Experiences of Pasifika mothers caring for a child with Autism Spectrum Disorder

in New Zealand

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements) nor material which to a substantial extent has been submitted for the award of any degree or diploma of a university or other institution of higher learning.

Signed _____ Date_____

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ABSTRACT

This research explores the experiences of Pasifika mothers' caring for a child with an autism spectrum disorder. Even though caregiving is a well-researched area that focuses on the pressures and challenges that are imposed on caregivers and the resources accessible to help caregivers meet those needs. Pasifika caregiver experience is an area that is not quite looked upon. There are several emotional, cognitive, intervention and coping mechanisms such as daily planning, emotional neutrality, and receiving informational and social support, which are used to alleviate burdens.

Despite being useful, several of these therapeutic models are based on studies regarding maternal populations. The New Zealand's Autism Spectrum Disorder Guidelines (2008), and the latest New Zealand Carers Strategy Action Plan 2019-2023, make it suitable to perform qualitative research to procure an even more in-depth and thorough understanding of Pasifika mothers' experiences of providing care in New Zealand. Five Pasifika mothers were invited to participate with the help of two Pasifika support groups.

Data were collected via zoom semi-structured interviews, and an interpretive phenomenological analysis was used to recognise and pick out three superordinate themes: support, coping mechanisms and emotional aspects of caregiving. The superordinate themes included eight emergent themes: 1) Experiences of support, 2) Support for Pasifika mothers, 3) Information searching, 4) Daily routine and planning, 5) Comparisons with neuro-typical parenting, 6) Normalising ASD in Pacific cultures, 7) Emotional burden and 8) Positive emotions. The findings support prior studies and demonstrate the concerns regarding the inadequate supply of information and its understanding. The findings also suggest that the current organisational initiatives and guidelines are relevant and can be applied to the Pasifika population of mothers' caring for an autistic child.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that emerges during the initial stages of childhood, affecting social communication and psychological functioning (Lord et al. 2018). Autism is characterized by a spectrum with differences in severity and symptom type (American Psychiatric Association, 2013). ASD children put additional stress on families, which can be due to the severity of symptoms, the shock of diagnosis, and also the extent of the disorder and the child's absence of adherence to cultural norms. These reasons establish difficulties in providing strong support for families caring for a child with autism, along with explaining the reasons why parents are at significant risks of experiencing parental stress and depression compared to parents who have a child without autism spectrum disorders (Padden & James, 2017). Parents with autistic children carry the weight of care that has been put in place as their role as parents. Even though parental stress has been fundamentally attributed to the child's difficult behaviours, few studies have concentrated on additional factors that influence parental stress or decision-making when caring for a child with ASD (Bonis, 2016).

Parental stress starts as parents struggle to grapple with their child's difficulty in behaviours along with their communication issues. Parents who have high levels of education and are from a higher socioeconomic background can detect the aberrant development patterns in their children and can seek professional help (Harstad et al. 2013). However, numerous parents spend years moving from one healthcare provider to another seeking to discover solutions or answers relating to their child's development and strange repetitive patterns of behaviour (Altiere & Von Kluge, 2009). However, Stuart & McGew (2009) opines that parental responses towards their child being diagnosed with ASD differ concerning the child's symptoms and severity which includes parental feelings of uncertainty, doubt and contradiction. Lutz et al. (2012) mention that many dwell on, or panic regarding their parenting styles and wonder if they are not doing enough or not putting in the work to help their child. This is where corresponding blame and distress relating to not being able to "mend" the problem guides parents to feel like a failure as various features of parents' lives change, including their relationships with friends, close families, dream goals, aspirations for the future and day to day routines (Altiere & Von Kluge, 2009).

There have been various studies investigating the experiences with parental distress, burden and vulnerability, indicating that mothers are progressively taking on the role of caring for their children with ASD, along with additional life stressors and the depletion of external and internal coping resources impacting mothers' quality of life (Bohadana et al. 2020). Caring for a child with ASD can place heavy demands on families and when these demands are challenging, can result in psychological and financial implications. This project aims to explore

the experiences of Pasifika mothers' who care for children with ASD in New Zealand. There is limited research addressing the experiences of Pasifika mothers' caring for a child with ASD in New Zealand. Areas for exploration include the challenges (positive & negative) experienced in their role as a parent, attitudes, perceptions, accessible support services and well-being. It is expected that when investigating these specific areas greater insight and awareness of the experience and the nature of this group of Pasifika parents will be attained. The aims are suitable and appropriate in a context of research where mothers' experiences have been primarily outlined, along with the establishment of appropriate effective interventions of both community and clinical acceptance are supported and confirmed as better practice. In addition, the New Zealand Autism Spectrum Guideline is an evidence-based document translating information about ASD in many Pasifika languages (Tongan, Samoan, Cook Island and Māori), however, Pasifika mothers may find the length of this evidence-based document suitable and appropriate.

Given the research's purpose of the lived experiences of Pasifika participants, an appropriate qualitative methodology was appointed. The qualitative methodology is the most suitable approach to attaining a thorough interpretation and understanding of Pasifika mothers' experiences of care within the New Zealand context. Specifically, the research project selected an interpretative phenomenological analysis (IPA), an approach that is based on lived experiences (Phenomenological paradigm) and interpretive epistemology (Alase, 2017). Even though it is expected of the participant to carry broad knowledge and understanding, the researcher and the participants' roles in this research are collected during the data collection process.

This introduction has outlined the purpose of the study, its involvement, and a brief introduction to the methodology. A literature review follows, presenting a thorough background summary on ASD, and research on caregiving highlighting the challenges (positives & negatives) of caregiving and coping with stressors. The following sections will offer a comprehensive account of the methodological approach of interpretive phenomenological analysis, methods of data collection, alongside ethical concerns. The section of the findings will provide demographic participant data and will describe each of the themes thoroughly in the context of the literature and within the New Zealand Pasifika caregiving field. Limitations and recommendations for future researchers will conclude the dissertation.

<div align="center">**Literature Review**</div>

This chapter will evaluate and critically evaluate the literature informing this study, whereby ASD is defined alongside its prevalence, resolution and diagnoses, before exploring caregiving research. Definitions of primary caregivers are discussed relating to the challenges (positive & negatives) of caregiving, coping with stressors are also considered as a contribution to the distress of mothers', the impact of culture on autism is discussed, and literature is critiqued. These challenges are examples that are related to the New Zealand caregiving context. Limitations and gaps in literature will be exposed throughout the chapter, which ends with an incentive for the present study.

Autism Spectrum Disorders

Defining Autism Spectrum Disorders

Autism is a set of neurodevelopmental conditions which commonly emerge throughout the initial stages of childhood, affecting social communication and psychological functioning (Lord et al. 2018). Autism is most commonly diagnosed or begins to develop, in infancy. Studies have shown that autism is commonly 4-5 times more prevalent in males compared to females, and is characterised by a spectrum of conditions with differences in severity and symptom presentation (American Psychiatric Association, 2013), and levels of impairment across main symptom groups (Lai et al. 2014). According to Lai et al. (2014), up to 70% of individuals who are diagnosed with autism undergo simultaneous medical, developmental, or psychological conditions including attention deficit hyperactivity disorder (ADHD), organizational language disorders, and cognitive impairments (American Psychiatric Association, 2013).

ASD is a persistent and lifelong incurable condition, although there are negative influences on performances that can be restricted or limited with treatment and therapy such as applied behavioural analysis. There are no specific causes of ASD, however, the American Psychiatric Association (2013) mentions various non-specific risk factors such as low birth weight and advanced parental age that may contribute to the risk of ASD. Genetic and physiological aspects also play a part, with a heritability coefficient of 37% to 90%, and 15% of cases of ASD have emerged to be connected with a well-known or familiar genetic mutation relating to the disorder in families (American Psychiatric Association, 2013).

Prevalence of ASD

Worldwide estimates have recommended that the prevalence of ASD is increasing due to better identification and definitions of ASD, widening the spectrum of neurological conditions, for example, Asperger's disorder and pervasive developmental disorder (Bowden et al. 2020).

These changes have been introduced in the DSM-5 incorporating the previously stated disorders under the umbrella term ASD.

Researchers exploring the experiences of ASD have not accurately evaluated the prevalence of ASD in New Zealand, nor the ages of diagnosis (Eggleston et al. 2019; Thabrew & Eggleston, 2018). The Ministry of Health still uses the NZ, ASD prevalence numbers which are related to older research from the United Kingdom conducted in 2006, which suggests that ASD affects 1% of the New Zealand population (Ministry of Health and Education, 2016), but have notified that these numbers must be considered inaccurate and are more likely to change. Since ASD awareness is increasing there is an increasing amount of adults who receive diagnoses - not indicative of a late-onset - but a relatively late diagnosis (Ministry of Health and Education, 2008). However, the Ministries of Health & Education (2008) have acknowledged that research is needed to create and build baseline prevalence rates, particularly for Pasifika populations. However, low rates of ASD in Pasifika children are considered compatible with previous New Zealand studies (Eggleston et. al (2019); Simpson et al. 2018), but there is doubt that the prevalence rates are likely to reflect the true ethnic differences (Elasbbagh & Colleagues, 2012).

Resolution and diagnosis of autism

The procedure of coming to terms with a child who is diagnosed with autism, along with dealing with acceptance and the resolution of feelings while showing respect, can be an unsettling and intimidating challenge or experience for most parents. This indicates that having resolution and acceptance about the diagnoses happens when the parents' central representation of their child, and their self as a parent before receiving the diagnosis of their child, are worked through and incorporated with a post-diagnostic central representation of the child and self (Milshtein et al. 2009). The idea of coming to accept the diagnosis was suggested by Pianta & Marvin (1996) to be like the idea of "reorganization", which was proposed by Bowlby's (1980) theory of attachment. The challenges parents face can lead to negative experiences, where negative emotions are experienced and are affected by environmental and diagnostic factors which include limited social support and severity of symptoms.

Pianta & Marvin (1996) conducted an open-ended interview to explore parents' place of mind relating to their child's diagnosis, which they called the "Reaction to Diagnosis Interview" (RDI). In this interview, parents were asked to remember or think of experiences and events connected to the time they received their child's diagnosis and the emotions they felt, and how these emotions have changed. However, Taylor & Warren (2011) established a model which acknowledges the "how what and when" of sharing a diagnosis of autism with mothers. In their retrospective study, the week following diagnosis, over three-quarters of mothers reported having depressive symptoms, and 37.3% of mothers continued to report outstanding stages of

depressive symptoms during follow up (Tayler & Warren, 2011). A limitation of this study is since depressive symptoms regarding mothers have been rapidly linked to when their child had first received their diagnosis, others were related to financial barriers during follow up along with limited information on depression relating to the ethnic-cultural background.

Following the diagnosis, parents face the difficult task of prioritizing their child's current and future realities above images of a "dream child" created before diagnosis (Lutz et al. 2012). Pianta et al. (1996) describe this as the phase of resolution to diagnosis and parents changing after receiving their child's diagnosis, arguing that if the resolution is not attained or achieved then attachment difficulties ensue. Both studies have explored mothers' experiences, however, the resolution to diagnosis can also be looked at through the negative and positive experiences of primary caregivers.

Primary Caregivers

Positives & Negative of Caregiving

The term primary caregiver is used to refer to mothers, fathers and grandparents who are primarily guardians and take care of children with autism daily and are their main source of support and nurture (Corman, 2009). Regarding past events, primary caregivers of autistic children, particularly mothers, were considered accountable and in charge of the emotional and unusual social behaviours related to their children, including the lack of interchange and attachment regarding social associations (Burkhardt, 2001). These reasons indicate that most caregiving research has focused only on the negative side of the caregiving experience, which may be bound to pathological models of stress. For example, Pearlin et al.'s (1981) framework of the process of stress mainly focused on the stressors (antecedents to stress) associated with caregiving, paying particular attention to the establishment of relationships, and changing the environment of these relationships over a grace period, which in the end leads to stress. However, a drive to document the more positive side of the caregiving spectrum was needed in exploring the experiences of mothers of children with an autism spectrum disorder. (Corman, 2009), even though mothers have largely portrayed their experience as stressful there were often expressions around the joys of caregiving.

Caregiving research had recently evaluated the gratification and the vital role of positive experiences relating to the experience of caregiving. For example, Schwartz (2003) defined caregiver gratification as "accomplishing parental duties, gaining a better understanding of what's more important in life, learning about personal qualities and becoming more aware of personal restrictions" (p.580). Schwartz's studies included 167 primary carers of people with cognitive, physiological or mental disabilities in the study. Schwartz discovered that carers who were young were unemployed and had poor mental health issues which were less likely to feel

fulfilled as a caregiver. Finally subjective (felt stress) versus objective (amount of care required) burden of care was linked to reduced caregiving gratification (Schwartz, 2003).

Research in the field of ASD has only offered a few insights into the most joyful and pleasant aspects of caregiving. Fleischmann (2004) researched narratives that were published on the internet by parents and found that, while there were challenging aspects of caregiving, most websites focused on the positive nature of children with autism along with its caregiving experience. Fleischmann's study has been well supported by other researchers who have made contributions relating to people with disabilities and how their families benefit from happiness, achievement, understanding, and strengthening family ties.

Corman (2009) documented the overall positive caregiving experiences of mothers who care for a child with ASD, where transformation was a part of growing, and their positive learning experiences are a result of their caregiving experience as a mother, like all mothers, in the end, have accepted and acknowledged their child's diagnosis concerning several factors. These include difficulty in dealing with the increase in their child's problem behaviour over time, the absence of support systems, being able to reduce and relieve stress, and the importance of coping with the pressure and requirement of caregiving. As a result, parents did not just report the positive side of caregiving, they outlined how the positive aspects were associated with the negative and stressful experiences and how they cope with associated stressors (Corman, 2009).

Coping with Stressors

Several research studies have been conducted investigating how parents cope with parenting stress. Coping refers to how individuals respond intellectually and behaviourally in managing stressful situations that arouse emotions (Lazarus & Folkman, 1984). Lai et al. (2015) mention two primary coping mechanisms that have been effective for parents who are raising children with ASD. In the ASD literature, problem-focused coping can potentially mediate stress and reduce the probability of stress-related health issues such as confusion, guilt, denial (Lutz & Patterson, 2012) and anger (Bekhet et al. 2012). These are all examples of stress-related health issues negatively influencing parents' ability to improve parental adjustment and allowing parents to control the necessity of the family and child (Dunn et al. 2001). Emotion-focused coping is associated with strategies that are aimed at managing or reducing feelings of psychological distress linked with the stressor (Pepperell et al. 2016)

Research around ASD have shown fathers frequently participate in problem-focused coping strategies (e.g., planning and focusing on tasks), while mothers engage in emotion-focused strategies (e.g., avoidance and denial), which are beneficial in assisting parents of children with ASD to reduce their depression levels (Hastings et al. 2005). Gray (2003) argued that emotion-focused coping is correlated with emotional discomfort, consequently considering it unhealthy.

However, problem-focused coping has no outstanding relation to stress as Gray (1994) found that there is no specific coping strategy that delivers a great outcome for parents as the main problem is adequately adapting or aligning the strategy to the situation. Whereas, coping techniques have been overestimated regarding how they respond to their child's diagnosis (Benson, 2010; Carver et al. 1989).

Using a factor analytical approach, Benson (2010) found four gross strategies that mothers of ASD children have used to cope with their child's diagnosis. Distraction coping, for example, was found in mothers who regulate their emotions through being expressive, use of self-distraction and self-blame. Whereas, disengagement, on the other hand, played a role among mothers who detached themselves from difficult events through medication use and avoidance. Cognitive reframing and engagement (Benson, 2010) are problem-focused coping styles that mirror the mother's participation in recognising the stressful circumstance and simply trying to revamp her viewpoints regarding the stressor, as well as moving more toward a positive understanding of their child's disability.

Hastings et al. (2005) investigated the differences in coping styles between mothers and fathers of children with ASD. Both types of research have indicated that problem-focused coping mechanisms aren't associated with unfavourable maternal outcomes which are similar to Benson's (2010) findings. This is where positive beliefs occur when facing stressful environments that are out of control (Benson, 2010). Benson, (2014), on the other hand, discovered a rise in the use of disengagement and distracting coping techniques which have been linked to mothers' uncertainty and mental distress. However, there is a lack of Pasifika mothers' experiences with ASD (Benson, 2010).

Impact of culture and autism

The reactions that families elicit to ASD can have an immediate influence on the decisions they make about the child's diagnosis, and treatment can be possibly influenced by their cultural background (Samadi, 2020). Culture can play a significant influence on how families perceive and experience disability. For example, the impact of a child with a disability contributes to how they are understood, classified and accepted in a family (Heer et al. 2015). Culture is defined as the "traditional beliefs", values, language and customs that are passed down and carried from generation to generation (Ennis-Cole et al. 2013). This indicates that culture forms and shapes individual and family beliefs concerning autism, and any other disability in general. However, diverse Pacific cultures have different ways of defining "disability" from other cultures. In general, the way Pasifika people view disability differs from the way non-Pasifika do, especially when it comes to explaining the roots, causes and the origin of the disability. For example, in the general New Zealand population, Pasifika people acknowledge and understand

disability from a medical perspective, whereby a disabled person experiences physical, intellectual impairment, or sensory deficits. However, Pasifika people tend to link and associate various reasons for the causes of disability which are not biomedical but are typically either cultural or religious related (Ministry of Health, 2008).

Parents' beliefs about ASD can inform their perspective and explanation of signs of ASD presentation, along with the time it takes for parents to seek interventions and the type of intervention they decide for their child (Ravindran & Myers, 2013). However, the perspectives of parents and their belief systems regarding the early signs of ASD, along with being attentive to their child, predict the probability of selecting or choosing an intervention. Considering the differential interpretation of ASD across cultures, it is critical to think about support providers, services, policymakers and practitioners to establish cross-cultural competence and sensitivity in helping families and their children with ASD.

According to Bagatell (2010), in Western cultures ASD perceptions are highly influenced by the biomedical community and framed as a "deficit", and deficits are required to be "solved or fixed". Whereas in the Indian culture, destiny/fate and karma were reported and described to be the dominant belief in the community by Ravindran & Myers (2013), who utilise traditional treatment adopted from the Indian culture. In a more recent study of Indian parents' beliefs and views on living in a more Westernised culture, traditional beliefs were lacking and as a result, a mix of biomedical and behavioural therapies for their children was utilised, combining alternative and complementary Western treatments (Ravindran & Myers, 2013). Even though there is a lack of research in this field, Gray (1995) found that Australian parents who care for a child with ASD have expressed concerns about the contributing factors to their child's diagnosis. Illness and birth trauma during pregnancy were potential causes, whereas others have reported religious beliefs were an indication of blame and feeling guilty (Riany et al. 2016). Mercer et al. (2006) found that even parents who attribute the ASD diagnosis of their child to a biomedical factor describe a sense of guilt in feeling responsible for passing on their genes that could have caused the diagnosis of their child. These differences in understanding and beliefs of ASD are deeply embedded in the parents' cultural background and their experiences of caring for a child with ASD.

In terms of the child's upbringing, Tremabath et al. (2005) argue that children need to work collectively, within groups, collaborate, and conform when needed. However, most families are more inclined in teaching their children to be independent learners who are self-directed along with being socially interactive (Trembath et al. 2005). These beliefs are frequently reflected in the kind of assistance brought by families and the values they have instilled in their children. Another example, in the Pacific culture, individuals carry their beliefs and cultural values while protecting the importance of family, respect, love, support, relationships and spirituality are core

values that reflect the fundamental significance of culture. Pulotu-Endermann (1995) states that culture is powerful, vital, and spirited and is, therefore, continuously progressing and adjusting. Culture incorporates the culture of New Zealand nurturing and teaching Pacific people who were raised and born in the islands. In many Pacific families, the culture of a certain family may incorporate a traditional Pacific cultural inclination where members of the family practice and live the cultural identity of that specific group. Where families live and practice the beliefs and values indicates living their lives on a spectrum that expands from a Pacific traditional cultural adaptation to a more Pakeha cultural adaptation (Pulotu-Endermann, 1995).

Pasifika mothers and autism spectrum disorders

Absence of Pasifika mothers in Autism Caregiving Literature

There is a need for research on Pasifika mothers and their experiences of caring for a child with autism in New Zealand. Pasifika research surrounding mothers' and fathers' experiences of caring for a child with autism is not widely explored and researched. However, internationally ASD research has been more heavily focused on maternal experiences and the challenges of raising a child with autism (Pianta et al. 1996; Tayler & Warren, 2011; Dunn et al. 2001; Boyd, 2002; Stuart & McGrew, 2009; Benson, 2002-2014; Heer et al. 2015, Papadopoulos, 2021). Most present literature about ASD is conducted in Western countries (Daley, 2002). Data from Statistics New Zealand (2014) indicates that Europeans are demographically the most represented ethnicity with 74%; while Maori (14.9%); Asian (11.8%) and Pacific people (7.4%) are perceived as vital contributors to NZ's demography. Since there is very little literature exploring the experience of raising children with ASD in New Zealand, Bevan-Browns (2004) conducted a study on behalf of the Ministry of Education 2004.

The Bevan-Browns qualitative research involved 23 Maori caregivers outlining several obstacles and difficulties in obtaining services for their children along with identifying the influences on their well-being. Such difficulties were talked through which included services and funding limitations; procedural, cultural, financial impediments to services; family, personal and financial distress; losing support, lifestyle goals; and prejudice were among the issues highlighted. A few participants reported and have voiced positive experiences, such as family support (even though this is diverse), becoming "professionals" on ASD, and developing self-confidence because of the experience. Even though positive experiences were included in the Bevan-Browns report, the purpose was to describe the challenges related to raising a child with ASD from a Maori approach.

Overall, research has suggested that the primary caregiver of the child can experience financial burden, time pressure, and separation, indicating a struggle to obtain appropriate and acceptable resources, service disappointment, distress, loss and declined psychological and physiological

wellbeing. Bevan-Brown's research also revealed an important and urgent need to increase the number of staff and employees in services that exist along with expanding and providing parents, whanau, and children with ASD, ensuring they have information, assistance, and ongoing assessment and support. Another important suggestion was providing a more effective programme that is culturally appropriate along with services that provide information to parents, ensuring they can access entitlements regarding resources that enable them to support them during their child's transition period (Bevan-Brown, 2004).

Bowden et al. (2020) suggested that the Maori's institutional experiences are shared by people from other Pacific countries. Traditionally Pasifika people would employ a community-based model of care along with mental health concerns as a way of maintaining knowledge that has been adopted from their cultural environment. Their primary responsibility for caring for a child with a disability would be first to confide in family or the community before seeking professional help, most particularly if that help is foreign in the Pacific community, along with instilling their cultural values. However, there is evidence that these trends appear to be alternating over time, as the following or future generation of Pasifika migrants can adapt those practices and health attitudes that are in line with other New Zealanders (Foliaki et al., 2006). Additionally, further research is needed to explain and discover the patterns of ASD-related issues in Pacific and Maori communities in New Zealand, mainly as international evidence argues that it is likely to close gaps for ethnic communities (Bowden et al. 2020).

Present Study

The experiences of Pasifika mothers are underrepresented in the ASD research database. However, even though the literature is heavily influenced by the accounts of maternal experiences, most of the present literature about ASD is conducted in Western countries with Caucasian participants (Daley, 2002). Even though professionals have stressed the need of increasing the awareness of cultural influences on ASD (Dyches et al. 2004) there is still a lack of understanding, and little is known regarding ASD across cultural contexts and the way it is acknowledged, understood and recognized in other cultures (Samadi, 2020). The representation of 'parental experiences' through the literature is most commonly applied in characterising outcomes that are primarily influenced by the experiences of mothers. Existing models have been established involving maternal caregiving populations, however, this can be applied to the experiences of Pasifika mothers but there is no evidence-based model that is appropriate and representative of the realities of Pasifika mothers.

The limitation of adapting international literature to Pasifika-based populations in New Zealand establishes the need for Pacific-based research, as recognised by the New Zealand Autism Guideline (2008). For example, even though the diversity of various Pacific cultures is

recognised there have been a few key recommendations for Pacific people's perspectives such as a research programme that would provide guideline information on ASD for Pacific people. A specific recruitment and progress plan should be created to assist in growing the knowledge and competence of the Pacific ASD-related workforce. Developing a strategy should be created to enhance the cultural awareness and sensitivity of the workforce for health professionals to gain greater understanding and knowledge of Pacific traditional influences (culture values), and viewpoints, and implement these appropriately.

This study will focus exclusively on the experiences of Pasifika mothers in caring for a child with ASD in New Zealand, and will adopt a qualitative methodology to maintain a detailed and in-depth understanding of the experiences of Pasifika mothers'. The study will investigate the nature of caring through both negative and positive experiences, to gain a better understanding of the caregiving role of Pasifika mothers of children with ASD in New Zealand. Obtaining information regarding the experiences of New Zealand Pasifika mothers in a New Zealand setting is essential for both organizations and professionals in the field of autism, including Pasifika mothers and their children.

Methodology

Methodological and Epistemological Position

The approach used for this research is interpretative phenomenological analysis (IPA) and qualitative inquiry. Qualitative methodology is common in psychological research because it focuses on experiences, making it a suitable approach for interpreting phenomena (Alase, 2017). When comparing IPA with the qualitative descriptive approach, the difference is that the latter aims to describe the experiences without the means of interpretation (Smith et al. 2009).

A paradigm is a worldview, a framework of values and methodological approaches used to conduct research (Kivunja & Kuyini, 2017). IPA is associated with the interpretative paradigm. Concepts involve focusing on what it means to be human and how meaning is formed. Both the researcher and participant share an interpersonal relationship where the researcher evaluates, attends and observes the contributions of the participant (Smith et al. 2009).

IPA has several characteristic features; these include being idiographic, inductive, interrogative, phenomenological and hermeneutic (Smith, 2004). Idiographic research focuses on the individual, outlining the inductive nature of IPA, moving through its main observation and working towards a theoretical establishment, instead of looking for remarks to contradict theory as in deductive research (Smith et al. 2009). The investigative nature of IPA is to explore truth or knowledge that is reflected in the purpose of the research. The focus on individuals, the

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emphasis on their personal experiences, and how they generate meaning from experience are clear phenomenological goals (Smith et al. 2009). Furthermore, IPA is hermeneutic in nature because interpretation is a critical component of the approach. The term "double hermeneutic" is frequently used to describe the IPA procedure in which researchers analyse how participants perceive their experiences.

Reflexivity

The interpretative nature of the research-participant relationship implies a level of researcher reflexivity, according to IPA's methodological and epistemological assumptions (Grant & Giddings, 2002). The hermeneutic perspective states that it is difficult for researchers to remove or detach themselves from the research, so they must ensure that their position is known or evident to allow others to understand how they influence the research. This is true, given IPA's nature of double hermeneutics (Smith et al. 2009).

As a university student of psychology, I am guided toward an evidence-based research approach. Even though evidence-based is traditionally connected to positivist, quantitative research, the structure of psychology, and psychological processes support its use of qualitative research in providing understanding and clarity regarding experience. As a researcher, I am motivated by the need to use evidence-based methodologies in forming a connection with participants and their experiences. Therefore, a post-positivist approach would accurately describe this position.

There are aspects of my own personal and professional experiences that I was aware and conscious of when conducting this research, having previously worked with Pasifika children with a diagnosis of autism in an educational setting. I acknowledge and understand some of the challenges and attitudes that can be associated with working to support children with autism. The education of Psychology focuses on the diagnosis, assessment, and treatment of psychological issues supports this interest in the diagnostic presentation. As a result, I was very cautious and vigilant in not letting my interest and desire take over the interviews. This was supported by the semi-structured interview process, where the interview is guided by the participants, enabling those qualities that are important to the experiences of Pasifika mothers as opposed to those that relate to my interests.

Ethical Considerations

Ethical approval for the study was requested from the AUT University Ethics Committee and was approved for three years until July 28, 2024 (see appendix A). Informed consent was obtained from all participants (see appendix B). Due to the study's approach which included face-to-face interviews and confidentiality could not be ensured; however, anonymity was assured. This was achieved using pseudonyms for all participants and removing any other identifying details from transcripts. The nature of confidentiality versus anonymity, and the expected study results, including the use of verbatim quotes were addressed with participants was a recommendation by Smith & Colleagues, (2009). Recordings and transcripts were only accessed and seen by the main researcher, which was also made available to participants upon request. Supervisors were also able to access these recordings and transcripts to identify information upon the collection of informed consent sheets. Electronic transcripts will be transferred to a memory stick after analysis and will be stored with informed consent documents in a secure cabinet in the primary supervisor's office at AUT University. Before destroying all data, it will be kept for six years.

The study is guided by the notion of avoiding harm. While addressing sensitive themes may give participants discomfort, stress or shame which is rare in qualitative research, along with acknowledging these issues (Smith et al. 2009). There is a risk of such vulnerability for participants when discussing their experiences of caregiving, especially such challenging aspects. The methodology's design enables participants to choose their degree of disclosure or discussion, reducing the danger of participants feeling vulnerable through exposure. The risk of harm was also minimized by allowing participants to stop or end the interview at any time. Participants were also provided with contact information such as Vaka Tautua if they felt distressed after taking part in the study and were taken into consideration in planning this dissertation and obtaining ethics approval. The New Zealand Health Research Council guidelines for Maori research ethics, Te Ara Tika, serves as a guideline document for such ethical considerations as well as maintaining that the Treaty of Waitangi principles of participation, protection, and partnership are honoured and upheld when involving Maori participants in research (Hudson et al. 2010). In following these guidelines, the researcher would have best contacted or spoken to a Maori staff ensuring what steps to take if the participant had responded to the researcher's recruitment invites. However, these were not required as the research study involved Pasifika participants.

Recruitment of Participants

Participants were recruited via two Pasifika organisation groups, the Pasifika Autism Support Group (PASG) and the Tongan Autism Support Group (TAG). These groups exist as online organisations with their leaders located in Auckland, New Zealand. PASG is a new intervention

for Pasifika parents and caregivers of ASD children to meet and socialise with others who support, gain, share and bring awareness to autism and the Pacific community. The Tongan Autism Support Group is to provide a culturally safe space for Tongan autism families to connect and support each other while navigating the world of autism. An advert was posted through the social media networks, and also distributed to the members of the organisation group.

Potential participants either emailed the researcher directly or gave consent for their leaders to pass their contact details on. Participants were contacted via email or mobile phone by the main researcher, were given initial information regarding the study, and the interview process, and were given the time to ask questions. Specific criteria were in place to ensure that participants fulfilled the inclusion criteria. A participant information sheet was sent via email (see Appendix C), for potential participants to ask additional questions, as interview times were arranged based on the availability of the participant.

Smith et al. (2009) suggested three to six participants are appropriate to be used in establishing a meaningful analysis without becoming overwhelmed by the data or resorting to moving away from an inductive approach to make generalisable statements. In line with this suggestion, the study focused on recruiting three to six participants. The selection criteria included that participants be the mother of a child with a diagnosis of an autism spectrum disorder, are of Pasifika descent, and are the primary caregivers for the child with ASD. The only participant who could engage in face-to-face interviews were therefore considered, however, disruptions occurred and zoom interviews were held due to COVID-19. Ten individuals responded to the advertisements for participants. Five out of ten interviews took place via zoom. A further five expressed interest via email but did not respond to further information concerning the study.

Data collection

Semi-structured interviews are appropriate in drawing out in-depth and detailed information from participants. The semi-structured approaches are often used in qualitative research, (DiCicco-Bloom & Crabtree, 2006), integrating flexibility in the direction of an interview and questioning, while maintaining the structure to make sure there is appropriate reporting of chosen areas. Prompts were used to enable and stimulate participants to address areas of interest. The goal was to use the interview schedule to assure that all topics were covered, but prompts, content and order of questions were adjusted depending on the responses of the participant. This allowed stories to flow, by accommodating the issues and concerns of the participant (Smith & Osborn, 2007). All questions were open-ended, evaluated to avoid any overlapping, and were developed to explore a variety of aspects of the participants' experiences.

This participant-led approach is consistent with the phenomenological epistemologies allowing the experiences of participants to transpire in research.

An interview schedule was established (see Appendix D), starting with the main question "What is your experience like caring for your son/daughter?". Additional questions were raised based on what participants expressed in response to the main question. This was to ensure that sub-areas of concern were explored. About interviews, DiCicco-Bloom & Crabtree (2006), describes an initial time of establishing rapport and awareness in interviews, before the phases of cooperation and exploration where participants engage in open discussions. Such questions, addressing a more emotional or sensitive issue concerning the influence of wellbeing on caregiving, and experiences of stigma and discrimination, were not discussed unless these issues were mentioned directly by the participant.

Interviews were conducted one-on-one, where participants were given the choice of location, either AUT's Manukau Campus or a quiet location most appropriate to the participant. Due to COVID-19, all five interviews were held on zoom. Interviews lasted between 30-and 60 minutes in length. All interviews were recorded on zoom and transcribed verbatim by the researcher.

Method of Analysis

The goal of IPA is to explore and understand the latent and the unknown, through the researcher's interpretation of the interview, stories were co-established by the interviewer and the participant.

However, the importance of the participant and the interpretive nature of IPA, each case must be considered in-depth, and each transcript must be thoroughly examined before the dataset can be analysed but still focused on how IPA is a reflective process.

A method for detecting, analysing, and reporting patterns (themes) within the data is thematic analysis. The thematic analysis integrates and describes the data that is rich and detailed. Furthermore, it often extends beyond this, interpreting many facets of the research topic (Braun & Clarke, 2006, p.79) There is a six-step process outlined by Braun & Clark, (2017) and is described below and was used as a guide for analysis in this study:

Step 1: Familiarising
The first phase is familiarising, this is where analysis begins with immersion into the dataset. Immersion requires the researcher to get into a mode of reading that is engaging with the data, as data being attentive, finding patterns of quirks and raising questions. In practice this indicates

re-reading all data sets, making informal observational notes along with re-watching or re-listening if the dataset involves video or audio.

Step 2: Generating Initial codes

As researchers become more involved in the data, they proceed to make notes in the margins about everything relevant to the research question, producing a rich set of notes and comments regarding the data. Qualitative data, expressive features, and connections to extensive theoretical concepts, along with differences, similarities and conflicts within the data are areas that may be considered useful to note. Since the interview transcripts remain as the primary data, notes and comments made in the initial noting are now considered to be part of the data set.

Step 3. Constructing prototype themes

The researcher expands on their previous engagement to create a preliminary version of salient patterning in the data. This is where the research question serves as a guide in determining what is, and what is not important in terms of possible pattern meaning. It serves as a basis for the researcher as they make choices as to which data segments are meaningful and what is significant about them, making sure the themes create a consistent and connected story about the data.

Step 4. Reviewing potential themes

The reviewing phase serves as a quality control check to make sure themes are consistent with the coded data, dataset, and research question. The evaluation of themes within the dataset indicates they perform effectively and create a meaningful and unique narrative addressing the research question.

Step 5. Defining and naming themes

In the analysis, the researcher should have shifted from a summary position to an interpretative orientation. This phase focuses on the development of thematic analysis ensuring clarity, coherence, consistency, and quality. These definitions are brief explanations of each theme and their main meaning and idea, as the act of writing, definitions can help in determining whether each of them has adequate detail and depth to stand on its own as a key chapter in the overall research.

Step 6. Producing the report

This is a distinct final phase of refinement and focuses during which the researcher puts together the data, and analysis, and links this focus to academic literature into a single output, answering

the researcher's research questions. Here, the researcher returns to the bigger picture of the overall project from a 'strictly' analytic phase in the research process.

Quality and Creditability

Overall research, the competence and integrity of the research process must be established. Quantitative research includes measurements of validity and reliability (Morrow, 2005), whereas qualitative research includes credibility, transferability, dependability and confirmability when conducting qualitative research.

The idea of credibility refers to the level to which the researcher has accurately represented the data, internal consistency, interpretation and analysis (Morrow, 2005). This is particularly important for qualitative methodologies like IPA, which enables researchers to become "part of the research" and involve themselves in the data (Smith et al. 2009). This emphasizes the need for research reflexivity, where researchers need to consider their own experiences, knowledge, beliefs and assumptions they carry. In the previous section of this chapter, a summary of the researchers' reflexive section is discussed. The use of data sources in the analysis and results phase was another approach used in the study to provide a realistic representation of the data. This helps to ensure the analysis and results remain true to the original interview data (Morrow, 2005), and maintain its powerful connection to it.

The relevance and significance of findings outside of the study environment are referred to as transferability (Korstjens & Moser, 2017). This is different from generalisability, or the ability to apply findings to wider populations, which is a feature of qualitative research methods that is uncommon. Transferability in qualitative approaches can be proven (Morrow 2005), by interpreting findings concerning a wider body of literature and its contexts. This is highlighted in the discussion portion of this study where connections are drawn between the study's conclusions along with involving other studies.

Dependability is based on the assumption that the research process should be documented as to where other researchers can understand and follow the researcher's approach and decisions (Korstjens & Moser, 2017). This study establishes dependability by implementing the study of Morrow's (2005) recommendations and providing guidance on how well the research was planned, analysed and conducted.

Confirmability refers to how researchers have reached their findings and analytic interpretations (Tobin & Begley, 2003). This is where researchers need to be taking notes, being reflexive and clarifying research outcomes as well as other factors that impact them during the study (Koch, 2006). Furthermore, the IPA methodology understands that a researcher can never be

completely impartial, however, with reflective processes, the researcher can make sure that analytic interpretations reflect and remain close to the data as possible (Smith et al. 2009). The use of original data in the presenting research guarantees that the data analysis remains focused on the statements of participants and their experiences.

<center>**Findings**</center>

This section will outline the findings of interpretative phenomenological analysis of the five interview transcripts. It will provide details regarding the demographic nature of participants, along with providing a summary of the themes with quotes and explanations supported by the participants.

Participants

All participants in the study had experiences of caring for a female or male child with ASD. Participants were aged between 28 and 43 and identified themselves as Pasifika descent and living in New Zealand. All mothers were married and living with their husbands and children. Demographic information is summarized in Table 1.

Ina has three children, two girls and one boy on the autism spectrum, as all three children have been formally diagnosed and fall differently on the spectrum. Tina has two children, one boy and one girl both diagnosed as being on the autism spectrum.

Table 1

Participant demographics

Mother information			Child information		
Pseudonym	**Age**	**Ethnicity**	**Gender**	**Age**	**Age at diagnosis**
Helen	43	Niuean/Tongan	Female	12	3 years
Cel	34	Tongan	Female	8	4 years
Mele	43	Tongan	Female	9	4 years
Tina	31	Tongan	Female	B/4 G/10	2/3 years
Ina	28	Samoan/Tongan	Female	G/5 G/3 B/2	2/3 years

Summary of Findings

The rest of this chapter outlines the themes that emerged from the data analysis. Participants were asked to speak about their experiences caring for their children, focusing mainly on their role as Pasifika mothers. The semi-structured interview schedule (Appendix D) had questions relating to the challenges and burdens of caregiving, the challenges, support, coping and its rewards.

However, the opening structure of the questions has enabled important aspects and features of the experiences of participants' to be disclosed such as reactions, emotions, similarities, and greater experiences across networks. Table 2, presents the themes that were discovered. Themes are divided into three categories: superordinate themes, emergent themes, and subordinate themes.

Table 2

Identified superordinate, emergent and subordinate themes

Superordinate themes	Emergent themes	Subordinate themes
Support	1: Experiences of support	1A: Extended family support
		1B: Professional support
		1C: School support
	2: Support for Pasifika mothers'	
Coping Mechanisms	3: Information searching	
	4: Daily routine and planning	
	5: Comparisons with neuro-typical parenting	5A: Expectation before Diagnosis
	6: Normalising ASD in Pacific cultures	
Emotional Aspects of caregiving	7: Emotional burdens	
	8: Positive emotions	

Three superordinate themes were extracted. The superordinate themes include 'Support', which includes three emergent themes. The first is experiences of support, which has three subthemes of extended family support, professional support, and school support. The second superordinate theme, 'coping mechanisms', includes three emergent themes: information searching, daily routine and planning, and normalizing ASD in Pacific cultures. Comparisons with neurological parenting have one subtheme: expectation before diagnosis. The third superordinate theme is the emotional aspects of caregiving, which incorporates the two emergent themes of emotional burden and positive emotion.

Superordinate Theme One: Support

Support was a dominant area of focus and discussion in the interviews, even though this area of focus was voluntarily guided by all the participants. This included experiences of family, professional, school support, and unsatisfied need of support. The analysis of support is divided into two themes, experiences of support and support for Pasifika mothers.

Theme 1: Experiences of Support

All participants articulated the positive and negative perspectives on support. Given participant concerns, participants had expressed their positive evaluation of previous support from family members, professionals, and their child's school environment.

Theme 1A: Extended Family Support

All participants identified an extended family member, church member, or close friend during the interview who had a genuine love for their family. Even though close friends and church members are not biologically related or close relatives, participants considered them as close family members, separating them from their other friends. This has been considered part of the subtheme of extended family support and for some participants, this support involved caring and practical help for the child.

Tina: Yes. [My husband's] in-laws, I live with them. So, they have been helpful and supportive, and they just love both my kids. They help in making dinner for the kids during times when I am sick. They also do school pick-ups every Friday, and then my dad will pick up the kids from mine. And that's allowed a bit of a break or stress relief.

Mele: My siblings are supportive and understanding when it comes to planning family dinners. They know when making a booking, they will check in with me and say, "Oh is this place ok?" And I would say "yup if you ask for a table next to the door that goes outside and it's away from loud noises". And that eases my mind a bit knowing, that they can cater for my daughter.

Cel: If I didn't have the support of my mum and siblings, I think I'll be a mess. Coming from a Pasifika mindset, it is quite common to have your village help you out such as your parents, aunts, uncles, and grandparents. So, there are times when my siblings have [him] for the weekend or over for the night. In a way where I can kind of recollect myself and feel like I am not overwhelmed or stressed.

Other participants have expressed concern that their supporters did not provide significant assistance, however, the participants described the presence of their extended family members as supportive and comforting.

Helen: Aunties, uncles, and grandparents that are present in her life, are part of her upbringing and village. Every chance they get to see her or spend time with her, they think she's such a little sweetheart and they just love it. Just having family time and being present just makes it a little bit easier and you feel a sense of comfort.

Neither of the participants reported a lack of support from their Pasifika families, as all described those who were relatively close to them as being supportive and helpful. However, some participants have acknowledged the difficult process and recurring challenges of helping their Pasifika family members understand their child's diagnoses. This was the case for Tina and Ina.

Tina: It was difficult to explain or communicate to my family why my kids were acting the way they are. My husband's family were very understanding. But my family, especially my mum had no understanding. And because she is a very strong religious person, she feels like I should discipline my kids a certain way. My dad changed hugely when he found out my kids had ASD. I know this because he went and looked up everything about ASD in the Tongan language. He listens to everything that I should know about ASD.

Ina: Yeah, my husband's family don't see or want to have a different mindset about my children, because they are elderly's it's hard to get them to understand or explain the disability of my kids in our Pasifika language because ASD is something that our culture is not aware of or is considered normal. Usually, there is the whole speculation of things that our people assume or speculate about. But I guess it goes both ways, and it will take time for them to understand or get used to it.

These quotes highlight the challenges and difficulties in helping extended family members to understand the nature of autism and bringing awareness to Pasifika families who have limited understanding. However, the support they provided and contributed spiritually and realistically was viewed positively. The following subtheme will explore the support participants experienced from professionals.

Theme 1B: Professional Support

Professional support was discussed by the participants who received help from speech therapists, support workers, psychologists, and paediatricians, along with other health professionals. Discussions of the professional support participants received were filled with positive experiences. Helen's comment regarding the early intervention and professional help she had received, especially from a speech therapist who had worked with her daughter, demonstrates this positive perspective.

Helen: The professional support we have been getting has been helpful along with the ones who we currently still have are still helping my daughter which has been awesome.

Exploring and engaging in support early was expressed by one of the participants as being highly important for them, following their daughter's diagnosis. This was examined in the context of arranging and seeking professional support services.

Helen: When she was diagnosed, the most helpful was early intervention and the therapy that she received such as dance therapy, music therapy, speech-language therapy, and swimming lessons. And now she is receiving dancing lessons. So yeah, the early intervention did help us figure things out a lot during our journey.

Many participants had stressed the importance of being motivated and driven to reach out for support, especially for the Pasifika population. There are times when extra support is needed beyond the support that parents are getting from professionals. Being motivated was discussed by Cel as a way of supporting her child.

Cel: I think the important thing was being motivated and eager regarding the help we would get and what we could do about it. So, we had to plan for funding to get my son into a special school. And it's called ORS funding. So, at one stage we had to sit with the early intervention teacher. And since my son was going to be 5, I wanted him to start school early. But the early intervention teacher decided that she was going to Tonga…. So, I thought that we were not going to get this ORS funding, since the process is a long wait. So, I decided to force this issue and put pressure and say "this is my son, and this is what he needs, I would like him to start school at the age of 5. I wanted her to finish this application before she leaves on holiday. I felt like I was a bit rough or harsh but... I am my son's advocate, and I don't see anyone else who is.

When participants expressed their negative experiences with professional support, they also discussed why they felt uncomfortable or felt out of place with the level of support they received. For example, Mele complained that there was a lack of cultural awareness in acknowledging Pasifika families with ASD. This was not seen as a negative aspect but something that Pasifika families wanted to see change or improve more from health professionals.

Mele: Yeah, professional support adds to the bag of knowledge when working with my family. Like if there were more brown professionals and I even mean…. Having many Pasifika professionals makes me feel comfortable and less judged. I can also be authentic in the way that I respond, but sometimes when it's a European, I am used to whitewashing some of my answers to feel more palatable or having them respond in a way that is helpful to me. Yeah, I feel like, there is a lack of cultural competence in acknowledging Pasifika families with ASD.

Additional clarification was made by Tina as to why professional support from Europeans seems insufficient. She believes that the support she received from European professionals, along with questions that were asked, were just too personal and sensitive regarding their two children with ASD.

Tina: Sometimes support from professionals depends on who's helping you if I was to get a specific person to help, they will know our cultural appropriation and what's not appropriate. Whereas I find European professionals a bit too upfront, even information that is a bit too sensitive such as what I do at home or how much I am making. So yeah… usually I tend to ignore dealing with European professionals and request a Pacific health professional who is more understanding.

These quotes demonstrate how significant it is for participants to get professional support after finding out about their child's diagnoses, along with how they associated negative experiences with a lack of support and cultural competence regarding the professionals themselves. The next subtheme focuses on school support.

Theme 1C: School Support
All four participants declared their child's school support system as being very supportive. Many participants were positive about their child's school environment and the support the schools give. Forming a good relationship with their child's teacher aid was mentioned by Cel, Mele and Ina:

Cel: The teachers at my son's school have been very supportive and communicated with me about some of the things that he does at school. And he's gotten to a point where at…one time where he uses a folk now. But before he used to use his fingers. So yeah, he can use the utensils at school and home. Yeah, so I think the teachers are doing an awesome job in supporting my son.
Mele: My daughters' teacher aid and I get along very well. She calls my daughter "our girl". So, when she texts me, she says "our girl", did this today which I appreciate, because it's those little things that I often won't hear about in a report. Yeah, so she fills me in with what my daughter did today such as playing ball with another girl. That's massive for me because she doesn't play with other children. So yeah… I am thankful that I have a great relationship with her teacher aid.

Ina: Honestly, my daughter's school has been the biggest support, all her teachers are incredible, and they can cater to her needs. They have an environment that is set for kids with

ASD, which I love. I just love their interaction with my daughter and the bond they have established, very flexible and patient.

One participant described their gratitude for working at their daughter's school as a teacher aid, which has allowed her to be with her daughter and see the things that she enjoys doing. Her son who attends a specialist school has a teacher aid who also shares similar experiences with raising a child that is also under the autism spectrum.

Tina: Since I'm a teacher aid at my daughters' school, I love watching her grow and develop into herself, she's got a Pacific teacher this year, and I've seen how much growth she has become like… she's so comfortable and can come out of her shell. And yeah, the teacher can understand my daughter. My son has a specific teacher that has been through what we go through, he has a son with autism too, but he's older. So yeah, my son's teacher knows what school work, he enjoys.

While all participants expressed their child's school environment as being supportive, Helen and Tina were the only participants who mentioned what needed improvement regarding the support they received from their child's school environment.

Helen: I think the ideal support that I would like to see in my daughter's school is having a full-time teacher aid that could help my daughter grow and develop more as she is growing older. This is where the teacher aid will work one on one with my daughter, following a programme or activity that is prepared by the teacher. That would be ideal at this stage, so yeah if anything, it would probably just be that.

Tina: My daughter going to mainstream school is not very well supported there. So yeah, when she tends to scream, self-harm herself or run away. I feel like there is no support in that area. I feel like in mainstream it's a lot harder to get the funding that we need. If we could get support in that area would be great.

These quotes highlight the participant's views of the support received from their child's school environment along with establishing a relationship with their child's teacher aid who is a part of their journey. Even though more support is needed in certain areas, the majority were perceived positively. The next theme will examine the support that is aimed toward Pasifika mothers.

Theme 2: Support for Pasifika Mothers

All participants expressed their gratitude for culturally relevant support for Pasifika mothers and their families. Some participants acknowledged that they were grateful for noticing Pasifika

support groups such as Pasifika Autism Support Group and The Tongan Autism Support Group. The following quotes from Mele, Cel and Tina capture their relief in coming across Pasifika support groups that have helped their family in a big way.

Mele: Being a part of the Tongan Autism Support Group run by Cel who started the group, has played a huge part in our village. It's just sharing those experiences with other Pasifika mothers like Cel who will get it, like the fact that my daughter doesn't like to exercise [laughing], and all that stuff like she understands that. And I've got two mums here in Wellington that help run the Pasifika Autism Support Group Branch, they're awesome as well. So, when my daughter started to pinch, um… some children at school, which got me quite stressed. They gave me awesome advice and stuff, so they're a good support network for me as well.

Cel: The reason for creating the Tongan Autism Support Group is to have a safe space for us Pasifika parents to be able to voice our experiences. Like if we have any concerns, questions or if we come across some type of information that would be useful for each of our Pasifika families. And just being a support system for each other and knowing that we're not alone in this and that we get it.

Tina: When I found out there was a Pasifika support group, they gave us a call, but first, I didn't want to go. I was like "everyone is going to know everyone's business." And I always felt awkward going to other support groups that weren't Pacific. So, I went and from the first moment that we went there, I felt at home with people. Pacific mothers knew what I was going through and knew when I needed advice such as, Ohh maybe try it this way and I'm like, oh it's easier coming from an Islander cause when a European tells me I'm like no, that doesn't work. But yeah, I'm glad there is a Pasifika Tongan Support Group because I've been dying for one in my native language. And that has been a massive help.

One mother discussed that there is a lack of support for Pasifika mothers and families when it comes to not knowing what services exist, what are available, and what funds Pasifika families are eligible for.

Mele: I do wish we had more support in terms of knowing what we could purchase and buy and do for my daughter. Yeah, we get all this funding that we have through the Ministry of Health, which is used for after school care. But I don't know what else we can use it for. It's just like many other things in this autism space. It's difficult to know where to go. You must go to different places for different bits of information like there's no kind of one-stop-shop.

These quotes express that all participants have agreed that there is support for Pasifika mothers. However, there are some inconsistencies regarding areas where support is most needed.

Summary of Superordinate Theme One:

The superordinate theme of support included 2 emergent themes: 1) experiences of support and 2) support for Pasifika mothers. In general, numerous descriptions of support received by family, professionals, and school were positive. There were unfavourable accounts of the provided support, linked to professionals and extended family members. Family members had limited understanding and knowledge of autism, so it was difficult to understand their grandchild was diagnosed with autism. Support from professionals was similar, but there was a lack of cultural awareness in addressing Pasifika families and their children on the autism spectrum. Participants' access to services experienced was generally positive. However, they did describe unsatisfied support needs regarding where to get information about the services they needed the most, or if they were eligible to apply for these services. Despite these issues, several participants described a sense of relief coming across Pasifika support groups for Pasifika families caring for a child on the spectrum.

Superordinate Theme Two: Coping Mechanisms

Coping mechanisms are strategies by which caregivers use resources and strategies to guard, protect or minimize the external and internal challenges, stressors, and responsibilities when it comes to caregiving. The superordinate theme is therefore divided into three emerging themes: information searching, routine and planning, and normalizing ASD in the Pasifika culture.

Theme 3: Information searching

All participants expressed an unfulfilled desire for information, as well as an alternative coping method of information searching. The techniques mentioned included formal strategies such as attending conferences, meetings, and seminars, as well as other informal approaches which included speaking and reading with other Pasifika parents and their child who is on the autism spectrum.

Participants mentioned how they normally attended meetings or other ASD-related events, which was helpful and would usually inform their husbands. However, they also found that it was difficult to recall and apply the information received in the long run.

Cel: So, like things that you learn from other support groups and your kind of like start doing it naturally which has been helpful and good. However, there are quite a lot of specific details which sometimes I get overwhelmed with, and it is a bit challenging trying to keep it going.

Participants also described reading information online as a strategy for information searching. This reading included social media and online sources. Reading researched topics such as strategies for controlling ASD-related problem behaviours along with searching what autism was. Mele discussed her sources of information when knowledge searching:

Mele: For me reading things, So when I see an article or suddenly come up through parent's email for altogether autism or the parents-to-parents support groups for like autistic children, it's making sure that I am following those emails. For example, they had a seminar for a couple of months for parents navigating the education system which has helped.

Information searching through informal approaches such as speaking to other parents was reported as a way of assisting participants as formal approaches may be ideal for their child and family.

Tina: So other parents we've spoken to, reported they didn't get much from that course – this was due to their child being of high function and having a hard time with social interaction and communication. So yeah…. they didn't get a lot out of it as they expected.

Mele considered herself and her husband fortunate regarding their ability to access information compared to other ASD Pasifika caregivers. Mele discussed how they were able to access more resources than other Pasifika parents with a child that is on the autism spectrum:

Mele: I think the support that we have now and the bits of information and knowledge that have been instilled in us have been a blessing. Because no one tells you where they are and what they can do for you. No one walks you through the funding and they just say sign if you want more money. But this is just speaking from my experience. I was telling my husband if I were less educated and if he was less educated then this might have been a much more challenging journey for us. And then [she] might not have gotten the support that she would have needed when she needed it. It took us time to read things, getting emails and if we did not have the skillset and the capabilities that we do, I am just thinking of my other Pasifika brothers and sisters and the challenges that they are experiencing or facing.

Cel discussed how sometimes information searching can lead to stress and tension regarding how they want to work with their son:

Cel: It can be a bit challenging talking about it at home or when we're in public. I think mainly when we are at home, we do try to talk about coming up with strategies to try and resolve the issue. And sometimes we both have different opinions and there are times when we both don't see eye to eye and how we want to work with him. So yeah, there is tension sometimes.

Information seeking was discussed by participants through both the process of informal and formal approaches, along with expressing how information was sought: seminars, readings, articles, and having normal discussions with other Pasifika parents from support groups.

Theme 4: Routine and Planning

Routine and planning were discussed as being part of the participants' autism journey, along with coping with their child and maintaining their family responsibility and function. All participants discussed their daily routine as a method for coping and making sure daily life runs smoothly.

Helen: We do have a daily routine, which helps me a lot such as making sure everything is ready before the kids wake up. This includes getting breakfast ready for everyone, and school lunches. My son is very independent which makes it a lot easier whereas I get my daughter out of bed because she is quite dependent on me in terms of getting herself ready for school. And so, I will help her with that in a big way. And then, I do the school drop-offs and my husband helps here and there. So yeah, this is just part of our daily routine which has helped me a lot in getting through the morning.

Ina: Having more than one child falls on the spectrum; my daily morning routine is busy. I think especially from waking up from 7-8 am, waking up the children and during this time it's very chaotic because they refuse to wake up. So, it's making sure breakfast is ready for all three of them. I do have set times for everything just so everything falls in place, usually, it goes to plan and sometimes it doesn't. But yeah, having a daily routine helps me get through the morning.

Further discussion followed, demonstrating the significance of planning. This included avoiding certain situations where things would likely not go to plan, or tantrums occur in public areas which can draw undesirable attention.

Cel: I use to put myself in that situation where I would take my kids without any planning, and you know that has drawn some negative attention. But then…. I have learnt not to put myself in that situation. So I make sure that when my kids are on school holidays that kind of gives us a little bit of leeway regarding the activities that we do. And I have to kind of like pre-plan activities if I want to take my kids out which I know can be a challenge.

Some participants discussed how planning can extend beyond personal activities and interaction with the child to involve and include all parts of life, such as socializing and shopping sprees.

Cel: So usually if we know that we have an important event coming up, such as one of my friend's birthdays and they are wanting to catch up over dinner etc. I must plan way before, along with knowing who will babysit my son, and it's not just anyone, we are selective about who it is and the time of day. So yeah, it all must be planned before anything happens really.

These quotes display the significance of routines and planning by participants. Cel, Ina and Helen stressed the importance of routine and planning as it helped them as a family to maintain their function along with their children who are on the autism spectrum.

Theme 5: Comparing real life with Neuro-Typical Parenting

The comparison of real-life with the expectation of neuro-typical parenting includes one subtheme regarding the experiences of participants and their expectations before diagnosis. Even though information regarding this facet of parenting was not expressively probed by the researcher, discussions were made about the lives they had hoped for their child.

Subtheme 5A: Comparisons to Expectations Before Diagnosis

Helen: It was not what I expected, usually we would want our children to be healthy, happy, and live a good life and that. So, it was difficult in accepting and coming to terms that things are going to change.

Some participants began to express their child's ability and their expectations before knowing the limitations and restrictions of their child's possibilities. Mele stated what she expected would happen.

Mele: Yeah, I felt a sense of mixed emotions regarding [the diagnosis]. Because a bit selfishly I know I would have like to raise my daughter like those "typical Tongan children" such as doing traditional Tongan dances, having long flowing hair, and dressing her up like a mini-me kind of thing but I know that won't happen. So yeah, it's different than I expected.

Participants also described the process of trying to adapt expectations and align their expectations to reality after the diagnosis. Expectations were adjusted leading to a sense of acceptance that prior expectations will rarely be fulfilled or accomplished.

Mele: I thought we would be able to do family things such as going to Tongan events or taking trips as a whole family together. But yeah. Now we've just learned to accept it and try not to force or pressure these kinds of things that just aren't going to work out. Because it usually just falls flat, and it can be frustrating. Even though I wanted to go, I usually just tell my husband to go with the boys while my daughter and I just chill at home.

Most participants had made comparisons between their expectations and what they realised is what you call reality. They talked about adaptation which is a coping strategy for dealing with their new reality and the feelings of loss that comes with it.

Theme 6: Normalising ASD in Pacific cultures

Many participants discussed normalising, by comparing their experiences with other ASD parents. Usually, normalising ASD in the Pasifika culture is challenging because ASD is seen as not normal. ASD is most often ignored and swept to the side due to families being afraid of receiving negative remarks. However, when speaking to other Pasifika ASD parents, stress is released where they are reassured and less anxious regarding what they are going through, which is common and normal amongst other Pasifika families caring for a child with ASD. For example, most participants described how their children had trouble sleeping which has affected them also. Ina mentioned normalizing this is a usual occurrence for autistic children since it's usually not spoken about in the context of neurotypical children.

Ina: Since three of my children are on the spectrum, I did notice that when it's time to put them to sleep, they have issues with their sleeping patterns…. which is honestly the hardest part of the day for me…and I hear that it's quite common for autistic children on the spectrum.

Participants also discussed normalising ASD behaviour, especially in the context of Pacific cultures where there is a lot of denial and shame brought upon the child. Denial was discussed by all the participants and was openly named as a coping process. This indicated, that as they were freely talking about it, they were aware and mindful that the experiences they are avoiding or denying are their everyday experience.

Mele: I do it sometimes and try not to push it or don't do it at all. But of course, there's a tiny bit of denial that comes with it…. such as expecting that this is a dream and that these behaviours will eventually go away or when I didn't believe that my daughter needed help when I heard she was starting to pinch other kids at school.

Many participants made several comments relating to their role as a Pasifika mother of an ASD child and similar positives and negatives as their role as a Pasifika mother of a neurotypical

child. These responses normalize some of their experiences, although the timing of their children's developmental stages is different.

> *Cel: I think with the positives it's similar for any Pasifika parents, such as when our child has accomplished something that they thought or haven't done before. And us Pasifika people are big on celebrations. Or you hear your child telling you about what they did and what they enjoyed doing at school. Yeah, so like those normal things. I think for me is taking more pride in the little things. Such as [him] using the bathroom for the first time, like that's a massive step. Yeah, so these are like the positive things. It's similar accomplishments with your neuro-typical kids.*

The quotes provided by the participants show how they normalise their own experiences through the process of denial, comparing other parents with children who are on the spectrum, and comparing parenting a neuro-typical child.

Several of these normalising comments were made through the comparisons of others, even though they could have been put together under subtheme: 5A. However, normalising and comparisons were often brought up by the participants, separate themes were supported.

Summary of Superordinate Theme Two:

The superordinate theme of coping mechanisms included 3 emergent themes: Information searching, daily routine and planning, comparing with neurotypical parenting, and normalising ASD in Pacific cultures. Many participants had discussed information searching by talking to other Pasifika mothers' families and professionals as a coping mechanism. This information searching had provided strategies for Pasifika mothers in managing their child's behaviour but had also demonstrated an area of stress and tension for one Pasifika mother and husband. Information searching demonstrates how routines and planning were established. All participants discussed these routines as required and described them as significant to Pasifika mothers of children with ASD. Participants also discussed how they made comparisons between the realities of parenting a child with autism and their parenting expectations as a Pasifika mother, with the thought that their child was born neurotypical. Participants also described the influence a child on the spectrum has on family relations. The disparity between the expectation of a child that is diagnosed with ASD and a neurotypical child created feelings of loss. Further comparisons were made regarding their child's abilities to other children who are on the autism spectrum, as well as stories from other ASD caregivers, with denial serving to normalise their own experiences.

Superordinate Theme Three: Emotional Aspects of Caregiving

All participants spoke about the emotional aspect of the caregiving experience and how it affected them. Both positive and negative aspects of their experiences were expressed. These emotional disclosures occurred at the participants' own choice throughout the interview and were not provoked by the researcher probing their emotional experiences. Participants were not restricted to a particular side of caregiving but were present in discussions regarding family situations, support, and finance.

Theme 7: Emotional Burden

Emotional burden was expressed by negative emotional experiences including feelings of worry, frustration, and loss. When participants discussed these concerns they became shaken up, by their tone of voice, the change of speed when talking about these issues, and the loss of words. All participants voiced their concerns regarding their child's future, both in terms of the near and the far future. Ina expressed her concern about the near future with questions:

Ina: Before I wake up, I wonder how's our morning going to look like? You know with having three kids on the spectrum. Are they going to be anxious? Are they going to eat their breakfast? Did they sleep ok? Is there something that I missed? All these worries and questions are usually what I wake up to in the morning.

Additionally, Cel expressed worry relating more to the far future for her child. All participants voiced similar concerns regarding their child's ability to live freely and participate as a member of their Pasifika community.

Cel: I think about it, What if I'm not here? Who's going to care for him? Who's going to speak for him as that worries me a lot. And there's a point where you think about, Will he get married because we're Mormon…. Will he get a chance to serve a mission? I'm' worried about how his life will be when I and my husband are not there, will he be able to cope?

Furthermore, Mele described her worry regarding her child's future:

Mele: What happens if my husband and I pass away? And who's going to look after her. Because like in the Tongan culture it is not appropriate that she stays with her brothers and nor do I want her to stay with them because I also want my sons to live their life and not have that massive responsibility that restricts them.

Despite the emotional disclosures, participants mainly used the word "stress" to express or describe their worries and concerns about their child's future.

Helen: And to be honest, I probably don't want to think about it. How far into the future, because it honestly can get overwhelming, and it does stress me out not knowing what the future holds for your autistic child. What will happen in five to 10 years?

Further emotions were discussed by participants, particularly frustration about their caregiving experiences. Frustration was mainly discussed when they could detect it in their child, who was often submerged in despair, frustration, and negative emotions. This was the case for Tina:

Tina: There are times when you've just had enough, and you just feel the urge of getting upset and frustrated and you're like that's it. My two kids are getting frustrated and I'm feeling it as well. But then again it does break my heart seeing my two kids upset or if one of them is upset and they can't communicate in being able to tell you what's wrong or did I not understand their cues [voice shaking]. Am I doing something wrong? So yeah, it is tough.

In the interviews, there were numerous expressions of emotional burden, the following theme is positive emotions which describes the positive side of the emotional continuum.

Theme 8: Positive Emotion

All participants expressed positive emotions by providing positive and hopeful statements about their children's future. The nature of these statements differ, but all are related to positivity about themselves and their child. Many participants did express positivity and hope regarding their children, whose potential will eventually develop over the following years.

Ina: I am looking forward to what the future brings, my daughter is in school she has the support that she needs, and it's just helping her focus and develop more, along with watching her grow so I am excited to see that happen.

All participants described the positive influence their child on the autism spectrum has made on their family. These responses frequently centred on how their childhood impacted their siblings and fathers, instead of linking this positive aspect to the participants themselves. Mele expressed how her autistic child had influenced their two neurotypical sons.

Mele: My daughter and her two older brothers have a great relationship. They love spending time with each other and playing around. She's just so happy and always fun. So, she has that smile that just lights up the whole house, which brings everyone joy.

Even though statements relating to burden were often more common when interviewing participants, the positive emotions demonstrate that the participants had also experienced these positive emotions with their autistic child.

Summary of Superordinate Theme Three

All participants' wide range of emotions and feelings indicates the emotional complexity of the Pasifika mother's caregiving experience. Even though the researcher never directly questioned or inquired about any emotional aspects of caregiving, all participants had given detailed explanations of their emotional experiences. Negative emotions included worry regarding the near and far future, and parent and child frustration. In contrast, participants' worries and concerns regarding skill establishment and positivity, were noted. Participants centred their focus on anticipated future skill development and support. Participants also discussed their child's significant contributions to the family structure.

Discussion

This research has focused on the experiences of Pasifika mothers in New Zealand caring for a child on the autism spectrum. With interpretative phenomenological analysis, the nature of the caregiving experience was explored, as well as the support services experienced. Eight themes were discovered and organised into three superordinate groups: support, coping mechanisms, and emotional aspects of caregiving. This chapter contains a discussion of themes classified into their superordinate groups, relating to the previously evaluated literature.

Experiences of Support

Participants did discuss informal social support in this research study, indicating that it was an important source of support for these Pasifika mothers. Even though support from close friends and church members was mentioned, this was still considered part of the extended family support. This echoes other studies in which social support is strongly linked with mothers' coping mechanisms, and is commonly more targeted toward mothers (Coultard, 2001). The support for Pasifika mothers indicates that maternal-focused models may be suitable for Pasifika carers, however, Pasifika based models would be the most appropriate.

Participants expressed their experiences received from professional support as mostly positive. The two negative views were discussed as being a result of limited understanding regarding autism involving extended family members, and the lack of culturally sensitive support from health professionals. These negative experiences are not only examples of individual experiences but are co-existing worries and concerns in the literature. New Zealand research has identified the integration of services and continually improving professional and caregiving communication skills as more significant in addressing support needs (McPherson et al., 2014;

Ministries of Health and Education, 2008). Consequently, this study recommends increasing communication between the parents' caregivers and services (see table 3: Recommendation 5).

Increasing awareness and understanding of autism are commonly cited for the increase in prevalence (Matson & Kozlowki, 2011). For Pasifika families with ASD, it is quite challenging, and therefore remains an issue in some areas, along with the lack of cultural competence when understanding the world views of working with Pasifika people. However, Tina's experience with a health professional indicates that not integrating cultural competence when working with ASD families can persist to create issues. The New Zealand Autism Guideline makes key recommendations for Pacific people's perspectives regarding what should be established between both professional and Pacific people (Ministry of Health & Education, 2008) (see table 3: Recommendations 3 & 4). Tiatia, (2008) literature on Pacific cultural competence provides recommendations for taking cultural competence forward when working with Pasifika ASD families, particularly for health professionals. For example, working with Pacific families requires developing cultural sensitivity and mutual trust practices that go beyond basic cultural beliefs (see Table 3: Recommendation 2). These suggestions are based on research that is beneficial in New Zealand when working with Pasifika families.

Participants' experiences of school support were all relatively positive, as well as their relationship with their child's teacher aid. In this study, participants were asked how their child's school impacted their caregiving experience. Garbacz, (2016) study of two Latino parents found that parent-teacher relationships were important and had helped support their children with an autism spectrum disorder. For families of children with ASD, having that parent-teacher relationship is key especially through the transition period from early childhood education to kindergarten. In contrast, no participants in this New Zealand Pasifika based study discussed a negative outcome, as all four reported having good relationships with the support they receive from their child's school environment.

When support for Pasifika mothers was discussed, Pasifika support groups were frequently mentioned in which mothers would come together and socialise, have a chance to meet other ASD parents and talk. Participation in parent support groups is linked to reducing stress and low mood (Kerr & McIntosh, 2000). However, Mandell & Salzer (2007) indicated white individuals who are married lean more toward using support groups. Despite their demographic alignment, being different to the study's participants, all five of the participants had attended support groups specifically Pasifika support groups. This is where participants discussed their relief in being able to share their own experiences along with developing strategies for dealing with specific situations.

The recognition of support groups is common in the literature such as having positive views of being supportive and being able to access support (Clifford & Minnes, 2013). According to Mandell & Salzer (2007), parents of children with autism join a support group if they were recommended or assigned to one by a health professional, and this echoes Mele's point of view that support should be referred or recommended, as she lamented, "support networks you find yourself, no one walks you through it". This provides an impetus regarding recommendations that health professionals should have access to information about existing support group networks and encourage uptake during the time of the diagnosis given (see table 3: Recommendation 1). The need for more support-related information was mentioned by Pasifika mothers who were struggling to navigate the system. They felt there was no support in theory on where to go for information, and felt that information was kept private or hidden. This is commonly described by parents who have a child that is on the autism spectrum (Gray, 1994; Wang et al., 2011). For parents of children on the spectrum, autism is related to feelings of being overwhelmed and uncertain (Muligan et al. 2012).

Coping Mechanisms

Participants described a variety of ways of dealing with stress. Participants did not refer to the strategies as coping mechanisms, even though these coping mechanisms were employed to alleviate additional stresses linked with the caregiving experience, and therefore fulfilled the criteria of coping mechanisms. Participants addressed ways that mirror Pianta and Colleagues' framework of effective caregiving. Emotional techniques included participants' comparing other ASD cases, regulating, normalising statements, and defusing emotion. Information searching is mostly seen as a cognitive strategy that aims to obtain understanding, whereas activity approaches involve the participant getting used to routines and planning.

Parents discussed their unfilled need for information, along with coping mechanisms for information searching. The demand for information by parents of children with developmental delays is well established. Ellis et al. (2002) mention that 47 per cent of parents that participated in a Canadian survey identified information as to their most important need. According to the New Zealand Autism Guideline, have advised that providing information can be a primary service for supporting families and is kept in line with the health professional (Ministry of Health & Education, 2008). This recommendation is supported and strengthened in the present study (see Table 3: Recommendation 5).

All participants discussed utilising a daily routine and planning as an essential way of managing the pressures, responsibilities, and challenges of caregiving, which is a common coping mechanism among parents caring for a child on the autism spectrum. Wang et al.'s (2011) study reported that parents of children who were on the autism spectrum were much more likely to utilise daily planning and routing as a strategy compared to other parents of children who have

other developmental disorders. This strategy is the most common way for carers to respond to people with autism. Establishing plans and routines is linked to self-efficacy and decreased levels of caregiver stress (Dunn et al., 2001; Poslawsky et al. (2014).

Participants made comparisons regarding their parent's expectations before the diagnosis. Participants assessed their child's position on the autisms spectrum, and these comparisons link to the process of resolution to diagnosis. This is where parents integrate pre- and post-diagnostic representations of their child when coming to terms with the reality of their child's condition (Pianta et al., 1996). Participants also compared their child's location on the autism spectrum to other Pasifika children. Normalising in the Pasifika culture is more linked to not being accepted as a whole and being more emotionally disconnected from close family members and the child.

Participants expressively marked or classified some of their behaviour as a denial. With denial, using avoidance as a coping mechanism has been linked to excessive levels of distress, especially when it occurs over an extended period (Taylor & Stanton, 2007). Parents who have a child that is on the autism spectrum use denial more than other parents with children who have other serious disorders (Wang et al., 2011). Denial, which is a cognitive distortion, was the only character from Pianta and Colleague's (1996) "Loss of resolution to diagnostic approach" study that participants expressed.

Emotional Aspects of Caregiving

The change in distinguishing emotional aspects of caregiving as a continuous spectrum that includes both positive and negative emotional aspects of caregiving is acknowledged in the thematic structure presented by Szmukler, (1996). The emotional burden is considered positive under the superordinate category of the "emotional aspects of caregiving". Although participants' perceptions of their emotional experiences were significantly weighed with emotions of frustration, worry and loss, the word burden was not mentioned by any of the participants. However, perceptions of negative and vague emotions suggest that emotional and stressful experiences expressed by the participants are consistent with the concept of subjective burden (Louiska, 1994). Negative emotions are often identified in studies about the psychological discomfort of parents who care for a child with an autism spectrum disorder. Much research has found that female experiences of burden are similar to emotional content, but more intense when compared to males. According to Barak-Levy and Atzaba-Poria (2013), even though emotions may be considered less severe in males does not indicate that they are less distressing. Participants in this study did become emotional at times, and it was quite easy for the participants to express themselves. Women have a deeper emotional expressivity and emotional responses compared to men, especially when it comes to negative emotions (Bradley et al., 2001).

In comparison to the literature, there are some significant changes in how the participants of this study expressed their emotional burden. Gray (2003), discussed the emotional aspects of caring for a child with high functioning autism and discovered that mothers often freely discussed the emotional effect of their caregiving experiences (i.e., the emotional burden that is placed on the mother is her experience with a child with autism instead of the child directly). This is linked to the fact that mothers are more directly involved one-on-one with their children, and are usually the main caregivers for their autistic children, whereas fathers help where they can. This could be due to the recruitment process, specifically asking for Pasifika mothers which therefore resulted in mothers being more involved in the life of their ASD child, and thus being more impacted. Furthermore, since the study's focus was more on the experiences of Pasifika mothers rather than comparing both mothers/fathers, the participants tended to talk about their partners less. Even though the superordinate theme of the emotional aspects of the caregiving experience was more directed toward negative emotions, participants did also comment on the positive aspects.

Research Implications and Recommendations

Several recommendations have been generated from the findings of this research and have been explored previously (see Table 3: Recommendations 1-7). The findings of this research are supported by the current international and New Zealand studies, even though there is a need for more Pasifika information programmes. As a result, many of the recommendations have already been implemented by the Carers Strategy Action Plan along with the New Zealand Autism Spectrum Guidelines. This is promising because it shows that these publications/guidelines are focused on the general community and can be used for the Pasifika population in New Zealand, along with health professionals and autism caregivers.

Table 3

Recommendations for health professionals, the field and policymakers, and researchers.

Recommendations for Health Professionals
1) Health professionals refer mothers to available support services at the time of diagnosis
2) Establishing Pacific cultural competency is key to understand the cultural differences across Pasifika families, and is critical for the development of establishing relationships and cultural competence.

Recommendations for the field and policy makers
3) A research programme should be established in providing a guideline of information on ASD and the Pacific peoples.

4) An approach should be developed with the goal of strengthening the cultural awareness of the main stream workforce to obtain knowledge and understanding of Pacific cultural values and belief systems and applying these values appropriately.

5) Improve the communication and co-operation between support services and caregiver/parents.

Recommendations for researchers

6) Repeat this study in assessing the changes in Pasifika mothers' experiences.

7) Explore the experiences of Pasifika mother's using larger participant numbers for a more generalisable focus compared to idiographic.

The New Zealand Carers' Strategy Action Plan shields the period from 2014-to 2018. This indicates the current study provides an idiographic perspective of mothers and a baseline to replicate this study, which evaluation would take place, and will therefore impact Pasifika mothers' experiences of caregiving. Even though several recommendations have been generated from the findings of this research will therefore replicate those that are present in the guideline and strategy document. This suggests or indicates; what criteria will be used to assess existing plans and recommendations?. The establishment of a monitoring framework to monitor the progress of the plan and strategy plans is discussed in the New Zealand Carers' Strategy Action Plan. This evaluation will entail examining the demographics of carers, as well as the nature and the types of difficulties they face, using current data and research. As a result, a replica of the existing study using the IPA approach for evaluating Pasifika mothers' experiences could help in assisting the evaluation of the planning process (see Table 3: Recommendation 6). Due to the idiographic aspect of the IPA approach, the findings in this study are idiographic, and while they provide an understanding of the experiences of Pasifika mothers caring for a child with ASD, this will not be possible to be generalised to the overall population. As a result, a research recommendation is made (see Table 3: Recommendation 7).

Limitations

There are several limitations to this study. Firstly, the findings cannot be applied to the entire population. This remains true for many qualitative approaches, but especially true for IPA. The five participants demonstrated a very narrow diverse demographic range, aging between 25 and 43 years, and all identify themselves as Pasifika females living in New Zealand. This homogeneity in the sample is also a product of the study's focus being Pasifika mothers of ASD children. The methodology of IPA can be inclusive regarding all participants of all different ethnicities, hence the semi-structured nature allows the researcher or cultural biases to be minimized in the interview. However, due to the demographic structure of responses to recruitment, this potential was not attained in this study.

Furthermore, self-selection bias is another limitation, as participants being self-selected could potentially be biased towards those with "axes to grind" or "stories to share" as described by Smith et al. (2009). This further suggests that this study might have attracted Pasifika mothers who are primary caregivers of their child with ASD to have a greater interest in the research topic, and had therefore more likely to respond to recruitment invites. However, the methodology required face-to-face interviews, but due to COVID-19 restrictions, the interviews were conducted via zoom as the best option. In regards to accommodating participants timewise, mothers were more than flexible to accommodate the time when they were available.

Researcher reflexivity is required by the IPA methodology, it is important to reflect on and consider how the interviewer's traits might have influenced the data analysis. Being a Pasifika female researcher aiming to obtain an insight into the Pasifika female experience of motherhood, may have influenced several Pasifika mothers. Many participants made statements that indicated they were aware of the research process, such as Cel's "*I don't know if it's the right thing to say…*" and Mele's *"Umm… *laughing*."* I'm not quite sure how I would describe or word it". These statements imply that, while rapport was being established during interviews, participants had sustained a certain level of mindfulness and attentiveness regarding the interview's focus as being a part of the research procedure. This is considered a limitation of the IPA approach, according to Smith and Colleagues (2009), because exposure to experience has always been dependent on the participant's admission.

Conclusion

This study looked into the caregiving experiences of Pasifika mothers in New Zealand caring for a child with autism spectrum disorder and opened various insights into the participant's experiences. This study has added to the body of knowledge through supporting prior findings along with opening new perspectives into the experiences of Pasifika mothers and drawing in comparisons from various international literature that was more focused on maternal experiences of caring for a child with autism, or with any developmental disabilities. Participants expressed mostly positive aspects regarding support from extended family and professional support, along with negative encounters, explained as a result of limited understanding and most importantly the lack of culturally sensitive support, from health professionals. While support groups were recognised as a way of decreasing parental stress and enhancing wellbeing, Pasifika mothers felt Pasifika based support groups were helpful where they felt comfortable being themselves around other Pasifika mothers and their families, which overall resulted in a positive impact. The findings have also confirmed previous research, indicating unmet information needs, culturally insensitive support, and awareness were major concerns and issues for Pasifika mothers caring for a child on the autism spectrum. This has flagged the significance of existing approaches along with guidelines for Pasifika mothers caring for a child on the spectrum. This research study has attained and achieved a purpose, awareness and perspective of a group of Pasifika caregivers whose experiences are not included in the autism research field, having the chance and allowing their point of view to be included at a vital time of re-evaluation and establishment of the caregiving field in New Zealand.

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APPENDICES

APPENDIX A: Ethical Approval

28 July 2021

Daniel Shepherd
Faculty of Health and Environmental Sciences

Dear Daniel

Re Ethics Application: 21/217 Experiences of Pasifika mothers who care for children with autism spectrum disorder (ASD)

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 28 July 2024.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: lesielimasi@gmail.com

Consent Form

Project title: **Experiences of Pasifika mothers' who care for children with autism spectrum disorder (ASD***)***

Project Supervisor: **Dr Daniel Shepherd**

Researcher: **Lesieli Masi**

O   I have read and understood the information provided about this research project in the Information Sheet dated? D/M/Y

O   I have had an opportunity to ask questions and to have them answered.

O   I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

O   I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

O   I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

O   I agree to take part in this research.

O   I wish to receive a summary of the research findings (please tick one): YesO NoO

Participant's signature:

....

Participant's name:

....

Participant's Contact Details (if appropriate):

....

....

....

....

Date:

Appendix A: Participant Information Sheet

Date Information Sheet Produced:

1 June 2021

Project Title

Experiences of Pasifika mothers caring for a child with autism spectrum disorder (ASD).

An Invitation

Malo e lelei, Talofa Lava, Bula Vinaka, and warm greetings, my name is Lesieli Masi, I am a Bachelor of Health Science student and the Primary Researcher for this study. I am interested in ensuring that you as a mother (Fa'e/Tina/Tinana/) are supported with the resources and services in providing support for your children/fanau/gone/ on the autism spectrum. For this purpose, I am interested in the valuable information you provide as there is limited research on Pasifika mothers caring for a child with ASD.

What is the purpose of this study?

The purpose of this study is to document our mother's (Fa'e/Tina/Tinana) perceptions of the challenges of caring for a child with ASD. Interviews will be conducted to examine your experiences and journey. Questions will be focused on you as the mother, the challenges (positive &negative), support and wellbeing. The data I receive from the participants after the interviews are therefore important as research-based for Pasifika mothers or in general, especially in New Zealand.

All data will remain confidential, and examples used in the final dissertation will be by way of a pseudonym and not include the names of the participants or give information that would enable the participant to be identifiable.

How was I identified and why am I being invited to participate in this research?

You will have responded to an advertisement from the researcher, inviting you to participate in this research. I am hoping to interview between 6-and 8 mothers who would like to participate in this important research.

How do I agree to participate in this study?

To take part in this study please make direct contact with Lesieli Masi as the Primary Researcher, via email or phone (see below), who will address any questions you may have about the research. Once you have agreed, I will arrange an interview at AUT University offices (Manukau South Campus). Address: 640 Great South Road, Manukau City Centre, Auckland, 2025.

Your participation in this study is voluntary (it is your choice) and your participation will neither advantage nor disadvantage you. You may choose to withdraw from the study at any time. If you choose to withdraw from the study, you will be offered the choice between having study data that you have given, removed, or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

A Consent Form has been forwarded with this Participant Information Sheet and must be signed and returned just before being interviewed.

What will happen in this study?

You will be invited to a one-hour semi-structured interview. There will only be yourself, which is the participant, and Lesieli Masi present at the interview unless you would prefer a support person, or whanau member, of your choosing to be present. The interview structure itself will involve some simple questions relating to our topic and will allow for additional questions if elaboration is needed. The information you provide is private and confidential and will not be used for any other purposes other than the analysis relating to

this research topic. To further protect your privacy, I will use pseudonyms in any correspondence and publications relating to this research. These research findings may be used for academic publications and presentations.

What are the discomforts and risks?

I will take all reasonable precautions to ensure that you do not experience discomfort or risk whilst participating in this evaluation. We will conduct the interviews at the venue of your choice and ensure the rooms are quiet and private. We will endeavour to word the interview questions clearly and respectfully; however, you only need to answer questions if you feel comfortable. You may withdraw from the study at any time.

How will these discomforts and risks be alleviated?

If for any reason you feel this experience has caused issues to arise, and you believe this is a direct result of participating in the research please contact the AUT Health, Counselling and Wellbeing service.

AUT Health Counselling and Wellbeing can offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

    You can find out more information about AUT counsellors and counselling at http://www.aut.ac.nz/being-a- student/current-postgraduates/your-health-and-wellbeing/counselling.

Alongside AUT counselling, participants from the Tongan Autism Group (02102601254) and Pasifika Autism Support Group (0272066675) can receive appropriate specialist counselling available free of charge.

What are the benefits?

This study will provide information regarding the experiences of our Pasifika mothers caring for a child on the autism spectrum. This will enable mothers who are struggling or who are going through the same experience to know that they are not alone and there are Pasifika support services that are available. The findings will be of interest to families, other Pasifika support groups and health service providers will allow them to develop more programmes and support to better meet the needs of our Pasifika children on the autism spectrum in New Zealand. Furthermore, it is hoped that capturing the impact of your experience will enable other Pasifika mothers to come forward despite the stigma that is surrounded

our Pasifika mothers and families and seek support for their children along with further government funding to aid in helping provide a safe environment that will allow our Pasifika children to enjoy doing activities they love.

How will my privacy be protected?

You will be asked to provide a pseudonym by which you will be known in the study, or I can provide a pseudonym for you. Only the research team will have access to data during the data collection and analysis stage. Only the project supervisor, Dr Daniel Shepherd, will have access to the data after the final dissertation is produced. Audio recordings of interviews will be destroyed following transcription. Consent forms and transcripts, using only pseudonyms, will be kept for six years in a locked filing cabinet in the Psychology Department on AUT premises.

What are the costs of participating in this evaluation?

I anticipate that interviews will take no longer than one hour plus your travel time. If you wish to review your transcript before the completion of the research this will take an additional, small amount of time.

What opportunity do I have to consider this invitation?

Once you have completed the Consent Form, I request that the form be returned to the researcher at the interview. If you have any questions regarding these forms, you are encouraged to contact the research team. Receipt of these completed and signed forms act as your acceptance to participate in this study.

Will I receive feedback on the results of this evaluation?

As a participant, you will be provided with a summary of the dissertation regarding the research findings via email after the study. Both Tongan Autism Support Group and Pasifika Autism Support Group will also be provided with a summary of the dissertation.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Assoc Prof Daniel Shepherd, daniel.shepherd@aut.ac.nz, ph. 09 921 9999 extension 7238

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Dr Carina Meares, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this evaluation?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Lesieli Masi, lesielimasi@gmail.com, ph.0212920371

Project Supervisor Contact Details:

Assoc Prof Daniel Shepherd, daniel.shepherd@aut.ac.nz, ph. 09 921 9999 extension 7238

Appendix D: Interview Schedule

Recording

Participant interviews will be recorded for transcription using audio recorders (video will not be used).

Indicative Questions for Semi-Structured Participant Interviews

Purpose of the study: To establish the Pasifika parent's experiences of caring for a child that has been diagnosed with Autism (ASD) in New Zealand. The questions will seek to understand the context of the role as a parent, support, services and well-being.

Form of welcoming: will be used in welcoming the participants as part of the cultural relevance in the interview process.

Hello, and warm greetings, we want to thank you for taking the time to share your journey/experiences with us. (This will be translated regarding the participant's ethnicity if needed)

Information about the individual being interviewed (Parent):

Demographics:

                 Biological parents? (if not, how long have they been caring?)

Age	**Ethnicity**	**Time as parent**
Parent to other children		**Engaged in other paid employment**

Information about the child with ASD:

Demographics: Age, Are they attending school?, Length of time since diagnosis.

Section II: Initial questions – establishing context

- Can you tell me a little about your role as a parent?
- How do you feel about your role as a parent?
- Daily structure – What does your average day look like?

- How did you feel when you learnt that your child had ASD?
- How has your life changed since you found out your child has ASD? If yes, how?
- Do you think this may be different to how life may have been if your child did not have ASD?
- What are the challenges you think you will face regarding your child's future?
- What has been most helpful/rewarding for you as a parent navigating the joys and struggles of caring for a son/daughter with autism?
- How have other people treated you and your family/whanau since you found your child has ASD?

  (If people have reacted differently):

  A) What do they do (or not do) that is different?

  B) Can you tell me why you think they have changed how they might treat you?

  C) Can you give some examples of a time and place when you notice this difference occurring more often?

- Do people sometimes say that "it takes a village to raise a child" (translate) what are your thoughts on this quote?

Section III: Support

- **How well supported do you feel as a parent?** o *Single / married / divorced / widowed*

o *Family nearby*

o *Help at home*

- How well financially supported do you feel?

- In an ideal world, how much support do you think would help (Child's name) more and in what type of community setting?

- What are the biggest barriers and biggest facilitators (helpers) in providing support?

- How accessible is it for support?

Section IV: Services

- Do you have access to any support services to help you? If so, which services are they and how do they help you?
- Does the interviewee consider the support by professionals to assist in all the above important?
- Do the services provided feel enough to support you?

Section V: Overall feelings of wellbeing

- How would you describe your overall well-being?
  - stresses / anxieties / hopes / content
  - How does caring for an Autistic child impact your overall wellbeing?

- What actions do you consider/take to keep your well-being in check?
- Do you feel like your wellbeing is often compromised due to the large periods of care?

Section VI: Other areas / Final remarks

- What advice would you give to other mothers who have a child that is on the autism spectrum?
- Is there anything else you would like to discuss regarding your role as a Pasifika mother?