network do you have? 12. What part of caregiving would you say is the most difficult? a. Is there anything you try to avoid? 13. Do you have any routines to make things easier? a. Do you argue about things?

	b. Is there anything you do to reduce arguments? c. Is there anything that particularly upsets (*the care-recipient*)?
Increasing Competence	14. How much time do you spend at home compared to going out? a. Can they go out without you? b. Is there anything you need to do to prepare for going out? 15. Have you tried anything caregiving related from your own research with success? a. Does this give you more confidence? b. Does it make you feel more positive about caregiving? c. Does it improve your relationship with (*the care-recipient*)? 16. Do you share any strategies and routines with other people who spend time with (*the care-recipient*)? a. Respite caregivers b. Other family members c. Teachers d. Therapists 17. Are you trying to help (*the care-recipient*) to develop independence? a. Do they have more self-awareness? b. Are they developing more independence?
Future Directions	18. Do you think there is more awareness in the general public for caregivers and people who need care? a. Are there any changes that you would like to see? b. Is there anything that you would like other people to know? 19. Are there any changes you would like to see for caregivers? 20. Is there anything that you think people who are knew to caregiving should know? 21. Is there anything we haven't talked about that you would like to mention?