School of Occupational Therapy, Social Work and Speech Pathology

Understanding the Experiences of Mothers of Children with Autism Spectrum Disorder in Constructing Family Routines

Tomomi McAuliffe

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number HR123/2014.

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Abstract

Family routines provide a structure that allows families to obtain stability in daily life. This stability assists families to cope with stressors and support health and wellbeing of the family. Families of children with autism spectrum disorder (ASD) use routines to provide a sense of security to the child to assist their participation in everyday activities. Commonly, the design of family routines centres on the needs of children with ASD to accommodate characteristics, such as rigid and repetitive behaviours. Catering for the needs of the child presents a challenge for families to engage in shared family routines. Families of children with ASD use a variety of strategies to accommodate and adapt their routines to enable them to continue to engage in shared family routines.

Mothers usually assume the main responsibility in constructing and managing family routines and their experiences can be arduous. The impact of these difficult experiences on their health and wellbeing have not been widely explored in previous research. Further, in the field of family routines, coupled mothers and mothers who live in major city areas have been the primary focus in previous studies. Consequently, there is a lack of representation of single mothers and mothers from regional areas. Given the global change in family structure and geographical challenges encountered in some countries, such as Australia, there is a need to explore the experiences of those two overlooked groups of mothers. The primary aim of this study *wa*s to examine the key roles mothers of children with ASD play in constructing family routines to develop a more accurate understanding of these mothers' experiences, with a particular focus on their health and wellbeing, and to compare and contrast their experiences by their household status (i.e., single versus coupled mothers) and region of residence (i.e., living in major city versus regional areas) to increase the current understanding of those populations who have been under researched. The thesis comprises five related studies. First, a secondary analysis of cross-

sectional data of the Western Australian population study to examine family routines, service usage, and stress levels among families of children with ASD (*N* = 535) was conducted [Chapter 3]. This study compared the experiences of families by their region of residence. The results indicated differences in employment opportunities and accessibility to medical services between regional and major city areas. The families from regional areas were found to experience less severe stress, suggesting differences in levels of community support between these two areas. However, the overall differences found between regional areas and major city areas were somewhat limited. The results indicated regardless of region of residence, the experiences of families of children with ASD were similar. The survey contained a wide range of questions; however, it did not use validated instruments.

Second, an online cross-sectional survey with 207 mothers of children with ASD who lived in Western Australia using validated instruments to investigate their QoL, stress levels, coping styles and time-use was conducted [Chapter 4]. Time-use was considered as a pre-cursor to family routines. The study used *Chi*-square and logistic regression analyses to compare the experiences of mothers by their household status. The cross-sectional online survey study found some differences between single and coupled mothers. Single mothers were found to experience lower environmental QoL than coupled mothers. Before adjusting for total number of children, household income and employment status, single mothers were found to use acceptance coping style more than coupled mothers. However, this result did not remain significant after adjusting demographic factors. There were no other significant differences between these two groups of mothers, suggesting that regardless of household status, the experiences of mothers of children were similar. Both Chapter 3 and 4 confirmed a need to use different methods to investigate family routines among mothers of children with ASD to obtain a more in-depth understanding of these mothers.

Third, experience sampling method (ESM) was conducted with 40 mothers who completed the online survey [Chapter 5]. This study investigated ‘*in-the-moment’* experiences of mothers while participating in everyday activities and their time-use. The participants were asked to carry a mobile device to record their time-use and experiences while engaging in activities for one week during the school days. Multilevel analysis and Mann-Whitney *U* test were used to analyse the ESM data, and the results were compared by household status and region of residence. Similar to Chapter 3, the ESM results indicated differences in employment opportunities and social support may exist between families living in regional and major city areas. The ESM results also highlighted the importance of providing appropriate support for mothers of children with ASD. For coupled mothers, types and levels of support provided by their spouses in domestic tasks should be further investigated. Supporting the findings of Chapter 3 and 4, regardless of household status and region of residence, the experiences of mothers of children with ASD found in the ESM study were similar. All mothers spent most time in childcare activities and the least time in self-care activities. When engaging in childcare, mothers felt more challenged and stressed, and less in control and supported.

Forth, individual interviews were conducted with 20 mothers who completed the ESM study to explore their accounts of constructing family routines in relation to their health and wellbeing [Chapter 6]. Mothers’ personal perspectives in constructing family routines could not be investigated by the methods employed in Chapter 3, 4 and 5. Interpretive phenomenological approach (IPA) was used to guide the study. This study found the major role mothers played in constructing family routines and their large responsibilities may come at the cost of their health and wellbeing. However, mothers continued their roles to support their children and family. Mothers allowed themselves to be imperfect to cope with everyday demands and acknowledged the needs to address their health and wellbeing.

Fifth, a mixed method study combining the ESM [Chapter 5] and interview data [Chapter 6] to formulate meta-inferences to advance the current knowledge of the experiences of mothers of children with ASD in managing family routines was conducted [Chapter 7]. An approach of joint display was used to compare and contrast findings from the two data sources. The mixed methods study identified meanings underlying mothers' experiences in constructing and managing family routines. The study found that family routines had the function of providing mothers with a sense of control over their external environment. Mothers sacrificed their own time to support their children and family, therefore it became a challenge to accommodate activities that address their own needs into family routines. Mothers were intrinsically motivated to participate in challenging activities due to their values and beliefs. Work provided a respite from everyday demands and a 'just-right' challenge for mothers to obtain a sense of achievement. For coupled mothers, actual support received was more important than perceived support in completing domestic tasks. The reason mothers from major city areas felt more challenged in completing self-care activities may be attributed to increased time-pressure, resulting from potential lifestyle differences between regional and major city areas.

The results of the thesis largely indicated regardless of household status and region of residence, the experiences of mothers of children with ASD were similar. The findings of this thesis revealed mothers of children with ASD experience constructing family routines to be arduous. Mothers assumed the main responsibilities and they sacrificed their own needs to support their children and family. Therefore, their health and wellbeing can be compromised. Including activities to address mothers' own needs, such as self-care and having '*me-time'*, in family routines became a difficult task for mothers. This difficulty created a complexity in constructing family routines, where mothers had to balance the demands of others, as well as their own. The thesis offers a new perspective of family routines that considers factors external

to individual families, such as health professionals, as part of and embedded within family routines. This new perspective adds to the complexities of constructing family routines that mothers of children with ASD need to navigate. Implications for health professionals to support health and wellbeing of mothers considering family routines are discussed.

List of Publication

This thesis includes the following three publications and two papers that have been submitted for publication:

McAuliffe, T., Vaz, S., Falkmer, T., & Cordier, R. (2016). A comparison of families of children with autism spectrum disorders in family daily routines, service usage, and stress levels by regionality. *Developmental Neurorehabilitation, 20*(8), 483-490. doi:10.1080/17518423.2016.1236844

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Statement of Author Contribution

The nature and extent of the intellectual input by the candidate and co-authors for the papers listed below have been confirmed by all authors.

Papers:

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All co-authors of the papers listed above confirm that Tomomi McAuliffe has been the primary author and has made the following contributions:

Contributions

- Conceptualisation and design of the research;
- Data analysis and interpretations; and
- Writing the manuscript and critical appraisal of the findings.

All co-authors for the papers listed above confirm that they have made the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Tomomi McAuliffe	Date 25/01/19
Reinie Cordier	Date 25/01/19
Sharmila Vaz	Date 22 / 01/19
Yvonne Thomas	Date 22/01/19
Torbjörn Falkmer	Date 25 /01 /19
Yu-Wei Chen	Date 22 / 01/19

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Key Abbreviations

ASD: Autism spectrum disorder

ASGS: Australian Statistical Geography Standards

APSI: Autism Parental Stress Index

CMOP-E: The Canadian Model of Occupational Performance and Engagement

DSC: Disability Service Commission

DSM: Diagnostic and Statistical Manual of Mental Health Disorders

DP: Densely populated areas

DV: Dependent variable

ESM: Experience sampling method

EST: Ecological systems theory

LDP: Less densely populated areas

IPA: Interpretive phenomenological approach

IVs: Independent variables

PIEL: Participation in Everyday Life Survey Application

QoL: Quality of Life

RA: Remoteness areas

SDAC: The Survey of Disability, Ageing and Carers

WHOQOL BREF: The World Health Organisation Quality of Life Brief

Chapter 1 Introduction

Background

The focus of this thesis is to develop an in-depth understanding of the experiences of mothers of children with autism spectrum disorder (ASD) in constructing family routines. Constructing family routines is part of the domestic responsibilities mainly assumed by mothers in everyday life (Bagatell, 2016). The reason for mothers to be the main persons to construct family routines may be because many families of children with ASD have a traditional division of household labour, where mothers act as primary carers for their children and hold domestic responsibilities (Hartley, Mihaila, Otalora-Fadner, & Bussanich, 2014; Pepperell, Paynter, & Gilmore, 2016). Indeed, about 90% of carers for children with ASD are mothers (Australian Institute of Health and Welfare, 2017b).

Family routines are commonly employed to assist children with ASD to cope with everyday demands, as routines provide stability and predictability during everyday life (Larson, 2006; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Parents of children with ASD adapt and accommodate family routines to cater for the needs of their children, while maintaining meaningful family activities (Bagatell, 2016; Bagby, Dickie, & Baranek, 2012). The results of earlier studies support the notion that functional family routines buffer stressors for family members, thus supporting family health and wellbeing (Churchill & Stoneman, 2004; Marquenie, Rodger, Mangohig, & Cronin, 2011). However, emerging evidence suggests that the process of constructing family routines can be burdensome and physically and mentally tiring experiences for parents of children with a disability (Larson & Miller-Bishoff, 2014). In the context of ASD, the specific experiences of mothers, the main creators of family routines, in relation to their health and wellbeing are largely unexplored (Kellegrew, 2000; O'Brien, 2004;

Thullen & Bonsall, 2017). Previous research on the health and wellbeing of mothers of children with ASD supports the notion that these mothers are at higher risk of experiencing negative health outcomes, such as increased stress levels and decreased quality of life (QoL), than other groups of mothers due to both child-related and parent-related factors (Bonis, 2016; Vasilopoulou & Nisbet, 2016; Zablotsky, Anderson, & Law, 2013). Further, although inconclusive, the majority of past research demonstrates that mothers of children with ASD experience higher levels of stress than fathers (Dabrowska & Pisula, 2010; Foody, James, & Leader, 2015; Jones, Totsika, Hastings, & Petalas, 2013). Therefore, the role these mothers play in constructing family routines in relation to their health and wellbeing should be further explored.

Investigating the experiences of mothers is important, particularly among families of children with ASD, given the global increase in prevalence rates (Elsabbagh et al., 2012). For example, in the United States, the prevalence rate in 2004 was 1 in 125 children; however, in 2014, it increased to 1 in 59 children (Centres for Disease Control and Prevention, 2018). In Australia, 164,000 people were found to have ASD in 2015, representing almost one in 150 people (Australian Bureau of Statistics, 2015a; Australian Institute of Health and Welfare, 2017b). This was an increase of 99,400 people from 2009, more than double the prevalence rate found in 2009 (Australian Bureau of Statistics, 2011).

ASD is a neurodevelopmental disorder that is characterised by social-communication deficits and restricted and repetitive interests or behaviours (American Psychiatric Association, 2013; Frazier et al., 2012; Grzadzinski, Huerta, & Lord, 2013). People with ASD experience barriers in various areas in life, such as education, employment and independent living skills and, depending on the severity of ASD, some people with ASD require high levels of assistance (Australian Bureau of Statistics, 2015a). In 2015, 856,000 people were primary carers for people with disability in Australia (Australian Bureau of Statistics, 2015a). In the ASD context, almost 70,000 people reported being the primary carers for both children and adults with ASD (Australian Institute of Health and Welfare, 2017a). The childcare demands that mothers of children with ASD experience can be higher when compared to the demands mothers of typically developing children experience due to various factors, such as a need for constant supervision and arranging multiple therapy services appointments (Bourke-Taylor, Howie, & Law, 2010; Crowe & Michael, 2011). ASD is a lifelong condition, thus caring for a child with ASD is a long-term commitment (Walter & Smith, 2016). Accordingly, the childcare demands among mothers of children with ASD continues to be higher than mothers of typically developing children, for some throughout their lifespan (Crowe & Michael, 2011). Therefore, the increasing prevalence rate and long-term caregiving demands point to the need to further study the caregiving routines of mothers of children with ASD.

Past research in the area of routines in ASD families focussed on a narrow group of participants (Crespo et al., 2013). Consequently, the main population group included in ASD related research is a rather homogenous group of coupled mothers who reside in major city areas (Marquenie et al., 2011; Rodger & Umaibalan, 2011). The narrow focus on this particular group of mothers has resulted in single mothers and mothers from regional and remote areas being under researched in the area of family routines. The proportion of single parent families has increased in Australia and this increase is expected to continue until 2031 (Australian Bureau of Statistics, 2007, 2010). Over 80% of all single parent families in Australia are led by single mothers and this pattern is likely to persist for the next 15 years (Australian Bureau of Statistics, 2010, 2017a). This overrepresentation of single mother led families in Australia warrants the need to investigate the experiences of single mothers of children with ASD in constructing family routines.

Australia presents unique challenges due to the geographical landscape, such as uneven population distribution between major cities and regional and remote areas. A lack of services is one of the common issues experienced in regional and remote areas, compared with major city areas where more services are available and easily accessible (Australian Bureau of Statistics, 2017b; Wacker et al., 2013). Parental abilities to manage daily challenges may be impacted if they are unable to receive appropriate support (Hoogsteen & Woodgate, 2013b). For example, parents of children with ASD who live in regional and remote areas have less opportunities to access ASD specific services that assist them in coping with everyday childcare demands (Farmer & Reupert, 2013). Therefore, issues associated with unique geographical landscape in Australia point to the need to study the experiences of mothers living in regional and remote areas.

Significance of the Thesis

Investigating the experiences of mothers of children with ASD is important for four reasons. First, mothers are often the key players in constructing family routines (Bagatell, 2016; Larson, 2006). In constructing family routines, mothers need to address the specific needs of their children with ASD (Schaaf et al., 2011), while balancing the needs of other family members (Larson, 2006). Due to the characteristics of ASD, such as rigid interests and unpredictable behaviour of the child, mothers of children with ASD encounter challenges in constructing family routines (DeGrace, 2004; Larson, 2006; Marquenie et al., 2011). Given the main responsibilities many mothers hold in constructing family routines (Bagatell, 2016) and the importance of functional family routines in promoting family health and wellbeing (Bagatell, 2016; Downs, 2008; Rodger & Umaibalan, 2011; Schaaf et al., 2011), investigating the experiences of mothers is important to gain an in-depth understanding of their key roles in supporting family health and wellbeing.

Second, families of children with ASD use multiple therapeutic services to support their children’s development (Carbone, Farley, & Davis, 2010; Goin-Kochel, Myers, & Mackintosh, 2007). Parents are asked to continue with the therapeutic interventions at home to maximise their children’s outcomes; however, unless the interventions fit with family routines, parents would not be able to deliver these interventions effectively (Bernheimer & Weisner, 2007). In fact, previous research highlighted the need for health professionals to understand the patterns of family routines when working with families with children with ASD (Bagatell, 2016). Therefore, exploring the experiences of mothers who construct family routines may provide a more accurate picture of the routines, which would assist health professionals to design more appropriate interventions. Mothers of children with ASD work closely with service providers by organising appointments, driving children to their appointments, deliver interventions at home, and take on a coordination role between services (Bourke-Taylor et al., 2010; Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2014). Hence, increasing the understanding of these mothers’ experiences may assist service providers to design interventions that fit better with family routines, which may, in turn, assist mothers to support their children with ASD.

Third, this thesis will extend the current knowledge of family routines by investigating the experiences of single mothers and mothers from regional and remote area. To date, only few empirical studies have been conducted to explore the experiences of these mothers of children with ASD in constructing family routines. Investigating if the experiences of single mothers and mothers from regional and remote areas differ from their counterparts (i.e., coupled mothers and mothers from major city areas) in designing family routines is therefore an important line of enquiry. By comparing the experiences of mothers of children with ASD by their household status (i.e., single versus coupled) and region of residence (i.e., major city versus regional and remote area), the thesis will address a significant gap in the area of family routines (Crespo et al., 2013).

Finally, the thesis focuses on the personal experiences of mothers of children with ASD in constructing family routines in relation to their health and wellbeing, which is largely an unexplored area (O'Brien, 2004). Mothers of children with ASD are at higher risk of experiencing negative health outcomes (Bonis, 2016; Vasilopoulou & Nisbet, 2016). Their negative health outcomes are of concern, because constructing family routines can be burdensome for parents of children with a disability (Larson & Miller-Bishoff, 2014). Therefore, by investigating the experiences of mothers in constructing family routines, health professionals will be better informed to design services that support mothers' health and wellbeing.

Overall Aim of the Thesis

The overall aim of the thesis is to examine the key roles mothers of children with ASD play in constructing family routines to develop a more accurate understanding of these mothers' experiences, with a particular focus on their health and wellbeing, and to compare and contrast their experiences by their household status (i.e., single versus coupled mothers) and region of residence (i.e., living in major city versus regional areas) to increase the current understanding of those populations who have been under researched. In this thesis, cross-sectional studies are used to investigate the relationships between the factors that pertain to management of family routines (e.g., time-use) and health status (e.g., stress levels), and household status (i.e., single versus coupled) or region of residence (i.e., major city versus regional) among mothers of children with ASD. Additionally, experience sampling method is used to investigate the 'in-the-moment' experiences of these mothers in managing family routines. The mothers' perspectives of family routine management and their health and wellbeing are explored by using a semi-structured interviews. The reason for collecting both quantitative and qualitative data is to compare the two forms of data to develop an in-depth understanding of the experiences of these mothers in managing family routines.

Specifically, this thesis addresses the following sub-aims:

1. To explore whether family routines, service usage and stress levels in families of children with ASD differ as a function of region of residence;
2. To examine the influence of differences in household status on the stress levels, coping styles, time-use and QoL among mothers of children with ASD;
3. To compare the everyday experiences of mothers of children with ASD by their household status, as well as region of residence in their everyday *in-the-moment* experiences (i.e., time-use and related feelings);
4. To explore the experiences of mothers of children with ASD in managing family routines in relation to their perceptions towards their health and wellbeing; and
5. To understand complex phenomena and generate new ideas by explicating mothers' experiences with family routines in the context of families of children with ASD.

Theoretical Frameworks

The following section discusses theoretical frameworks that underpin this thesis: 1) the transactional model (Sameroff, 2009) and 2) family systems theories (Bowen, 1966; Minuchin, 1988). The transactional model (Sameroff, 2009) is useful in highlighting the intricacies involved in constructing family routines, whereas family systems theories aid in contextualising family dynamics by depicting intertwined family relationships. The transactional model (Sameroff, 2009) and family systems theories are complementary in contextualising this thesis by uncovering the complex process of constructing family routines while simultaneously considering the experiences of mothers in relation to the entire family context.

Transactional Model

The transactional model is often considered in the area of developmental psychology to depict the dynamic relationships between children and the experiences provided by their social context, such as parents and school (Fogel, 2009; Sameroff, 2009; Sameroff & Mackenzie, 2003). The transactional model considers children's developmental outcomes as a result of these dynamic relationships (Sameroff & Mackenzie, 2003). The relationship between children and their environment is bidirectional and, in this model, both children and contextual factors are equally emphasised (Fogel, 2009; Kuczynski & Parkin, 2009; Sameroff & Mackenzie, 2003). This model does not consider children or their contexts as an independent factor (Sameroff & Mackenzie, 2003) and the transactions that occur between these two factors are continuous and evolving overtime (Sameroff, 2009; Sameroff & Fiese, 2000). Consequently, both children and parents are active participants in these interdependent relationships, influencing each other (Fogel, 2009; Kuczynski & Parkin, 2009; Sameroff, 2009, 2010). Therefore, both child and contextual factors should be simultaneously considered to support children's development (Sameroff & Fiese, 2000; Sameroff & Mackenzie, 2003). The transactional model demonstrates the complexity involved in child development (Sameroff & Fiese, 2000).

The complexity that arises from interdependent relationships between children and their contexts in the transactional model aligns with the synchronised reciprocal family interactions required to develop functional family routines (Jensen, James, Boyce, & Hartnett, 1983; Sameroff & Fiese, 2000). To develop functional family routines, each family member is expected to contribute and when this contribution is not present, families may experience disruption in family routines (Boyd, Harkins McCarty, & Sethi, 2014; Fiese et al., 2002). For example, a child with ASD may demonstrate strong food selectivity and related challenging behaviour during meal time routines (Marquenie et al., 2011; Thullen & Bonsall, 2017). As a result, families of children with ASD may experience some difficulty in organising and participating meal time routines (Suarez, Atchison, & Lagerwey, 2014). Meal time routines may become stressful, influencing other members’ participation in the routines (Marquenie et al., 2011). Families interpret the interactions that occur in family routines and, subsequently, their interpretations influence how family members perceive and respond to each other while participating in family routines (Sameroff & Fiese, 2000). In response to the challenges presented by the interactions with children who experience strong food selectivity combined with considering the needs of other family members, their mothers may attempt to separate meals for different family members, which may leave them feeling that achieving ‘normalcy’ of having family meal time is challenging (Suarez et al., 2014). This meal time example demonstrates the complex transactions involved in constructing family routines among families of children with ASD.

Routines are continuously repeated activities in which family members are required to commit their times momentarily (Boyce, Jensen, James, & Peacock, 1983; Fiese et al., 2002). Similarly, transactions occur through continuous “moment-to-moment interplay” between participants, where each participant interprets and responds to each other (Fogel, 2009, p. 273; Kuczynski & Parkin, 2009). The repeated and continuous transactions occur in everyday context, including family routines, and become predictable and stable (Fiese, Wilder, & Bickham, 2000; Sameroff & Fiese, 2000). The stability provided through the repetitive transactions supports the development of family coherence (Fiese et al., 2000). Likewise, family routines provide stability and a sense of belonging for families of children with ASD (Larson, 2006; Rodger & Umaibalan, 2011). This model, therefore, is useful when considering the transactional nature of family routines and its intricacy involved when exploring the experiences of mothers of children with ASD.

Family Systems Theory

Family systems theory (Bowen, 1966; Minuchin, 1988) is commonly used in the field of family therapy to understand multifaceted interactions that occurs between family members (Nichols & Schwarts, 2008). This theory views family as a complex system that is comprised of hierarchically organised subsystems, including marital, parent-child and sibling relationships (Cox & Paley, 1997; Fiese et al., 2000). Within a functional family system, interactions between subsystems occur fluidly, while maintaining boundaries between subsystems and balancing the influence from the outside environments, such as school (Fiese et al., 2000). Families maintain or restore order in their systems by balancing the needs between individual family members and the environment when internal or external stressors are identified, thereby demonstrating resiliency (Fiese et al., 2000; Morgan, 1988).

This theory focusses on a '*wholeness of family*', rather than just being a collection of individuals (Bavelas & Segal, 1982; Nichols & Schwarts, 2008). Therefore, family systems theory considers communication, patterns of relationships and connections between family members (i.e., subsystems) in the context of a whole family (Bavelas & Segal, 1982; Christian, 2006; Nichols & Schwarts, 2008). The focus on '*wholeness of family*' implies that the development of an individual family member is not solely a result of the person, but a result of transactions between the person and family members (Fiese et al., 2000). Individual family members are systems of its own function within a family system and complex transactions occur between, across, and within the family systems (Cox & Paley, 1997; Minuchin, 1988). Therefore, in exploring complex transactions 'within' family systems, investigating family routines that arise from the transactions of family members is insightful (Sameroff & Fiese, 2000). Mothers often take main responsibility in constructing family routines and the process of constructing family routines can influence their health and wellbeing (Bagatell, 2016; Larson &

Miller-Bishoff, 2014). The transactions that occur between family members mean that individual family members influence one another, that is, their relationships are multidirectional (Bowen, 1966; Fiese et al., 2000; Morgan, 1988). Therefore, exploring the experiences of mothers in constructing family routines is necessary to increase the understanding of the experiences of the entire family as well as that of mothers (Cridland, Jones, Magee, & Caputi, 2014).

Structure of Thesis

The thesis takes a ‘thesis containing publications’ format, comprising chapters that include traditional thesis chapters, published papers, and papers submitted for publication. Chapter 1, the current chapter, provides a brief introduction to the thesis topic and the overall project. Chapter 2 includes a review of the literature pertaining to family routines with a specific focus on the experiences of mothers, thus providing a rationale for the aim of the thesis, and Chapter 8 comprises a discussion and conclusion of the research findings. The remaining five chapters (i.e., Chapter 3 to 7) have been published or are currently under review in peer-reviewed journals and constitute the main body of the thesis. Chapter 3 to 7 are stand-alone documents, each comprising aspects of the overall study, resulting in some inherent repetition throughout the thesis. APA 6th referencing style and Australian grammar and spelling are used in this thesis. Due to the requirements of each journal, papers included in this thesis vary in structure (i.e., headings and abstract format). Figure 1.1 presents a structure of the thesis. The following section presents a summary of each chapter and research methods used in the thesis.

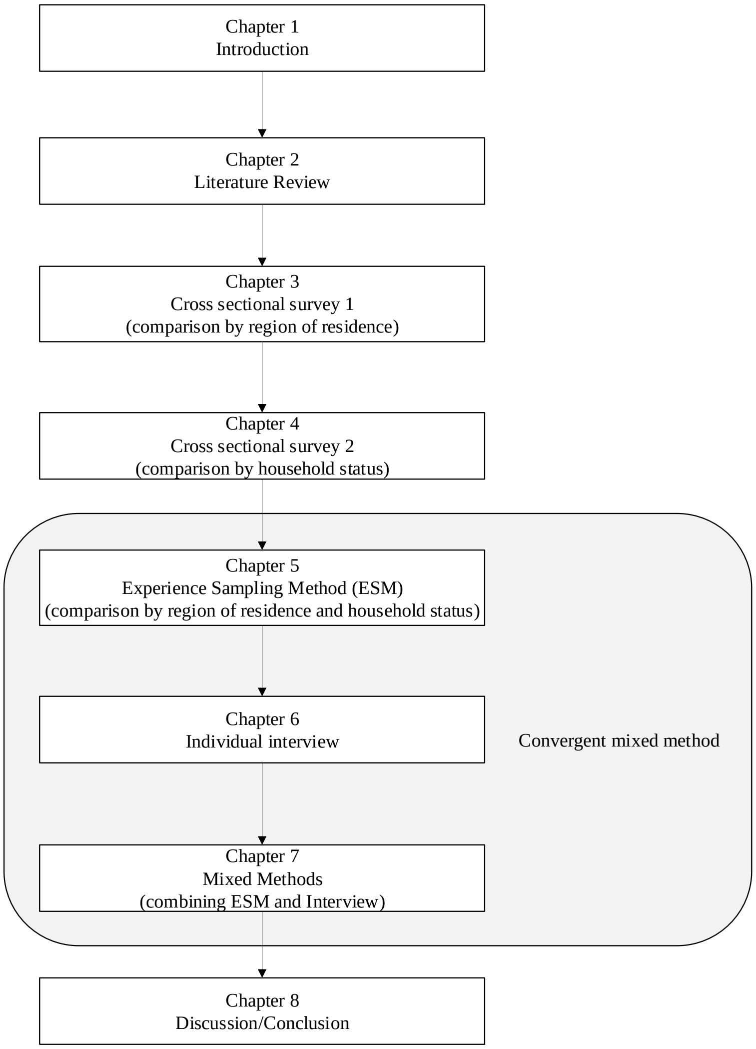


Figure 1.1: Thesis structure

Chapter 1: Introduction

This chapter provides an introduction and overview of the thesis to contextualise the rest of the thesis. The overview provided in this chapter assists in situating the overall aim of the thesis, research questions, and the significance of the thesis. The transactional model and family systems theory that underpin this thesis are also presented.

Chapter 2: Literature Review

This chapter provides an overview of the family routines literature, introduces key constructs, and provides an in-depth narration of what is known about mothers' experiences of family routines. The definitions of key terminologies, such as family routines, are provided in this chapter. The review identifies the gaps that exist in the field of family routines in the context of ASD and provides a rationale for the aim of the thesis.

Chapters 3: Cross Sectional Survey Study (secondary analysis)

Chapter 3 contains a study that compares family routines, service usage and stress levels of mothers using their region of residence (i.e., comparing mothers who live in regional and remote areas against mothers who live in major city areas). The following section provides a brief overview of the methods employed in this chapter. More detailed information can be found in Chapter 3. This chapter is presented as a published paper.

Design. This chapter is a secondary analysis of a cross sectional survey that was primarily developed for a study that examined the costs associated with raising a child with ASD (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014). One of the strengths of a secondary analysis is that it is a cost-effective way to inform the conceptualisation of subsequent studies (Kiecolt & Nathan, 1985; Shaw, 2005). Given that the experiences of mothers of children with ASD living in regional and remote areas have not been widely investigated, a secondary analysis of the existing data is an appropriate initial method to explore this research topic. The original survey items were created by the researchers in consultation with clinicians and service users (Horlin et al., 2014). Although the survey was developed for a particular purpose (i.e., calculating the costs associated with raising a child with ASD), it contained a broad range of questions. Thirty five out of 71 items of the original survey are chosen for the purpose of conducting this secondary analysis study.

Participant recruitment and Procedures. In 2013, a total of 3,965 surveys were distributed to the families of children with ASD who were registered with the Disability Service Commission (DSC) in Western Australia. The survey packages that contained the survey and a returned envelop were mailed out to each family using the DSC register. After one month, follow-up notices to complete the survey was published online, in newspapers, DSC newsletters and on community radio. In total, 545 surveys were returned and, of those, 535 surveys contained the required information to conduct this secondary analysis study. There are 476 participants who lived in major city areas and 59 participants who lived in regional and remote areas. The Australian Geography Standards remoteness structure is used to classify participants' region of residence (Australian Bureau of Statistics, 2013).

Data analysis. Descriptive statistics are conducted to analyse the demographic data. Analysis of non-response is also conducted (see Table 3.4 Appendix H2). To identify key factors that are associated with region of residence, several analyses are conducted. First, *chi*-square or independent sample *t*-test are conducted to compare variables (i.e., family routines, service usage and stress levels) between mothers from regional and remote areas and mothers from major city areas. Normal distribution and outliers of dependent variables are checked prior to conducting *t*-tests (Field, 2013). For all *t*-tests, Levene's test for equality of variance is checked (Urdan, 2017) and equal variance is assumed between the two groups of mothers ($p > 0.05$). Variables that are categorical, such as types of school attended by the child with ASD, are analysed by using *chi*-square tests. For all missing values, one discrete value of -99 is specified in SPSS (Field, 2013). Those variables that are found to be significantly different between the two groups using *chi*-square and *t*-tests are then entered into the univariate analysis to identify significant associations between those identified variables (independent variables) and region of residence (dependent variable), prior to conducting the multivariate logistic regression.

In conducting the multivariate logistic regression, a stepwise method of backward elimination is used. This method has been criticised due to the risk of selecting irrelevant variables (Griffiths & Pope, 1987; Hosmer, Lemeshow & Sturdivant, 2013). It is recommended that the selection of variables should be informed by theory and, subsequently, the use of regression methods such as forced entry (Field, 2013; Tabachnick & Fidell, 2001). However, as there is a paucity of research that compared the experiences of mothers of children with ASD by their region of residence, selecting variables based on theory is not feasible. As such, the stepwise backward elimination method is selected, as the purpose of the stepwise method is not to identify ‘best’ models or to find the order of importance in variables (Derksen & Keselman, 1992). Rather, this method allows researchers to identify independent variables that are useful in predicting the dependent variable in a study that is exploratory in nature (Field, 2013; Tabachnick & Fidell, 2001).

The initial variables to be included in the pool of a stepwise regression analysis is important, as this could impact on the number of irrelevant variables included in the final model (Derksen & Keselman, 1992; Tabachnick & Fidell, 2001). Therefore, prior to logistic regression analysis, *chi*-square test, *t*-test and univariate analysis are conducted to identify variables which are significantly associated with the region of residence (i.e., the dependent variable in logistic regression analysis). In conducting logistic regression analysis, the issue of multicollinearity may arise (Field, 2013). Multicollinearity occurs when predicting variables that are highly correlated with each other (Tabachnick & Fidell, 2001). It leads to problems such as increasing the size of errors and limiting the size of correlations (Field, 2013; Tabachnick & Fidell, 2001). To check multicollinearity, variance inflation factor (VIF) and tolerance statistics are run with the variables included in the final model. Although there is no agreed values of VIF and tolerance statistics that indicate multicollinearity (Field, 2013), the VIF value that is greater than 10 and tolerance that is below 0.2 are indicative of high correlation (Bowerman & O’Connell, 1990; Menard, 2002). All the VIF values for the variables included in the final model are below 10 and tolerance is above 0.1 and, therefore, no multicollinearity is evident.

Summary. This chapter investigates the experiences of mothers of children with ASD in relation to family routines, service usage and stress levels, using secondary analysis of data. The experiences of these mothers are compared by their region of residence. The results of this chapter informs subsequent chapters by highlighting the importance of using validated instruments to obtain more reliable results. In addition, the chapter highlights the need to develop more specific questions related to family routines. The approach of time-use investigation that breaks down everyday activities was recommended to closely examine the experiences of these mothers in managing family routines.

Chapter 4: Cross Sectional Survey Study

Chapter 4 includes an analysis of a cross-sectional survey that uses validated instruments to investigate stress levels, quality of life (QoL), coping strategies and time-use among mothers of children with ASD in relation to their household status (i.e., single versus coupled mothers). Following section will present a brief overview of methods used to conduct this study. More detailed information is presented in Chapter 4. This chapter is presented as a published paper.

Study design. This study is a part of larger study that investigated a broad topic that is related to the experiences of families of children with ASD in Western Australia, using a cross-sectional survey. A number of topics were included in the survey under the following four sections: family demographic information, ASD diagnostic processes and access to services, behavioural difficulties related to ASD characteristics and the potential impact of having a child on family life. A pilot study was conducted using convenience sampling.

Participant recruitment. Parents who have a child aged between 2 and 18 years with a diagnosis of ASD living in Western Australia are eligible to participate in this study. The participants are recruited through contact lists compiled by Curtin University, Telethon Kids Institute and other disability service providers in Western Australia. A total of 226 participants completed the survey for the larger study. Of those, 207 participants are mothers whose results were included in this study. The definition of a single parent is adopted from the Australian

Bureau of Statistics (2015) to define single mothers in this study. There are 43 single mothers and 164 coupled mothers.

Instruments used. This study uses three validated instruments, including The World Health Organisation Quality of Life Brief (WHOQOL BREF) (The WHOQOL Group, 1998), Autism Parental Stress Index (APSI) (Silva & Schalock, 2002) and Brief COPE (Carver, 1997). Detailed information on the psychometric properties for each instrument is provided in Chapter 4. To investigate time-use of mothers, a 24-hour time-use estimate table is also included. Participants completed this table to report their average time-use for weekday and weekend day against everyday activities listed in the table.

Procedures. Participants completed the survey by choosing one of the following three methods: 1) online, 2) a telephone interview, and 3) a paper and pencil version. The survey was made available for a year in 2015. Due to the procedures used to collect data, it was not possible to conduct a non-response analysis.

Data analysis. The demographic information is analysed using descriptive statistics. A factor analysis is conducted to explore the structure of the Brief COPE. A principle component analysis with oblimin rotation is used. More detailed information of the factor analysis can be found in Chapter 4. The factor analysis yielded five factors. A *chi*-square test is conducted to identify differences between single and coupled mothers (i.e., household status). Similar to the method used in Chapter 3, univariate analyses are conducted to identify variables, including WHOQOL BREF and APSI scores, coping factors, and time-use that were significantly associated with the household status (i.e., dependent variable). Those variables identified as significant at an univariate level are then entered into the multivariate analysis to identify factors associated with household status. A backward elimination method is used to conduct the multivariate analysis. Once the final model is developed, those demographic variables that were identified as significantly different between single and coupled mothers using *chi*-square tests, such as cognitive impairment of the child and household income, are used to adjust the model. The process of backward elimination is repeated until the final model with demographic variables was developed. The child having a cognitive impairment and mothers' education levels did not significantly contribute to the final model. Multicollinearity is checked using VIF and tolerance statistics; no evidence of multicollinearity is found.

Summary. This chapter compares stress levels, QoL, coping strategies and time-use between single and coupled mothers of children with ASD, using a cross-sectional survey. Building on the previous chapter, this chapter presents findings that are based on validated instruments and the inclusion of a time-use estimate table that specifically investigated these mothers' everyday experiences. Further, the experiences of these mothers are compared by their household status, which was not possible in previous chapters due to the design of the survey. Use of a time-use table is a common method to investigate the everyday experiences; however, past research found that people could under or overestimate their time when completing a time-use table, which may result in inaccurate findings (Järbrink et al. 2003). Methods, such as experience sampling method (ESM), are considered to obtain a more accurate and nuanced account of everyday time-use. As such, the decision was made to use ESM in subsequent studies to investigate mothers' everyday time-use related to family routines.

Chapter 5: Experience Sampling Method Study

Chapter 5 comprises of an experience sampling method (ESM) study to investigate mothers' in-the-moment experiences and time-use in the areas of childcare, domestic tasks, productivity, self-care and leisure activities. The results are compared by mothers' household status and region of residence. In the following section, the method employed to conduct this

ESM study is briefly explained. More detailed information of the method is available in Chapter 5. This chapter is presented as a paper submitted for publication.

Study design. Chapter 5 employs ESM that allows researchers to investigate time-use and in-the-moment experiences of participants (Hektner et al., 2007; Shiffman et al., 2008). Traditional methods, such as daily diary entry, cannot explore in-the-moment experiences to investigate participants' everyday experiences. Furthermore, ESM has not been widely used with this population of mothers (Dunton et al., 2017), which is surprising given that it requires less cognitive demand than traditional methods (Chen et al., 2016). Therefore, ESM is deemed suitable for investigating the everyday experience of this population who commonly experience time pressure (Curran et al., 2001).

Participant recruitment. Convenience sampling is used to recruit participants. Participants who completed the cross-sectional study (Chapter 4) were invited to participate in this study by email and phone. In total, 40 mothers participated in this ESM study. The region of residence is classified using the same criteria as described in Chapter 3 and the same definition of a single parent household as defined in Chapter 4 is used to determine the household status.

Instruments used. The ESM survey is conducted using an iOS application, Participation in Everyday Life Survey Application (PIEL© survey). The survey contains 14 questions that were developed by the PhD candidate and co-authors to investigate mothers' in-the-moment feelings related to participating in everyday activities and their time-use was recorded. Six activity categories are investigated in this survey: 1) resting or doing nothing, 2) childcare, 3) domestic tasks, 4) self-care, 5) personal leisure, and 6) productivity.

Procedures. The ESM survey was downloaded to participants' iPhone or iPad, depending on their choice. The device randomly prompted participants 7 times a day over a 7-

day period during school terms to answer a survey. Following a training session, the participants were instructed to carry the device between 7.30 am and 9 pm and answer as many surveys as possible.

Data analysis. The data analysis in this chapter involves a two-step process. First, Mann-Whitney *U* test is conducted to compare the time-use of mothers by their household status and region of residence. The proportion of time spent in each activity category is calculated (Hektner et al., 2007). As some of the data from each category was not normally distributed, use of a non-parametric alternative of *t*-test was an appropriate option in comparing mother's time-use (Urdan, 2017). Assumptions for non-parametric tests are met (Pallant, 2007).

Second, multilevel linear analyses are conducted to investigate the relationships between mothers' in-the-moment feelings and activities, and the moderating effects of household status and region of residence on the relationships between in-the-moment feelings and activities. The ESM data has a hierarchical structure with multiple surveys (Level 1) that are nested within the same participants (Level 2), creating dependency within the participants (Leeuw & Meijer, 2008; Snijders & Bosker, 2012). As multilevel analyses account for this dependency (Snijders & Bosker, 2012), this analytical approach is deemed appropriate to analyse ESM data, instead of conventional ordinary least squares (Nezlek, 2001).

Summary. In-the-moment feelings and time-use of mothers of children with ASD are investigated in this chapter. In line with the purpose of this thesis, the results are compared by mothers' household status and region of residence to examine similarities and differences. As the previous cross-sectional study (Chapter 4) used a 24-hour time-use table, which involves a retrospective approach that does not capture in-the-moment feelings, ESM is used in the study reported in Chapter 5. This chapter adds to the previous chapters by providing new perspectives of mothers’ everyday experiences (i.e., more accurate time-use data and in-the-moment feelings) and building further evidence by comparing single and coupled mothers, as well as mothers from regional and major city areas. All previous chapters (Chapter 3 to 5) employed quantitative methods (i.e., cross-sectional surveys and ESM) in investigating the experiences of mothers of children with ASD. Although results from these chapters have contributed to develop an understanding of the experiences of mothers, such as identify daily activities that are particularly challenging, reasons or meaning behind these results remain unknown. Therefore, to further elicit an in-depth understanding of the experiences of these mothers, a qualitative method (i.e., interpretive phenomenological approach) will be used in the next study to explore individual accounts of these mothers in managing family routines.

Chapter 6: Individual Interview Study

Chapter 6 comprises of a phenomenological study to explore mothers’ perceptions of family routines in relation to their own health and wellbeing. The following section provides a brief summary of the methods employed to conduct this interview study. More detailed information of the method is available in Chapter 6. This chapter is presented as a published paper.

Study design. Interpretive phenomenological approach (IPA) is employed to obtain meaningful and important accounts from mothers of children with ASD in constructing family routines in relation to their health and wellbeing. The theoretical origin of IPA is critical realism and the cognitive paradigm (Bhaskar, 1978; Fiske & Taylor, 1991). IPA emphasises the exploration of meaning and sense-making of participants and this emphasis aligns with the cognitive paradigm (Smith & Osborn, 2008). Under critical realism, each individual is believed to attach different meanings to experiences, because each of them lives in different realities. This belief aligns with IPA that aims to develop an in-depth understanding of individual human experiences (Smith, Flowers, & Larkin, 2009). IPA is appropriate in exploring the experiences of mothers of children with ASD, as it allows researchers to obtain unique perspectives of individual participants while developing a meaningful theme (Larkin, Watts, & Clifton, 2006). The process of IPA is ‘double hermeneutic’ and is, therefore, dynamic (Smith et al., 2009).

Participant recruitment. The participants are purposively selected in line with the overall aim of this thesis (i.e., increasing the current understanding of single mothers and mothers who live in regional areas that have been under researched in the area of family routines). Unlike quantitative studies that aim to generalise findings to other populations, using purposive sampling to include a diverse range of participants is important in a qualitative study, in particular when a nuanced understanding of complex phenomena needs to be explored (Moen & Middlethon, 2015). In total, twenty mothers participated in this study. Of those 20, ten were coupled mothers and five were mothers who resided in regional areas. The same recruitment strategy as the ESM study (Chapter 5) is employed.

Procedures. A semi-structured interview guide is used to obtain meaningful and important descriptions of participants’ experiences (Larkin et al., 2006). The question guide comprised five open-ended questions that explore the experiences of mothers in managing family routines in relation to their health and wellbeing. The PhD candidate conducted all the interviews either face-to-face or telephonically.

Data analysis. The previously recommended IPA steps are used as a guide (Smith & Osborne, 2008). To promote rigour of the study, the PhD candidate engaged in reflexivity. For example, the candidate and a supervisor constantly reflected on the personal background of the candidate (i.e., a mother of a young child) throughout the analysis process. This process allowed the candidate to understand the perspectives she brought when interpreting the interview data.

Summary. The meanings attributed to family routines are explored in this chapter, which could not be investigated by the methods used in previous chapters (i.e., cross-sectional surveys and ESM). Both cross-sectional survey studies (Chapters 3 and 4) investigated aspects of mothers' health and wellbeing, such as levels of stress, and the ESM study investigated how mothers constructed family routines (i.e., time-use). However, a rich account of the individual experiences of mothers could not be explicated. This chapter adds to the previous studies by addressing the unique experiences of mothers and their perspectives of their health and wellbeing in relation to family routine management. Family routines, however, are intricate involving multiple factors. As such there is a need to understand the transactional nature of constructing functional family routines between and among family members (Sameroff & Fiese, 2000). Therefore, the next study (Chapter 7) adopted a mixed methods approach that allowed the researcher to unpack the complexities involved for mothers of children with ASD in managing family routines (Creswell & Plano Clark, 2011).

Chapter 7: Mixed Methods Study

Chapter 7 comprises of a mixed methods study where data from the ESM study (Chapter 5) and the individual interview study (Chapter 6) are combined to construct meta-inferences. The findings of the ESM and interview studies are extended to explore potential new understanding of the experiences of mothers of children with ASD in constructing family routines. In the following section, the method employed to conduct this mixed method study is explained. This chapter is presented as a paper submitted for publication.

Study design. A convergent mixed method design is adopted whereby quantitative and qualitative data is collected and analysed separately before being integrated to enhance existing interpretations (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). In a convergent mixed methods approach, both quantitative and qualitative methods are equally emphasised

(Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). Placing equal emphasis on both methods is particularly important in investigating the experiences of family routine management among mothers of children with ASD, as their experiences can be complex, thus requiring multiple perspectives to develop a sound understanding (Sameroff & Fiese, 2000; Suarez et al., 2014). ESM (Chapter 5: quantitative) and individual interview (Chapter 6: qualitative) data is combined to obtain a more in-depth understanding of these mothers. The benefits of this design are both its efficiency, where both quantitative and qualitative data are collected concurrently, and its complementary nature that may lead to the development of substantiated findings (Plano Clark & Ivankova, 2016).

Theoretical foundation of mixed method approach. Although mixed methods can be useful to address complex questions through multiple perspectives (Taket, 2010), the difference in paradigms and assumptions about ontology and epistemology between quantitative and qualitative approaches has led to an ongoing debate of incommensurability of the two approaches (Creswell & Plano Clark, 2011; Giddings, 2006; Sale, Lohfeld & Brazil, 2002; Taket, 2010). To overcome the issue of the incommensurability between quantitative and qualitative approaches, some authors suggested that pragmatism should be adopted as a theoretical foundation that underpins mixed methods (Creswell & Plano Clark, 2011; Morgan, 2007; Tashakkori & Teddlie, 2003). Using this theoretical underpinning, researchers seek a consensus point between quantitative and qualitative approaches, rather than opposing each approach based on the difference in assumptions or paradigms (Morgan, 2007). In applying pragmatism, it is believed that research methods should not be constricted due to a difference in paradigms (Gorard, 2004), as the strengths of mixed method research lie in its possibility to develop a more complete understanding of a complex phenomenon (Creswell & Plano Clark, 2011). When investigating complex phenomena, the divide between quantitative and qualitative approaches can impoverish the quality of study outcomes by limiting the number of approaches to solve important research questions (Gorard, 2004, 2010). Although the importance of assumptions should be considered when adopting pragmatism (Morgan, 2007), the focus of this theoretical foundation is to generate outcomes that address research questions in a meaningful manner, while making decisions to use a number of different methods instead of emphasising theoretical issues (Greene & Hall, 2015). By adopting pragmatism, the complexities that exist in addressing research questions or explaining human phenomena can be acknowledged (Gorard, 2010; Morgan, 2007).

Participant recruitment. The eligibility criteria and the recruitment processes explained for Chapters 5 and 6 apply to this chapter (Chapter 7). The participants who were included in this study are those who participated in both the ESM (Chapter 5) and interview (Chapter 6) studies. Recruiting the same participants for quantitative and qualitative strands is recommended as the purpose of the study was to extend the knowledge of mothers of children with ASD by integrating the two sets of findings (Creswell & Plano Clark, 2011). The number of participants for the ESM study was 40, while the number of participants for the interview study was 20. The difference in sample size is not an issue, as the purposes of data gathering process for each method are distinct (Creswell & Plano Clark, 2011).

Data analysis. As a convergent mixed method was employed, the ESM (quantitative) and interview (qualitative) data were analysed separately. Explanations and justifications for the analysis processes employed for the ESM and interview studies are provided in Chapter 5 and 6 respectively. The results of the ESM and interview studies are integrated using the approach of joint display. Using a figure or table, researchers arrange both quantitative and qualitative data to directly compare the two sources (Creswell & Plano Clark, 2011). The dimensions used to compare the two sources were childcare, productivity, personal leisure, self-care, and domestic tasks. The decision to use these dimensions was made because these were used in designing the ESM survey and were discussed during the semi-structured interviews. More specific analytical procedures are discussed in Chapter 7.

Summary. This chapter synthesised findings from the ESM (Chapter 5) and interview studies (Chapter 6) by using a convergent mixed method design. The ESM study provided the data on daily time-use and 'in-the-moment' feelings of mothers of children with ASD and the interview study provided insights of these mothers in managing family routines. Through combining the two studies, this chapter extends the current knowledge by offering a more in-depth understanding of the complexity involved in managing family routines among mothers of children with ASD.

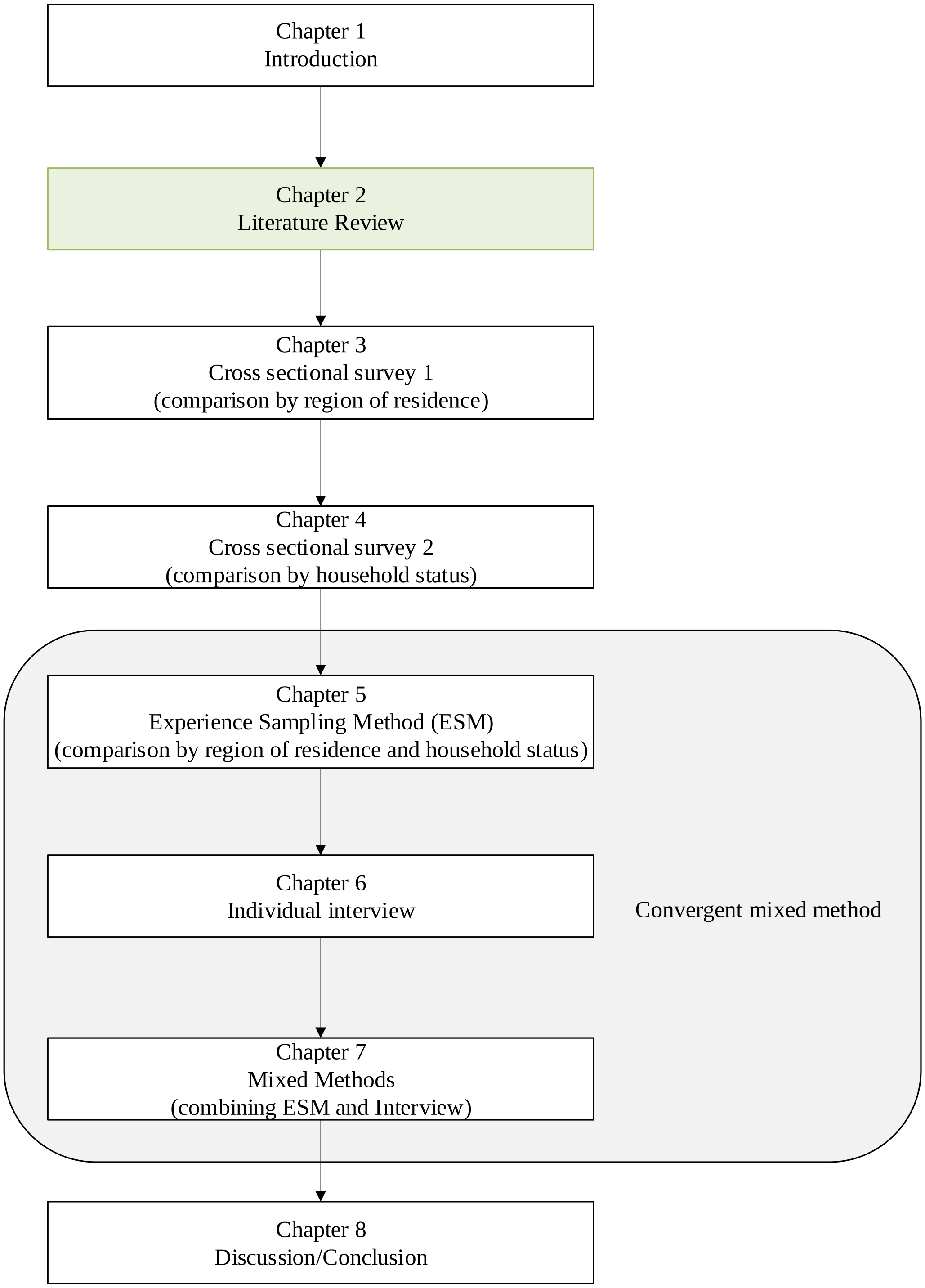
Chapter 8: Discussion and Conclusion

Chapter 8, the final chapter of the thesis, comprises of a synthesis of the findings and conclusions. A summary of each study is provided to recap the main points. A detailed discussion of the unique experiences of mothers of children with ASD when constructing family routines is presented using a theoretical framework to depict its complexity. The thesis concludes by suggesting strategies for clinical practice to promote health and wellbeing of mothers.

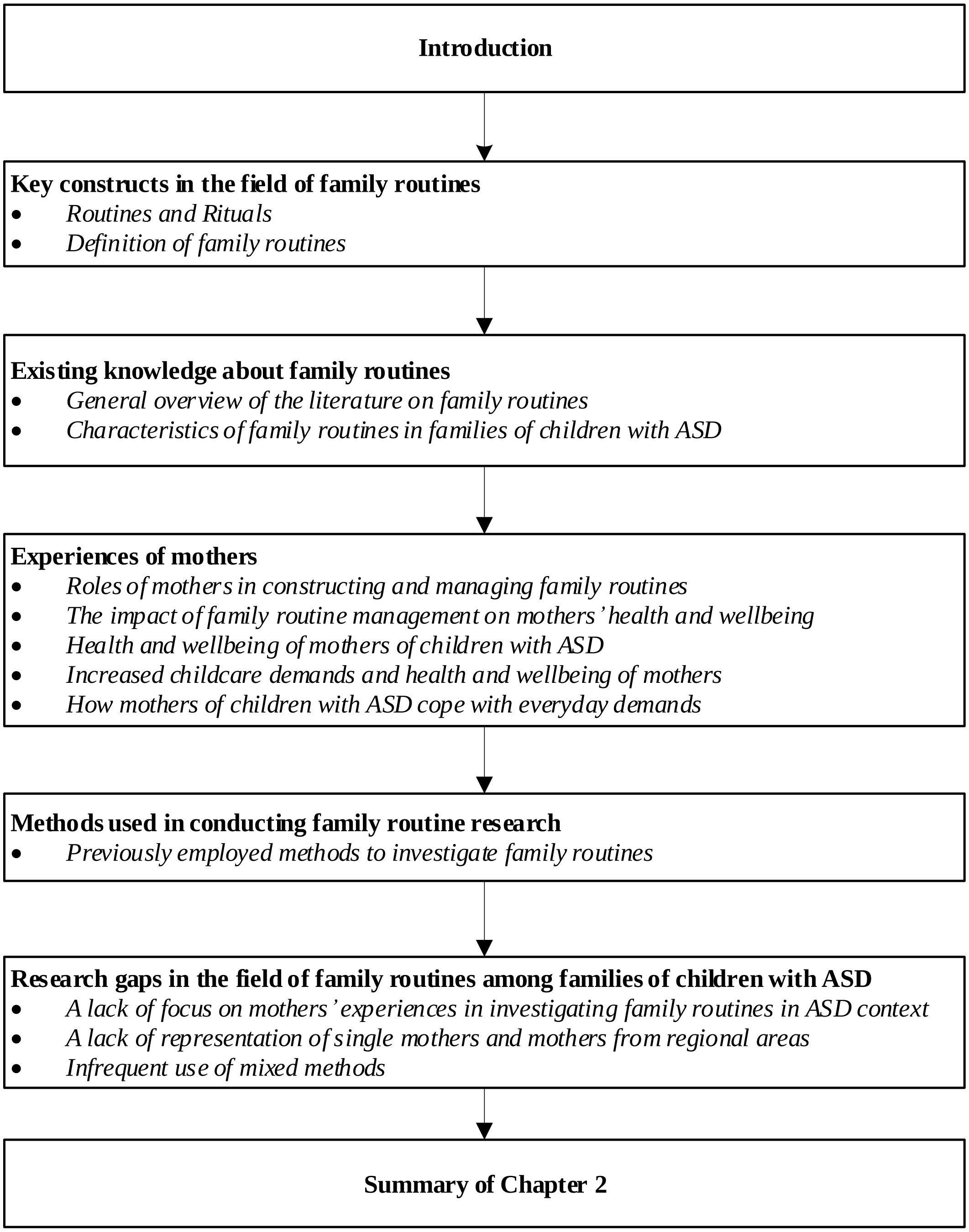
Summary of Chapter 1

This chapter provided a brief background to the thesis, which situated the overall aim and sub-aims of the thesis. The significance of the thesis was presented to demonstrate the need to investigate the experiences of the mothers of children with ASD in constructing family routines. Two theoretical frameworks that underpin this thesis, as well as the thesis structure were also presented. The next chapter will present a literature review that synthesises previous family routine studies, while focusing on the experiences of mothers of children with ASD. The constructs relevant to the field of family routine research, as well as a definition of family routines in this thesis will be presented. The literature review will identify three gaps in the area of family routines, which provide a rationale for the thesis.

Chapter 2 Literature Review



This chapter provides a literature review on family routines, discussing existing literature in five sections as outlined in the flowchart below (Figure 2.1).



Introduction

Key constructs in the field of family routines
- *Routines and Rituals*
- *Definition of family routines*

Existing knowledge about family routines
- *General overview of the literature on family routines*
- *Characteristics of family routines in families of children with ASD*

Experiences of mothers
- *Roles of mothers in constructing and managing family routines*
- *The impact of family routine management on mothers' health and wellbeing*
- *Health and wellbeing of mothers of children with ASD*
- *Increased childcare demands and health and wellbeing of mothers*
- *How mothers of children with ASD cope with everyday demands*

Methods used in conducting family routine research
- *Previously employed methods to investigate family routines*

Research gaps in the field of family routines among families of children with ASD
- *A lack of focus on mothers' experiences in investigating family routines in ASD context*
- *A lack of representation of single mothers and mothers from regional areas*
- *Infrequent use of mixed methods*

Summary of Chapter 2

Figure 2.1 Structure of literature review

The literature review will discuss the following points: 1) Introduction; 2) Key constructs in the field of family routines: the two key constructs, routines and rituals, that are commonly used in the literature and provides the definition of family routines that is relevant to this thesis; 3) Existing knowledge about family routines: an overview of family routines, including the common characteristics and benefits of family routines in the context of ASD; 4) Experiences of mothers: the experiences of mothers of children with ASD and their health and wellbeing in relation to family routines; and 5) Methods used in conducting family routine research: research methods commonly employed in the field of family routines. Three gaps in the family routine research that are identified in the current review will be discussed followed by a summary of this chapter.

Introduction

Three major literature reviews have been conducted in the field of family routines (Boyd et al., 2014; Crespo et al., 2013; Fiese et al., 2002); however, these reviews do not provide an essential context for the purpose of this thesis. The most recent review by Boyd et al. (2014) synthesised literature of family routines of children with autism spectrum disorder (ASD); however, their review was limited to occupational science and occupational therapy literature. An older review by Fiese et al. (2002) covered 50 years of literature on family routines spanning from 1950 to 2000. Although their review included literature from a broader discipline and discussed naturally occurring routines in community-based samples, it requires update. The review by Crespo et al. (2013) synthesised the literature that investigated the impact of chronic conditions, including both adult and paediatric conditions on family routines; however, it did not address the specific experience of families of children with ASD. Therefore, the current review aims to synthesise a broad overview of key findings of family routines with a specific focus on the experiences of mothers of children with ASD.

Key Constructs in the Field of Family Routines

Routines and Rituals

Routines and rituals are two prominent constructs in the field of family routines used by researchers to investigate the impact of family life on individual family members and the impact of individual members' perspectives or characteristics on family life (Fiese, 2007). Fiese et al. (2002) proposed three dimensions: *communication, commitment*, and *continuity* that distinguish these two constructs. Routines are patterned and continually repeated activities that involve *instrumental communication* to complete certain tasks, while making a *momentary time commitment* (Boyce et al., 1983; Fiese et al., 2002). Rituals are also repeated activities; however, rituals have an added layer of *symbolic communication* that assists in developing group identity, together with *commitment* and *continuity* over time, which provide affective experiences for the group, such as development of a sense of belonging and the passing on of family traditions (Fiese et al., 2002; Wolin & Bennett, 1984). Family routine is a foundation for developing rituals, which, in turn, provide meaning deriving from engaging in routines (Fiese et al., 2002; Marquenie et al., 2011; Schuck & Bucy, 1997; Segal, 2004a). The relationship between routines and rituals is not linear, but intricate and multidimensional, as rituals support participation in routines (Segal, 2004a). Family rituals encourage interactions, while promoting cohesion and reducing stress levels (Marquenie et al., 2011). If routines are disrupted, a family may experience stress in daily life; whereas if rituals are disrupted, a sense of cohesion may be reduced (Fiese et al., 2002; Spagnola & Fiese, 2007).

Examining family routines and rituals provide a window to consider its transactional nature (Fiese, 2007; Sameroff & Fiese, 2000). To construct family routines, two or more people need to be involved (Jensen et al., 1983). Family routines develop through interactions between family members and each member needs to mutually contribute to the process of its development

(Boyd et al., 2014; Fiese et al., 2002). Routines need to be mutually agreed upon between family members to convey traditions and values across generations (Boyce et al., 1983). This mutuality in constructing family routines resonates with the transactional model (Sameroff & Mackenzie, 2003). The transactional model that is commonly used in the field of developmental psychology considers reciprocal interactions between parents and children that influence one another and their environments (Sameroff, 2009; Sameroff & Mackenzie, 2003). This means that if some family members, such as children with disability, experience difficulty with participating in reciprocal interactions, that difficulty can influence the construction of family routines as a whole (Fiese et al., 2002). A family works together to construct routines that achieve certain instrumental goals, as well as provide meaningfulness in life (Boyd et al., 2014). In this sense, family routines can be viewed as “behavioural units of family life” (Jensen et al., 1983, p. 201).

Definition of Family Routines

Despite attempts by some authors to distinguish between routines and rituals (Evans & Rodger, 2008; Marquenie et al., 2011; Rodger & Umaibalan, 2011), the two constructs have been used interchangeably by others (Denham, 2003). These two related constructs are conflated in earlier definitions of the term ‘family routines’, leading to confusion. An earlier study defined family routines as an “…enveloping framework within which daily lives are given shape and meaning (Koome, Hocking, & Sutton, 2012, p. 320)”, that includes the element of ritual (i.e., meaning). This confusion is due to the overlap between the two constructs. For example, children’s bedtime or sleep time routines allow parents to complete necessary tasks with their children (e.g., brushing teeth) that serve an instrumental purpose; however, these two routines can also act as family rituals where families, in particular mothers and their children, are able to spend time together to connect with each other, which, in turn, promote family identity (Evans & Rodger, 2008).

This thesis acknowledges the distinction between the two constructs and its relative importance that were argued in previous literature (Crespo et al., 2013; Fiese et al., 2002; Spagnola & Fiese, 2007). However, similar to Boyd et al. (2014), due to the overlap of the two constructs, in the current thesis, the term ‘family routines’ will be used to include the term ‘family rituals.’ The author acknowledges that a single definition will not encompass all elements of routines as they are unique to each family and individual thoughts and beliefs influence its constructions (Boyce et al., 1983; Fiese et al., 2002; Reich & Williams, 2003). However, for the purpose of the thesis, ‘family routines’ is defined as follows. Family routines are organised, sequenced activity patterns that are developed through mutual interactions and participation between two or more family members (Jensen et al., 1983; Larson & Miller-Bishoff, 2014). Family routines “…occur at specific time and in specific space. This tight and intricate sequencing allows the family to organise the individual and shared activities necessary to sustain health, well-being and connectedness among family members” (Larson & Miller-Bishoff, 2014, p. 1).

Existing Knowledge about Family Routines

General Overview of the Literature on Family Routines

Family routines organise daily life to provide structure, a sense of security, belonging and opportunities for family members to emotionally connect with one another (Crespo et al., 2013; Larson, 2006; Muñiz, Silver, & Stein, 2014; Rodger & Umaibalan, 2011). The predictability, stability and meaningful experiences obtained through family routines act as a buffer against everyday stressors in family life (Churchill & Stoneman, 2004; Markson & Fiese, 2000; Wolin & Bennett, 1984). The benefits of routines to family health and wellbeing is well documented for both families of typically developing children, as well as for those with children with disability (Downs, 2008; Fiese, 2007; Fiese, Foley, & Spagnola, 2006; Muñiz et al., 2014). Regular participation in family routines support children's social and emotional health (Muñiz et al., 2014). For example, increased frequency of family mealtime is associated with better social skills development and school engagement among children with and without disability (DeGrace, Foust, Sisson, & Lora, 2016; Lora, Sisson, DeGrace, & Morris, 2014). Moreover, common family routines, such as leisure, provide opportunities for the family to share happiness and create normalcy in life, while fostering a sense of control over their life and environment (Downs, 2008).

Commonly studied populations in family routine literature include: (a) families of children or adolescents with disability, including ASD (Bagatell, 2016; Bagatell, Cram, Alvarez, & Loehle, 2014; DeGrace, 2004; DeGrace et al., 2016; Downs, 2008; Evans & Rodger, 2008; Larson, 2006; Larson & Miller-Bishoff, 2014; Marquenie et al., 2011; Rodger & Umaibalan, 2011; Schaaf et al., 2011; Segal, 2004b; Segal & Frank, 1998); (b) children and adults with chronic illness, such as asthma (Denham, Manoogian, & Shuster, 2007; Markson & Fiese, 2000); (c) adolescents or adults with mental health and alcohol problems (Bennett, Wolin, Reiss, & Teitelbaum, 1987; Koome et al., 2012); and (d) typically developing children (Churchill & Stoneman, 2004; Lora et al., 2014; Muñiz et al., 2014). Notably, families of children with disability are the most commonly examined population (DeGrace, 2004; Marquenie et al., 2011; Rodger & Umaibalan, 2011).

Some studies included family members as study participants (Bagatell et al., 2014; DeGrace, 2004; Koome et al., 2012); however, in many previous studies, mothers are the primary participants being interviewed to answer on behalf of their families (Bagatell, 2016; Churchill & Stoneman, 2004; Evans & Rodger, 2008; Larson, 2006; Marquenie et al., 2011; Schaaf et al., 2011). These mothers are commonly coupled mothers who lived in major city areas, thus representing the experiences of a homogenous group of mothers (Downs, 2008; Marquenie et al., 2011; Rodger & Umaibalan, 2011).

The most commonly investigated domains of family routine studies include: mealtime (DeGrace et al., 2016; Evans & Rodger, 2008; Lora et al., 2014; Marquenie et al., 2011); bedtime (Evans & Rodger, 2008; Marquenie et al., 2011); morning routine (Clarke, Dunlap, & Vaughn, 1999); and leisure (Downs, 2008). Some studies investigated family routines, not in its component parts, but as a whole (Bagatell, 2016; Bagatell et al., 2014; Rodger & Umaibalan, 2011). Family routines have predominantly been studied in relation to the characteristics of the child with disability and its impact on family life or child outcomes from mothers' perspectives (Bagatell, 2016; Bagatell et al., 2014; Marquenie et al., 2011; Rodger & Umaibalan, 2011; Schaaf et al., 2011). Mothers often assume major responsibility in constructing family routines; however, their personal experiences have not been the main focus in the area of family routines (Kellegrew, 2000; Larson & Miller-Bishoff, 2014; O'Brien, 2004; Thullen & Bonsall, 2017).

Characteristics of Family Routines in Families of Children with ASD

The triad of ASD symptomology involving impaired communication, impaired reciprocal social interaction and restricted, repetitive and stereotyped patterns of behaviours or interests, as well as concomitant issues, such as challenging behaviours and anxiety, can present challenges to families in designing practical routines (DeGrace, 2004; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Larson, 2006; Marquenie et al., 2011). Clear expectations, stability, and regularity provided through family routines can assist the child with ASD to feel secure in coping with changes that occur in daily life (Larson, 2006; Schaaf et al., 2011).

Families of children with ASD construct family routines, such as mealtime, to address the needs of the child, often at the expense of other family members (DeGrace, 2004; Hoogsteen & Woodgate, 2013a; Marquenie et al., 2011; Suarez et al., 2014). This tendency to organise routines around the needs of the family members with a disability can define the identity of the whole family (Fiese, 2007). Some families may experience difficulties in having ‘normal’ family time (DeGrace, 2004; Larson, 2006; Suarez et al., 2014) and feel that their family life is dictated by the child with ASD’s behaviour (DeGrace, 2004; Larson, 2006). However, to maintain meaningful family routines, there is a need for the routines to be flexible to meet the demands of the children (DeGrace, 2004; Schaaf et al., 2011).

Shared family routines are important for developing family relationships, bonding and togetherness, and hence these routines provide unique meaning to family members (Bagby et al., 2012; Fiese et al., 2002). The tendency to design family routines around the needs of the child with ASD can lead to some difficulties in shared family routines (DeGrace, 2004; Schaaf et al., 2011). For example, shared family routines like mealtime can be particularly challenging, stressful and energy consuming experiences for families of children with ASD (Curtin et al., 2015; Marquenie et al., 2011; Suarez et al., 2014; Thullen & Bonsall, 2017). Children with ASD often demonstrate strong food selectivity and sensitivity and their preferences may influence what other family members eat (Curtin et al., 2015; Thullen & Bonsall, 2017). Families of children with ASD frequently separate meals for different family members to reduce the challenges during mealtime (Suarez et al., 2014). The realisation that it is not possible to have shared family routines as envisioned can create a sense of discontent among mothers (Suarez et al., 2014). This example of mealtime routines demonstrates a disruption in shared family routines that can create stress and discordance in family life (DeGrace, 2004; Marquenie et al., 2011). However, shared family routines can also assist families to develop a sense of cohesiveness and increase family quality of life (Ausderau & Juarez, 2013; Evans & Rodger, 2008; Fiese et al., 2002).

Parents of children with ASD often accommodate or adapt their routines to integrate the unique needs of their child (Ausderau & Juarez, 2013; Bagby et al., 2012; Bernheimer & Weisner, 2007). Although the individualised accommodation or adaptation techniques used are unique to each family, due to individual family characteristics such as relationship dynamics (Bernheimer & Weisner, 2007), the overriding principle of minimising sensory stimuli or unpredictability in routines are common among families of children with ASD. For example, parents avoid activities that involve particular people or places that can trigger their child's challenging behaviours due to sensory experiences (Bagby et al., 2012; Larson, 2006; Schaaf et al., 2011). Families of children with ASD use their own unique strategies to adapt routines to engage with meaningful activities (Bagatell, 2016; Bernheimer & Weisner, 2007). For many, the process of accommodation and adaptation of family routines in changing everyday context can be challenging and stressful (Bagatell et al., 2014; Boyd et al., 2014).

Routines become more meaningful to individual families when children contribute to the construction of family routines (Fiese et al., 2002) and some families of children with ASD find particular routines, such as bedtime or bath time, more meaningful than others (Bagby et al., 2012; Marquenie et al., 2011). Unlike mealtime that typically involves all family members, bedtime routines often only involve the mother and the child with ASD (Marquenie et al., 2011). Mothers can foster their relationship with their children by appropriately addressing the needs of the child to minimise challenging behaviours and disruption during bedtime routines (Marquenie et al., 2011). However, it is important to note that each family is unique and the same family routine, such as bedtime, may not be meaningful to all families of children with ASD (Schaaf et al., 2011).

Focusing on Mothers' Experiences

Role of Mothers in Constructing and Managing Family Routines

Managing family routines can be a burdensome and challenging experience for mothers of children with a disability (Fiese, 2007; Larson & Miller-Bishoff, 2014). Mothers play a major role in constructing family routines and appropriate support may not be readily available (Bagatell, 2016; Larson, 2006; Larson & Miller-Bishoff, 2014). In constructing family routines, mothers often prioritise the needs of their child with disability, while balancing the needs of other family members (Larson, 2006). Constructing family routines is a complex and dynamic process as internal and external factors that are unique to each family need to be considered (Churchill & Stoneman, 2004; Fiese et al., 2002; Larson & Miller-Bishoff, 2014). For example, the interplay between various unique factors, such as the language and socioemotional development of children (Muñiz et al., 2014; Spagnola & Fiese, 2007), parental health issues (Churchill & Stoneman, 2004), work, school, health service provisions, culture (Fiese et al., 2002; E. Larson & Miller-Bishoff, 2014; Segal & Frank, 1998), illness of family members, and related medical and therapy appointments (Faw & Leustek, 2015; Fiese & Womboldt, 2000) require consideration. Evidence suggests that a parent's ability to develop and maintain family routine is associated with his or her sense of parental competence (Sprunger, Boyce, & Gaines, 1985). However, it is common for mothers of children with ASD to experience some difficulties in developing and maintaining family routines due to their child's unpredictable behaviours, which can undermine their parental competence (Larson, 2006). These difficulties could create or perpetuate a cyclic process; whereby parents who feel competent are able to construct family routines that assist children with their behavioural issues, and in turn, parents feel satisfied with their parenting ability (Fiese et al., 2002; Sprunger et al., 1985).

The Impact of Family Routine Management on Mothers' Health and Wellbeing

Limited empirical studies specifically investigate the health and wellbeing of mothers of children with disability, including ASD, in relation to family routines (Larson & Miller-Bishoff, 2014; O'Brien, 2004; Thullen & Bonsall, 2017). Findings from a study that specifically investigated this relationship found mothers of children with disability experience higher levels of stress while constructing family routines when compared to mothers of children without disabilities (O'Brien, 2004). Another study that examined the relationship between family routine management and psychological wellbeing of parents of children with disability found that the maternal level of fatigue is a factor that determines their levels of engagement in constructing family routines (Larson & Miller-Bishoff, 2014). When mothers feel tired and impatient, it is difficult for them to adequately address the needs of their children. Hence, some routines, such as dinnertime, become a challenge for these mothers (Larson & Miller-Bishoff, 2014). The current literature review could not identify previous research that focused on mothers' health and wellbeing in relation to the construction of family routines as a whole in the context of ASD. Instead, previous studies that examined parental health and wellbeing, such as stress levels, in relation to family routines in the ASD context often focused on particular routines, such as mealtime (Ausderau & Juarez, 2013; Thullen & Bonsall, 2017). For parents of children with ASD, mealtime can increase their stress levels due to the efforts required in constructing routines, as well as challenging behaviours of the child with ASD, such as food refusal and mealtime rigidity (Ausderau & Juarez, 2013; Thullen & Bonsall, 2017). Though limited in number, previous studies seem to support the notion that the impact of family routine management on health and wellbeing of mothers requires further investigation, particularly in the context of families of children with ASD (Larson & Miller-Bishoff, 2014; O'Brien, 2004; Thullen & Bonsall, 2017).

Health and Wellbeing of Mothers of Children with ASD

Parental stress levels have been widely investigated in previous studies of the health and wellbeing of parents of children with disability. In fact, when investigating parental experiences, parental stress levels seem to be the dominant focus (Benson & Karlof, 2009; Bitsika, Sharpley, & Bell, 2013; Bonis, 2016; Dabrowska & Pisula, 2010; Griffith, Hastings, Nash, & Hill, 2010; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; McStay, Trembath, & Dissanayake, 2014; Mori, Ujiie, Smith, & Howlin, 2009; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). The breadth of research available in this area may be attributed to the deficit focus approach that has been employed with an assumption that these parents would show grief because having a child with a disability is seen as a ‘problem’ (McConnell, Savage, Sobsey, & Uditsky, 2015; Potter, 2016).

Existing research has consistently demonstrated that mothers of children with ASD experience higher levels of stress than other groups of mothers, such as parents of typically developing children and parents of children with Down syndrome or cerebral palsy (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Bonis, 2016; Dabrowska & Pisula, 2010; Griffith et al., 2010; Hayes & Watson, 2013; Kuhaneck et al., 2010; Montes & Halterman, 2007; Zablotsky, Bradshaw, & Stuart, 2013). Parents feel stressed especially during the initial phase of ASD diagnosis (Rivard et al., 2014). The existing body of literature commonly discuss two categories of factors that are associated with stress levels among parents of children with ASD, parent and child related factors. Child related factors include: age and gender, their adaptive behaviour, severity of symptomology, presence of cognitive impairment, and social competence and challenging behaviours (Baker-Ericzén et al., 2005; Benson, 2006; Bromley, Hare, Davison, & Emerson, 2004; Davis & Carter, 2008; Falk, Norris, & Quinn, 2014; Griffith et al., 2010; Hastings, Kovshoff, Ward, et al., 2005; Lindsey & Barry, 2018; Rivard et al., 2014). Parent related factors include: age, education levels, a sense of control in parenting, coping style, and social and economic capital (Bromley et al., 2004; Dabrowska & Pisula, 2010; Falk et al., 2014; Lindsey & Barry, 2018).

When comparing parental stress levels by gender, Davis and Carter (2008) and Hastings, Kovshoff, Ward, et al. (2005) reported no difference in parental stress levels between mothers and fathers of children with ASD. Conversely, a study by Rivard et al. (2014) found that fathers experience higher stress levels than mothers. However, the majority of studies found that mothers experience higher levels of stress than fathers regardless of differences in instruments used to measure stress levels and the age of children included in these studies (Dabrowska & Pisula, 2010; Foody et al., 2015; Jones et al., 2013; Little, 2002; McStay et al., 2014; Tehee, Honan, & Hevey, 2009).

Previous research suggest that when challenging behaviours are present, mothers of children with ASD experience high stress levels, increased levels of anxiety and depression, as well as increased levels of fatigue (Bourke-Taylor, Pallant, Law, & Howie, 2012; Bromley et al., 2004; Lindsey & Barry, 2018; Seymour, Wood, Giallo, & Jellett, 2013). However, a recent longitudinal study found that maternal psychological wellbeing is a risk factor for child’s challenging behaviours, not vice versa (Totsika et al., 2013). Although the relationships between maternal health and wellbeing and child’s challenging behaviours are intricate with some authors reporting the bidirectional nature of these relationships (Lecavalier, Leone, & Wiltz, 2006), the results of Totsika et al. (2013) support the importance of addressing health and wellbeing of mothers of children with ASD. Protective factors such as social support, family resources (i.e., finance), and participation in leisure activities buffer stress levels and promote parental mental health (Bourke-Taylor et al., 2012; Larson & Miller-Bishoff, 2014; Lindsey & Barry, 2018; Smith, Greenberg, & Seltzer, 2012; Zaidman-Zait et al., 2017). Social support has been shown to mediate the relationship between perceived health and resilience among parents of children with ASD (Ruiz-Robledillo, De Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014). However, the role of social support in buffering daily stressors can be intricate. Parental characteristics, such as personality, impact parental abilities to seek social support (Boyd, 2002). Further, identifying appropriate social supports can be challenging, in particular for parents of children with ASD, due to the unique needs of their children (Bromley et al., 2004). If parents of children with ASD do not receive appropriate social support to cope with stressful situations, this could result in them experiencing negative mood, such as feeling irritable and upset (Pottie & Ingram, 2008).

Along with stress levels, quality of life (QoL) among parents of children with ASD has been investigated to explore parental adjustment in dealing with everyday stressors (Vasilopoulou & Nisbet, 2016). Although the definition of QoL varies between studies, there seems to be a concensus that QoL encompasses broad aspects in life, forming a multidimentional construct (Karimi & Brazier, 2016). The main limitation with previous studies that investigated QoL among parents of children with ASD is the wide variety of instruments used to measure this construct (Vasilopoulou & Nisbet, 2016). Some of the instruments used in the area of QoL among parents of children with ASD include: the World Health Organisation Quality of Life Bref (WHOQOL-BREF) (The WHOQOL Group, 1996), the 12 Item Short Form Survey (SF-12) (Ware, Kosinski, Turner-Bowker, & Gandek, 2002), the Short Form Six-Dimension (SF-6D) (Brazier, Roberts, & Deverill, 2002), the EuroQol Five-Dimension (EQ-5D) (The EuroQol Group, 1990), the Medical outcomes Study (MOS) 36-Item Short-Form Health Survey (Ware & Sherbourne, 1992), the Personal Wellbeing Index (International Wellbeing Group, 2006), and Family Quality of Life Survey (Hoffman, Marquis, Poston, Summer, & Turnbull, 2006).

The lack of consistency with instruments used in previous studies makes the process of synthesising the knowledge of QoL among parents of children with ASD challenging. This challenge is demonstrated in a recent systematic literature review on the QoL among parents of children with ASD that employed a broad definition of QoL, including health-related QoL (HRQOL) (Vasilopoulou & Nisbet, 2016). However, some authors argue that HRQOL measures health through aspects of functioning and wellbeing and, therefore, measures perceived health status rather than QoL (Karimi & Brazier, 2016). Hence, for the purpose of this thesis, the definition of the World Health Organisation is employed to define QoL. QoL in this thesis is defined as "…individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1996, p. 5). This definition demonstartes the multidimentionality of the construct that should be useful in investigating the complexity of the lives of parents of children with ASD (Dardas & Ahmad, 2014a; The WHOQOL Group, 1996).

Similar to parental stress levels, QoL of mothers of children with ASD has been found to be lower than that of fathers (Allik, Larsson, & Smedje, 2006; McStay et al., 2014). Further, evidence suggests that QoL of parents of children with ASD is lower than that of parents of typically developing children or the general population (Tung et al., 2014; Vasilopoulou & Nisbet, 2016). Factors that are related to the child with ASD, such as challenging behaviours (Allik et al., 2006; Baghdadli, Pry, Michelon, & Rattaz, 2014; Dardas & Ahmad, 2014a; McStay et al., 2014; Tung et al., 2014), the child's social competence (Allik et al., 2006), and severity of ASD symptomology (Pozo, Sarria, & Brioso, 2014), as well as those factors that are related to family and parents, such as number of children (Lee et al., 2009), household income (Dardas & Ahmad, 2014a; Lee et al., 2009), decreased levels of social support (Pozo et al., 2014), parental stress levels (Lee et al., 2009), and parental coping styles (Dardas & Ahmad, 2014a; Pozo et al., 2014), have been found to be associated with parental QoL. Preliminary evidence suggests that the physical health domain of QoL is more likely to be affected than other domains among parents of children with ASD (Vasilopoulou & Nisbet, 2016). This finding is not surprising given mothers of children with ASD often experience increased levels of fatigue (Giallo, Wood, Jellett, & Porter, 2013) and the childcare demands are often high among these mothers (Järbrink, Fombonne, & Knapp, 2003; Sawyer et al., 2010).

Increased Childcare Demands and Health and Wellbeing of Mothers

Increased childcare demands are associated with high levels of parental stress, decreased QoL, and a high prevalence of depression and anxiety among parents of children with ASD (Allik et al., 2006; Benson & Karlof, 2009; Ekas & Whitman, 2010; Estes et al., 2013; Sawyer et al., 2010; Zablotsky, Bradshaw, et al., 2013). Parents of children with ASD are three times more likely to be clinically depressed and anxious than the general population and the risk is higher for mothers than for fathers (Bitsika et al., 2013). Järbrink et al. (2003) and Sawyer et al. (2010) found that parents of children with ASD spent, on average, 42 hours per week in childcare activities. The most recent Australian data show that the average time spent engaging in caring activities among primary carers for people with ASD is more likely to be 60 hours per week, while the overall primary carers in Australia spend on average 40 hours per week on caring activities (Australian Institute of Health and Welfare, 2017a). However, it should be noted that childcare activities were defined and measured in different ways in previous studies (Australian Institute of Health and Welfare, 2017a; Järbrink et al., 2003; Sawyer et al., 2010). For example, in the study by Järbrink et al. (2003), participants were asked to complete a daily diary for two weeks, while in the study of Sawyer et al. (2010), participants chose to complete a 24 hour diary either on a weekday or a weekend day.

Factors, such as functional limitations of the child with a disability, the severity of the disability, and the age of the child have been found to increase the proportion of time spent in childcare activities (Crowe & Florez, 2006; Järbrink et al., 2003; McCann, Bull, & Winzenberg, 2012; Sawyer et al., 2010). Although parents usually spend less time in childcare as children grow older, parents of adolescents with disability were found to spend longer time in childcare than parents of typically developing adolescents (Crowe & Michael, 2011). A literature review on time-use among parents of children with complex needs, including ASD, found that the need to constantly supervise children contributes towards increased time in childcare (McCann et al., 2012). Indeed, being vigilant is a common task among mothers of children with ASD in caring for their children (Bourke-Taylor et al., 2010; Hoogsteen & Woodgate, 2013a). Other childcare activities, such as coordinating therapy services, can also contribute to increased childcare time within a disability context (Green, 2007; Rassafiani, Kahjoogh, Hosseini, & Sahaf, 2012). The unique care requirements to address the needs of children with disability increase parenting demands to support their children (McCann et al., 2012).

A common issue that arises from increased childcare demands is a lack of time for other activities, such as parental self-care and leisure, socialising, and employment (Crowe & Florez, 2006; Crowe & Michael, 2011; Curran, Sharples, White, & Knapp, 2001; Fletcher, Markoulakis, & Bryden, 2012; Gevir, Goldstand, Weintraub, & Parush, 2006; Gray, 2003; Green, 2007). Australian primary carers for people with ASD were more likely to be working part-time than primary carers for people with other conditions (Australian Institute of Health and Welfare, 2017a) and financial costs associated with loss of or reduced employment due to increased care demands among families of children with ASD is significant (Horlin et al., 2014). An Australian study that compared time-use on leisure, socialising, and self-care activities between working parents of children with and without disability found that mothers of children with disability spent 5.5 hours less per week on leisure and self-care activities during weekdays than their counterparts (Brandon, 2007). The limited time available to participate in discretional activities due to high childcare demands has negative consequences, as those activities can support parental health and wellbeing (Kuhaneck et al., 2010; Larson & Miller-Bishoff, 2014).

How Mothers of Children with ASD Cope with Everyday Demands

Coping is a behavioural or thought process that occurs when events or situations are appraised as stressful (Goh, Sawang, & Oei, 2010; Lazarus & Folkman, 1984). The process changes depending on the extent of harm or challenges the context presents, resource availability, and personality in appraising the events (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Skinner & Zimmer-Gembeck, 2007). Traditionally, coping is categorised as problem or emotion focused (Lazarus & Folkman, 1984). A wide range of coping styles such as positive reframing, avoidance, denial, humour, seeking social support, self-control, meaning focused, and acceptance, have been studied previously (Carver, 1997; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Hall, 2012; Marshall & Long, 2010; Park & Folkman, 1997). As coping is a multidimensional process, it is difficult to determine if a particular coping style is adaptive or maladaptive (Folkman & Moskowitz, 2004). However, some coping styles that are emotion-focused have been found to increase stress levels, rather than defuse the situation (Dabrowska & Pisula, 2010).

Whether parents of children with ASD use more adaptive or maladaptive coping styles is inconclusive. Some research suggest that these parents use counterproductive or maladaptive coping styles, such as emotion-oriented coping, avoidance, withdrawal and escaping, in dealing with everyday challenges (Benson, 2014; Dabrowska & Pisula, 2010; Hall & Graff, 2011; Hastings, Kovshoff, Brown, et al., 2005; Lai, Goh, Oei, & Sung, 2015; Pottie & Ingram, 2008; Sivberg, 2002). Use of a maladaptive coping style can lead parents of children with ASD to not only experience high stress levels, but also experience decreased positive mood, such as not feeling excited and interested, and feelings of decreased parental efficacy (Dabrowska & Pisula, 2010; Pottie & Ingram, 2008). However, these findings remain inconclusive as a recent meta-synthesis on parenting experiences among parents of children with ASD found they adopt adaptive coping styles, such as acceptance and problem solving, to cope with challenges presented due to ASD symptomology (Ooi, Ong, Jacob, & Khan, 2016). The use of adaptive coping styles, such as adopting a problem-focused approach, are encouraged (Carver, 1997). However, previous research suggest that predominantly using problem-focused approach can, conversely, create a problem for parents of children with ASD, as they may encounter some issues that cannot be easily changed or modified, due to the nature of ASD (Pottie & Ingram, 2008; Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). Nevertheless, these parents' abilities to develop more adaptive coping styles may reflect their resilience (Ooi et al., 2016; Twoy, Connolly, & Novak, 2007).

One way to deal with the everyday demands of parenting a child with ASD is for mothers to address their own needs through leisure, self-care, and socialising. Phrases, such as 'me-time' or 'my-time', are commonly used to describe the time spent on addressing parental needs, rather than carrying childcare responsibilities (Kuhaneck et al., 2010; Larson & Miller-Bishoff, 2014). For example, exercise has been shown to be an effective coping mechanism to deal with stress that is related to intensive childcare activities (Kuhaneck et al., 2010). Similarly, having 'me-time' is essential to enable mothers to cope with daily stressors (Larson & Miller-Bishoff, 2014).

Methods Used in Conducting Family Routine Research

Previously Employed Methods to Investigate Family Routines

The literature demonstrates a range of methods used to investigate family routines. This is not surprising given that family routines are complex phenomena (Fiese, 2007). Interviewing mothers or primary care givers is one of the main methods employed to investigate family routines (Evans & Rodger, 2008; Kellegrew, 2000; Larson, 2006; Marquenie et al., 2011; Schaaf et al., 2011; Segal, 2004a; Segal & Frank, 1998). Standardised assessment tools are also commonly used in previous research (Bagatell et al., 2014; Churchill & Stoneman, 2004; Crowe, 2002; Larson & Miller-Bishoff, 2014; Markson & Fiese, 2000; Rodger & Umaibalan, 2011; Schlebusch, Samuels, & Dada, 2016), such as the Family Ritual Questionnaire (FRQ) (Fiese & Kline, 1993), the Family Routines Inventory (FRI) (Jensen et al., 1983) and the Family Time and Routine Index (McCubbin, Thompson, & McCubbin, 1996). A systematic review of family routines among families with individuals with chronic conditions found that FRQ was the most frequently used assessment tool in the area of family routines (Crespo et al., 2013). Each method has advantages in investigating family routines, for example, interviews allow researchers to obtain an in-depth understanding, thus a more appropriate method to explore ‘meaning’ of family routines (Evans & Rodger, 2008); however, due to the complexity of family routines (Fiese, 2007; Larson & Miller-Bishoff, 2014), employing a single method alone may not provide a whole picture. Indeed, a literature review on family routines in the context of chronic conditions, including ASD, has identified a need for mixed-methods research to obtain a more comprehensive understanding of family routines (Crespo et al., 2013). Although not widely used, other methods such as observations and a time-use diary are also employed to investigate family routines (Bagatell, 2016; Kellegrew, 2000; Koome et al., 2012; Roy, Tubbs, & Burton, 2004).

Time-use diary in investigating family routines allows researchers to record day-to-day patterns of routines. As family routines are sequenced activity patterns (Larson & Miller-Bishoff, 2014), exploring daily time-use provides more in-depth information on the day-to-day operations of family routines (i.e., time-use is a pre-cursor to family routines). Koome et al. (2012) used a time-use diary as a method to collect the data when studying family routines among families of adolescents with mental illness. The participants in the Koome et al. (2012) study completed a time-use diary over a three day period prior to conducting in-depth interviews. The information collected with the time-use diary assisted the authors to corroborate and expand on the participants' comments on family routines during the interviews. Similarly, Roy et al. (2004) investigated time-use among low-income mothers in relation to the construction of daily routines, such as activities related to jobs, children and the whole family. The authors used interviews and daily charts that recorded the type and location of activities and people involved in the activity during each hour of a typical day to collect the participants' time-use and daily routines information. The authors found external factors, such as proximity of available schools and work place that shaped daily routines and impacted daily time-use. For example, mothers who used public transport to go to work had to organise their routines around the public transport schedule and the extensive waits on public transport reduced time spent in engaging other activities, such as self-care and domestic tasks, during typical waking hours. Thus, mothers had to re-structure their routines to complete these activities late at night or early morning (Roy et al., 2004). The findings of Roy et al. (2004) study demonstrate a close link between routines and time-use.

Research Gaps in the Field of Family Routines among Families of Children with ASD

The current literature review identified three gaps in the field of family routine studies: 1) a lack of focus on mothers' experiences in investigating family routines; 2) a lack of representation of single mothers and mothers from regional areas; and 3) limited use of mixed methods.

A Lack of Focus on Mothers' Experiences in Investigating Family Routines in an ASD Context

Many of the family routine studies explored the entire family experiences or child outcomes from mothers' perspectives, rather than focusing on mothers' experiences themselves (Bagatell et al., 2014; Evans & Rodger, 2008; Rodger & Umaibalan, 2011; Schaaf et al., 2011). Further, although emerging, limited empirical studies have investigated how parents construct family routines in the context of ASD (Boyd et al., 2014). One of the few studies that investigated mothers' experiences in constructing family routines in the context of disability reported mothers' constant efforts to create an optimal foundation for their children's skill development in designing family routines (Kellegrew, 2000). However, this qualitative study of Kellegrew (2000) involved six mothers and the routines considered were limited, including only mealtime and child dressing routines. Emerging evidence suggests that there are some relationships between family routines and health and wellbeing of mothers of children with disability (Larson & Miller-Bishoff, 2014; O'Brien, 2004; Thullen & Bonsall, 2017). However, the heterogeneity of the children's disabilities included in the previous research points to the need for further research to explore the experiences of mothers of children with ASD that may be different from other groups of mothers (Kellegrew, 2000; Larson & Miller-Bishoff, 2014; O'Brien, 2004; Ryan & Runswick-Cole, 2008). A Lack of Representation of Single Mothers and Mothers from Regional Areas

Previous studies have not widely considered participants' backgrounds, such as parental gender and family structure (Crespo et al., 2013). Past family routine studies predominantly recruited coupled mothers (Hoogsteen & Woodgate, 2013a; Kellegrew, 2000; Marquenie et al., 2011; Rodger & Umaibalan, 2011) and mothers from major city areas (Bagatell, 2016; Evans & Rodger, 2008; Marquenie et al., 2011). The limited diversity in participants' background included in previous studies has led to single mothers and mothers from regional areas being the frequently overlooked population in the family routines research. A narrow focus of the participants' background does not accurately portray family routines that are unique to individual family contexts (Crespo et al., 2013).

Single mothers. A lack of representation of single mothers is problematic since single parent households are projected to increase globally (The Organisation for Economic Co-operation and Development [OECD], 2012). Previous studies indicate that single mothers are at a higher risk of experiencing mental health challenges compared with coupled mothers (Cairney, Boyle, Offord, & Racine, 2003; Crosier, Butterworth, & Rodgers, 2007; Wang, 2004). For example, an Australian study with 354 single and 1,689 coupled mothers was conducted to determine the prevalence of mental health diagnosis. The findings indicated that single mothers were more likely to experience poor mental health, such as increased depression and anxiety, compared with their counterparts (Crosier et al., 2007). Although the number of participants was smaller than Crosier et al. (2007), a similar trend was found among mothers of children with disability, including ASD (Olsson & Hwang, 2001). Compared to coupled mothers (n = 170), single mothers of children with disability (n = 36) were more likely to experience severe depression (Olsson & Hwang, 2001). Financial resources and social support are some of the protective factors that promote mothers' mental health (Lindsey & Barry, 2018; Zaidman-Zait et al., 2017); however, in exploring single mother's experiences, financial hardship, as well as lack of social support are recurring themes (Crosier et al., 2007; Larson & Miller-Bishoff, 2014). Given emerging evidence suggests that single mothers are more prone to experience health issues than their counterparts, their everyday experiences should be further investigated.

The current literature review reveals there is a scarcity of research that investigated family routines in the context of general single parent households (Brody & Flor, 1997; Moriarty

& Wagner, 2004; Morrison, 1995). In investigating the link between financial issues and family routines, Brody and Flor (1997) found that single mothers felt a sense of self-esteem when adequate financial resources were available, and in turn, these single mothers were able to provide a stable household environment through development of family routines for their children. However, single mothers of African American descent living in rural communities were the focus of the Brody and Flor (1997) study. Therefore, their findings may reflect unique issues, such as increased rate of poverty that are pertain to this specific population (Fontenot, Semega, & Kollar, 2018). Nonetheless, being able to construct efficient routines can assist single mothers in dealing with constant pressures to manage family responsibilities by themselves (Morrison, 1995). Moriarty and Wagner (2004) found that single parents used family routines to buffer stress that arises from being overloaded with family responsibilities, while instigating family values and enhancing family cohesion (Moriarty & Wagner, 2004). Although previous findings demonstrate some of the unique experiences among single parents, Moriarty and Wagner (2004) and Morrison (1995) were both qualitative studies with seven and twelve participants respectively. Future research should employ other methods, such as mixed methods, with a larger number of participants to obtain more accurate pictures of these mothers.

In a disability context, the experiences of family routines among single mothers have rarely been examined. In the context of ASD, the experiences of these mothers, in general, have not been a prominent focus (Dyches, Christensen, Harper, Mandleco, & Roper, 2016). Although single mothers’ experiences were not the main focus of the study by Larson and Miller-Bishoff (2014), the authors alluded to the notion that single mothers of children with disability experience more challenges in maintaining regular routines (Larson & Miller-Bishoff, 2014). Spousal support is beneficial for mothers’ psychological wellbeing and is considered important in managing everyday activities when sharing household and childcare responsibilities

(Kuhaneck et al., 2010; Larson & Miller-Bishoff, 2014). Therefore, the experiences of family routines may be different for single mothers who do not have spousal support, which warrant further research.

Mothers from regional and remote areas. The current literature review could not identify previous studies that specifically investigated family routines among families of children with ASD living in regional and remote areas. However, emerging evidence suggests that a lack of appropriate formal support in regional and remote areas impact parental abilities to deal with daily challenges (Farmer & Reupert, 2013; Hoogsteen & Woodgate, 2013a). It is common for families of children with ASD who live in regional and remote areas to travel long distance to seek appropriate services for their children to develop social skills, increase independence, and reduce maladaptive behaviours (Carbone et al., 2010; Myers & Johnson, 2007; Wacker et al., 2013). Therefore, a lack of services in regional and remote areas may lead to increased everyday demands in childcare, which may also add unique challenges to family routines among parents of children with ASD. Another point to consider is lower income among family caregivers, including parents of children with disability, in regional and remote areas compared to their counterparts (Bouldin, Shaull, Andresen, Edwards, & McGuire, 2018). This financial issue may prevent mothers, who live in regional and remote areas, from accessing formal services to reduce caregiver burden. Further, previous research reports differences in children’s lifestyles due to region of residence. For example, children in regional areas engaged in different extracurricular activities and spent more time outside compared to children from major city areas (Baxter, Gray, & Hayes, 2011). Although fathers participate in household activities, including childcare and domestic roles, the majority of these responsibilities are still assumed by mothers (Allen, Walker, & McCann, 2013). Given the differences in children’s lifestyle, there may be differences in how mothers construct everyday routines due to their region of residence.

Infrequent Use of Mixed Methods

Mixed methods have not been widely employed in the field of family routines (Crespo et al., 2013; Larson & Miller-Bishoff, 2014), despite gaining popularity in health sciences (Guetterman, Fetters, & Creswell, 2015; Johnson, Grove, & Clarke, 2017). There are four basic types of mixed method designs: 1) convergent parallel, 2) explanatory sequential, 3) explanatory sequential, and 4) exploratory sequential design (Creswell, 2013). There is no specific guideline in conducting mixed methods studies in the field of health sciences (Leech, Onwuegbuzie, & Combs, 2011). However, appropriate designs should be chosen by considering the levels of interaction between qualitative and quantitative strands, the priority of the strands, the timing of the strands, and the process in blending the strands (Creswell, 2013).

Mixed methods assist researchers to develop a more complete understanding of complex health issues that exist in contemporary practice (Andrew & Halcomb, 2011). Given the complex nature of family routines (Churchill & Stoneman, 2004; Fiese et al., 2002), mixed methods could help deconstruct intricacies of routines and generate a deeper understanding to advance the current knowledge (Greene, 2007). For example, Larson and Miller-Bishoff (2014) employed a mixed method design to investigate the construction of family routines and psychological wellbeing among 39 caregivers of children with disabilities. Their findings demonstrated the complexities involved in constructing family routines; however, the diagnosis of the children included in their study were broad (e.g., ASD, cerebral palsy, dyspraxia and foetal alcohol syndrome) (Larson & Miller-Bishoff, 2014). The characteristics of the condition may influence how families constructing family routines (Crespo et al., 2013). Therefore, research focusing on a particular diagnosis, such as ASD is needed. Further, the study by Larson and Miller-Bishoff (2014) did not clearly indicate the mixed method design employed, making the level and process of integration between quantitative and qualitative data unclear. The key purpose of mixed methods is integration of quantitative and qualitative data within a single study or project (Palinkas, 2011). By integrating quantitative and qualitative data, mixed methods studies intend to develop a whole picture rather than the sum of individual components (Fetters & Freshwater, 2015). Mixed methods, therefore, seem to be an appropriate method to study family routines as it provides a richer avenue to examine complicated complex constructs (Creswell & Plano Clark, 2011).

Summary of Literature Review

This literature review provided an overview of the current understanding of family routines with a specific focus on the experiences of mothers of children with ASD. Family routines can be seen as the outcome of a transactional process between family members and the environment in which they live, which provide structure and stability in family life that, in turn, protect families from daily stressors (Churchill & Stoneman, 2004; Crespo et al., 2013; Markson & Fiese, 2000; Wolin & Bennett, 1984). Family health and wellbeing is supported through meaningful experiences that arise from family routines (DeGrace, 2004; Downs, 2008; Fiese, 2007). For families of children with ASD, the process of designing and managing family routines becomes child-centric as the needs of the child are often addressed at the expense of other family members (Hoogsteen & Woodgate, 2013a; Marquenie et al., 2011; Suarez et al., 2014). Some families may feel a loss of ‘normalcy’ in constructing family routines, due to the high demand to cater for the needs of ASD characteristics (DeGrace, 2004; Larson, 2006). However, stability and regularity derived from family routines assist children with ASD to participate in everyday activities, including shared family routines (Larson, 2006; Schaaf et al., 2011). Shared family routines provide a sense of cohesiveness and bonding and allow a family to develop relationships (Bagby et al., 2012; Evans & Rodger, 2008; Fiese et al., 2002). The families of children with ASD use a variety of strategies to accommodate or adapt routines in catering to the needs of the child with ASD to maintain shared family routines (Ausderau & Juarez, 2013; Bagby et al., 2012).

Mothers are often the main contributors to the process of constructing family routines (Bagatell, 2016; Larson & Miller-Bishoff, 2014). Previous research suggests that developing and managing family routines is a complex process involving multiple factors, such as work, school, and illness and disability of family members (Bagatell, 2016; Evans & Rodger, 2008; Fiese & Womboldt, 2000; Larson & Miller-Bishoff, 2014; Muñiz et al., 2014). Many mothers navigate this complexity with limited support (Bagatell, 2016; Larson, 2006). However, previous studies that investigated family routines commonly focused on the children's outcomes or the entire family's experiences rather than the experiences of mothers and their functions in constructing family routines (Bagatell et al., 2014; Boyd et al., 2014; Rodger & Umaibalan, 2011). Furthermore, there is a paucity of research that investigated health and wellbeing of mothers of children with ASD in relation to their involvement in family routines (Larson & Miller-Bishoff, 2014; O'Brien, 2004). The emerging evidence suggests managing family routines may be burdensome for mothers of children with disability (Larson & Miller-Bishoff, 2014) and there is a higher risk for mothers of children with ASD to experience poor health status, such as increased stress levels, than other groups of mothers (Bonis, 2016; Hayes & Watson, 2013; Vasilopoulou & Nisbet, 2016; Zablotsky, Bradshaw, et al., 2013). Therefore, there is a need to investigate the experiences of mothers of children in constructing family routines in relation to their health and wellbeing.

In the area of family routines, study populations have mainly been coupled mothers living in major city areas (Crespo et al., 2013). In the ASD context, limited research on the experiences of single mothers as well as mothers from regional areas has been conducted (Bagatell, 2016; Evans & Rodger, 2008; Marquenie et al., 2011). Single mothers in particular have been found to experience unique issues, such as lack of support (Crosier et al., 2007). However, in managing daily responsibilities, spousal support is considered crucial by coupled mothers (Kuhaneck et al., 2010). Further, emerging evidence suggests that maintaining routines can be more challenging for single mothers of children with disability than their counterparts (Larson & Miller-Bishoff, 2014). Therefore, there is a need to investigate the experiences of single mothers with children with ASD. Similarly, the experiences of mothers of children with ASD who live in regional and remote areas have not been widely investigated. Limited access to formal services, which is a common issue in those areas, may increase daily demands for parents of children with ASD (Myers & Johnson, 2007; Wacker et al., 2013). A previous study reports that children’s lifestyles differ between major city and regional and remote areas (Baxter et al., 2011). Therefore, how mothers of children with ASD who live in regional areas construct family routines may be different from their counterparts in accommodating the lack of services and children’s lifestyles.

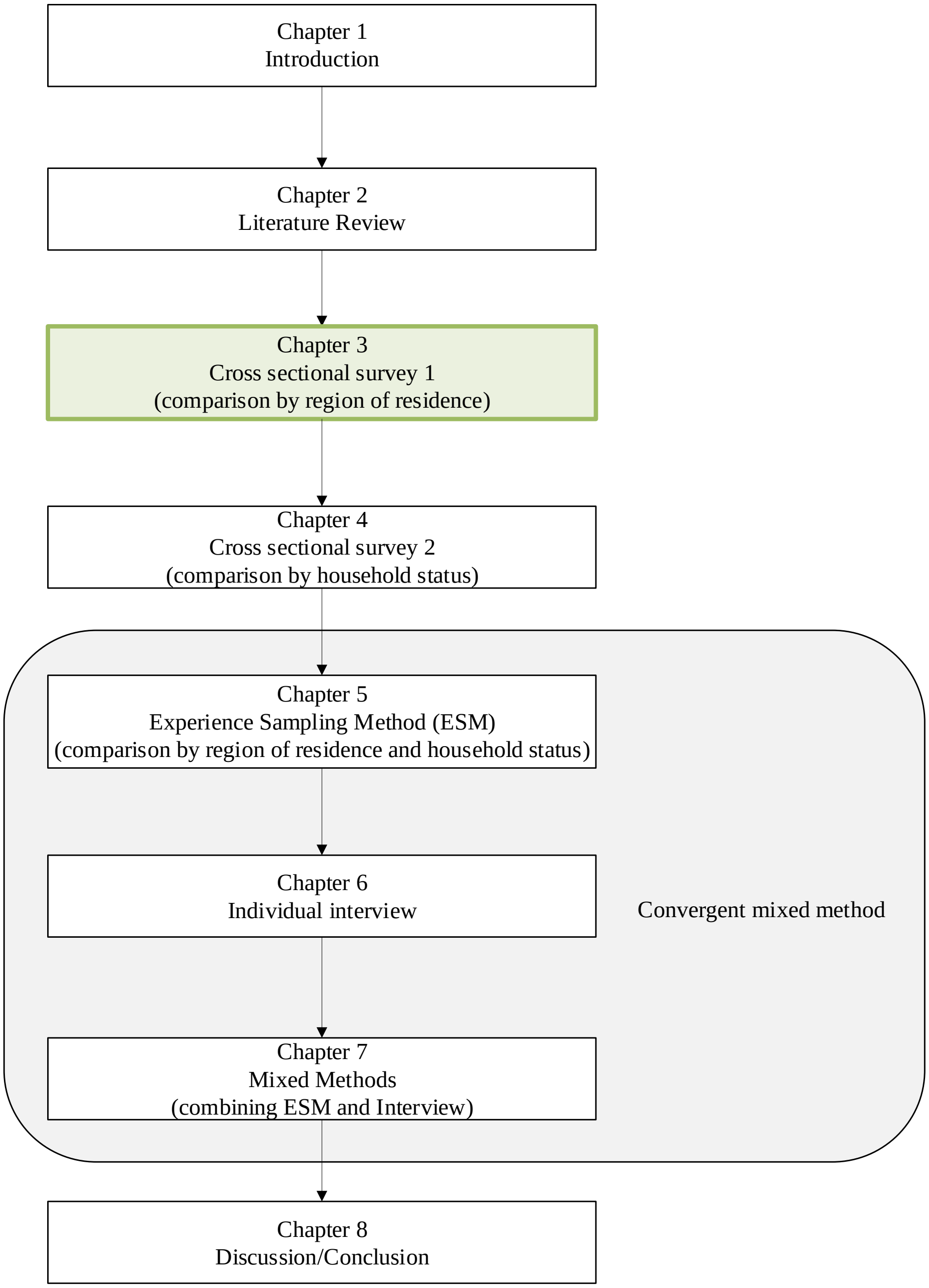
Mixed methods designs have not been commonly employed to investigate family routines (Crespo et al., 2013). Instead, family routines have been investigated either by quantitative method, such as standardised instruments, or qualitative method, such as interviews (Churchill & Stoneman, 2004; Evans & Rodger, 2008; Marquenie et al., 2011; Schaaf et al., 2011). However, family routines are complex phenomena involving internal and external factors, such as illness of family members, work and health service provisions (Bagatell, 2016; Fiese et al., 2002; Fiese & Womboldt, 2000; Muñiz et al., 2014). Mixed methods provide a more in-depth picture in investigating complex issues (Creswell & Plano Clark, 2011; Greene, 2007). Therefore, the use of mixed methods designs may assist researchers in developing a more accurate understanding of family routines. The gaps identified in the review warrant the need to study family routines with a specific focus on the experiences of mothers of children with ASD.

Summary of Chapter 2

This chapter provided a rationale to support the overall aim of this thesis that is to explore the experiences of mothers of children with ASD in constructing family routines concerning their health and wellbeing. The next chapter reports on a cross sectional study that compared the experiences of families of children with ASD by their region of residence. The next chapter addresses the first sub-aim to explore whether family routines, service usage and stress levels in families of children with ASD differ between regional and major city areas.

Chapter 3 Cross Sectional Survey 1

(Published paper)



Title: A comparison of families of children with autism spectrum disorders in family daily routines, service usage and stress levels by regionality

Chapter 3 comprises a study that compared family routines, service usage and stress levels among families of children with ASD by region of residence. The study was a secondary analysis of the population-based data that were collected in Western Australia. The findings of this chapter confirmed the need to use other research methods, such as validated instruments, to obtain more accurate picture of the experiences of families of children with ASD with family routines, in particular that of mothers[1].

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[1] This chapter has been published in Developmental Neurorehabilitation (See Appendix D). Authors: Tomomi McAuliffe, Sharmila Vaz, Torbjorn Falkmer, and Reinie Cordier

Abstract

Purpose: To explore whether family routines, service usage and stress levels in families of children with autism spectrum disorder differ as a function of regionality.

Methods: Secondary analysis of data was undertaken from 535 surveys. Univariate and multivariate analyses were performed to investigate differences between families living in densely populated areas (DP) and less densely populated areas (LDP).

Results: Families living in LDP were found to: (1) have reduced employment hours (a two-parent household: Exp (B) = 3.48, $p < .001$, a single-parent household: Exp (B) = 3.32, $p = .011$); (2) travel greater distance to access medical facilities (Exp (B) = 1.27, $p = .006$); and (3) report less severe stress levels (Exp (B) = 0.22, $p = .014$).

Conclusions: There were no differences in family routines; however, flexible employment opportunities and travel distance to medical services need to be considered in families living in LDP areas.

Introduction

It is estimated that 0.5% of all Australians had autism in 2012; equating to a 79% increase from the 2009 Australian national survey (Australian Bureau of Statistics, 2014). Individuals with Autism Spectrum Disorder (ASD) have difficulties in (1) communication, (2) establishing reciprocal relationships with others, and (3) displaying rigid and repetitive interests and activities (American Psychiatric Association, 2000), which are related to the triad of ASD symptoms. These symptoms and other common issues, such as challenging behaviour and anxiety, cause stress within the family (DeGrace, 2004; Marquenie et al., 2011; Marshall & Long, 2010); which, in turn, may impact on activity participation, everyday family functioning, and quality of life (QoL) (Allik et al., 2006; Ekas, Lickenbrock, & Whitman, 2010; Ekas, Whitman, & Shivers, 2009; Estes et al., 2013; Sawyer et al., 2010; Zablotsky, Bradshaw, et al., 2013).

The experiences and needs of families of children with ASD living in regional and remote areas are often overlooked as previous research in the area of family routines, family stress and QoL has predominantly collected data from highly populated areas (Bagatell et al., 2014; Cashin, 2004; DeGrace, 2004; Evans & Rodger, 2008; Marquenie et al., 2011; Rodger & Umaibalan, 2011; Woodgate, Ateah, & Secco, 2008). This has resulted in gaining a limited understanding of specific experiences of those families living in regional and remote areas. Regionality in this study is defined in terms of difference in population density; with the terms densely populated (DP) areas and less densely populated (LDP) areas used to contrast the difference between highly populated areas and regional and remote areas. On average, families of children with ASD use between four and eight different treatments for their child (Goin-Kochel et al., 2007; Green et al., 2006; Kohler, 1999; Ruble & McGrew, 2007); some families use as many as seven treatments concurrently (Green et al., 2006). Parents of children with ASD regularly schedule therapeutic services for their children to maximise their functional independence, promote social and play skills, enhance development and learning, and reduce maladaptive behaviours (Carbone et al., 2010; McCann et al., 2012; Myers & Johnson, 2007). Families of children with ASD spend more time attending therapeutic appointments to manage their children's symptoms, compared with families of typically developing children (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; McCann et al., 2012). The extra visits to health services and the increased length of time for appointments places extra burden on the child care demands for those parents (McCann et al., 2012). This increased demand on child care is associated with higher levels of parental stress, decreased QoL, and a higher prevalence of depression and anxiety among parents of children with ASD (Allik et al., 2006; Benson & Karlof, 2009; Ekas & Whitman, 2010; Ekas et al., 2009; Eskow, Pineles, & Summers, 2011; Estes et al., 2013; Sawyer et al., 2010; Zablotsky, Bradshaw, et al., 2013). While meeting the increased demands in caring for the child with ASD, parents make remarkable efforts to sustain family daily routines by using different strategies, such as changing environments and detailed planning (Bagatell, 2016; Bagby et al., 2012; Schaaf et al., 2011).

Effective family routines assist in organising, sustaining, and propagating a family's everyday life and provide stability and continuity to the household (Denham, 2003; Fiese et al., 2002; Larson, 2006). The daily routines in families of children with ASD often centre on the idiosyncratic demands of the child with ASD rather than the family as a unit (Boyd et al., 2014; DeGrace, 2004; Larson, 2006; Rodger & Umaibalan, 2011). For example, families of children with ASD often report difficulties in engaging in mealtime activities as a family unit, due to the sensory needs of the child with ASD (Schaaf et al., 2011), or experiencing increased stress due to the need to accommodate the unique demands of the child with ASD (Bagby et al., 2012; Marquenie et al., 2011; Schaaf et al., 2011).

The evidence to date on the nature and degree of the impact of ASD on family daily routine is largely inconclusive (Denham, 2003). For example, findings from some studies have found no significant differences in the mean number of routines that families with and without a child with ASD engage in (Bagatell et al., 2014; Rodger & Umaibalan, 2011). Conversely, others report adjustments in daily routines in families of children with ASD in order to accommodate the idiosyncratic demands of the child with ASD (DeGrace, 2004; Larson, 2006; Marquenie et al., 2011), which are associated with the triad of ASD (American Psychiatric Association, 2013). What is largely unexplored is whether there exists differences in family routines, stress and QoL between families living in DP areas compared with LDP areas.

The construct of regionality takes on precedence within the Australian context given the geography of the continent. In Australia, nearly 90% of the population live in DP areas (The Regional Australia Institute, 2015). This uneven spread of population density has resulted in increased service availability in those areas. Families living in LDP areas reported limited access to ASD specific therapy services (Farmer & Reupert, 2013). Similar findings of reduced access to ASD specific therapeutic service have been reported by families of children with ASD living in rural Canada (Hoogsteen & Woodgate, 2013b) and rural USA (Thomas, McLaurin, Daniels, & Morrissey, 2007). This reduced accessibility to service may influence the ability of families of children with ASD to form and maintain their family daily routines.

As such there is a need to compare those families living in LDP areas to those who live in DP areas to obtain a better understanding of the geographical constraint encountered, in order to inform appropriate services development and delivery. Thus, the aim of the current study was to explore differences due to regionality in: (1) family daily routines (for example, hours of parental employment, parental ability to socialise, parental participation in leisure activities, and engagement in play activities outside of school), (2) service usage (for example, travel distance to medical facility and average weekly hours of attending therapeutic services) and (3) perceived stress levels.

Methods

Development of the Questionnaire

The questionnaire was originally developed for a study which investigated the cost associated with raising a child with ASD (Horlin et al., 2014). Although the questionnaire was developed for a specific purpose, it contained a broader range of questions, including socio-demographic status of family; children's official ASD diagnosis, presence of intellectual disability and other medical conditions; travel distance to the medical and therapeutic services; frequency in visiting the medical and therapeutic services; hours partaking in Early Intervention Therapy; the types of school the children with ASD attend; the types and use of childcare services; parental employment status; the levels of social support received; the impact of ASD diagnosis on parental ability to socialise; and the parental perception of family's stress levels due to having a child with ASD. The full questionnaire is available from Horlin et al. (Horlin et al., 2014). The development of the questionnaire was informed by anecdotal reports from clinicians, families of children with ASD, current literature and insurance reports on expenses related to having a child with ASD. It was refined following the comments from clinicians and service providers and pilot testing was conducted with three families of children with ASD. The questionnaire was further adjusted following the pilot testing and 73 items were included in the full version of the questionnaire. Most of the questions had a Likert scale with an average of seven options to choose from. Researchers experienced in the field of ASD, the second and third authors, selected thirty-five questions which were relevant to the aim of the current study from these questionnaire items. The last page of the questionnaire included a diagnostic checklist of DSM-IV-TR/ICD10 symptoms of ASD (Matson, Wilkins, Boisjoli, & Smith, 2008) to verify that child meet diagnostic criteria at the time of completing the survey. This checklist contains three main domains of ASD symptoms, including: impairment in social interaction; communication impairment; and restricted, repetitive, stereo typed patterns of behaviour. The respondents were asked to indicate if any of the symptoms listed in each domain were currently present or were previously present for their children with ASD.

Participants and Procedures

In 2013 the questionnaire was distributed to 3,723 families of children with ASD who were under the age of 18 years and registered with the Disability Service Commission (DSC) of Western Australia. The DSC recommended to include only families of children with ASD under the age of 18 years to increase the chance of obtaining correct/valid information from the register. Those families with more than one child with ASD received one questionnaire per child with ASD. A total of 3,965 questionnaires were distributed and 192 were returned as ‘address unknown’. A total of 545 questionnaires were returned, resulting in a response rate of 14%. Of those, 535 contained relevant data to the current study.

Data Analyses

Analysis of non-respondents. Six months after the initial mail out, 405 families were randomly selected and contacted telephonically from the DSC register for the purpose of a drop-out analysis. If the families reported that they did not complete the original questionnaire, they were asked to complete the abbreviated version of the original questionnaire, which contained twenty questions, including the socio-demographic status of the family; children’s official ASD diagnosis, presence of cognitive/intellectual disability and other medical conditions; cost of medical/therapeutic treatment; parental employment status; and the parental perception of family’s stress levels. A comparison of demographic variables between non-respondents and those families who completed the original questionnaire was made using *t*- and *chi*-square tests of independence. One hundred and thirty-eight out of 405 families could not be reached largely due to incorrect phone numbers recorded on the DSC register. Sixty-four families completed the original questionnaire, therefore were excluded and 55 families declined to participate. One hundred and forty-eight families agreed to complete the short-form questionnaire; of those, two families did not have children with ASD therefore were excluded. No significant difference was found in children's age, children's official ASD diagnosis, and household composition. However, the timing of receiving formal diagnosis of ASD was earlier among the respondents. Further, the child with ASD in the respondents' families was slightly more likely to be male and the respondents had noticed developmental abnormality of their children earlier than non-respondents. Nevertheless, the non-respondent analysis largely confirmed that the limited sample of 535 families in the current study represented the much larger target group.

Statistical Analysis. Data were analysed by using the Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp, 2013). Descriptive statistics were analysed to provide demographic information of the study participants.

The Australian Statistical Geography Standards (ASGS) remoteness structure was used to classify postcodes. The ASGS remoteness structure is classified into five Remoteness Areas (RAs) (Australian Bureau of Statistics, 2013c). RAs are based on road distances to the nearest service centres and average scores are calculated using the Accessibility/Remoteness Index of Australia (ARIA +) grid, which is a one square kilometre grid covering all of Australia (Australian Bureau of Statistics, 2013b). The RAs include the following five remoteness categories: (1) major cities (average scores between 0 to 0.2); (2) inner regional (average scores greater than 0.2 and less than or equal to 2.4); (3) outer regional (average scores greater than 2.4 and less than or equal to 5.92); (4) remote (average scores greater than 5.92 and less than or equal to 10.53); and (6) very remote (average scores greater than 10.53) (Australian Bureau of

Statistics, 2013b). Participants' postcodes in the current study were recoded based on this classification. The RAs were further collapsed into a dichotomous variable for the purpose of undertaking logistic regression. In doing so, DP category was formed by collapsing the major city and inner regional city post codes and LDP category was formed by merging the outer regional, remote and very remote postcodes.

The selected thirty-five questions were structured into demographic, family daily routines and accessibility to services categories and used as independent variables (IVs). Chi-square and *t*-tests were conducted to identify IVs which significantly associated with the regionality, which was the dependent variable (DV). Binary logistic regression analyses were then run with the identified IVs to identify key factors associated with LDP areas in family daily routines, the service usage and their stress levels.

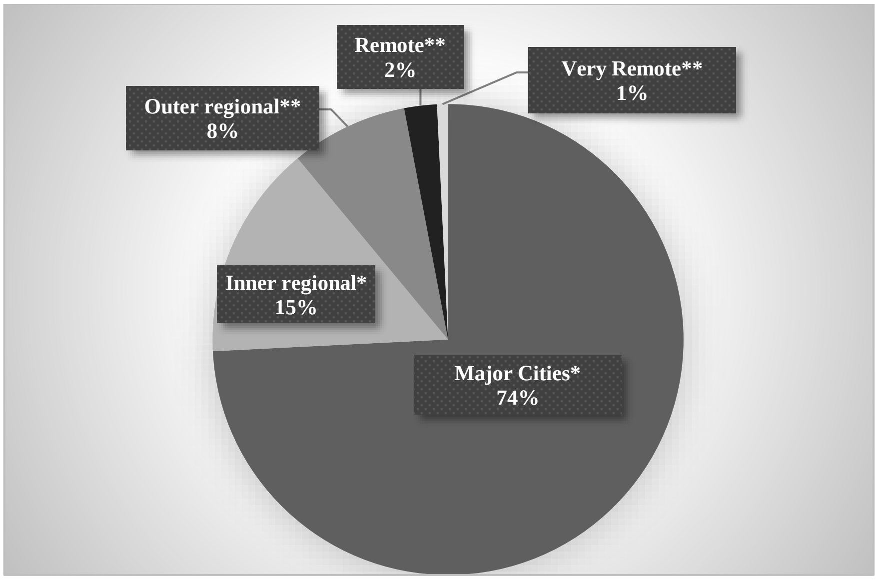
Ethical approval. The study conformed to the principles of the Declaration of Helsinki (The World Medical Association [Internet], 2016 [cited in 2016 Jan 22]). Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR138/2012) and the internal ethical review board in Western Australia. When respondents completed and returned the questionnaire, it was considered that they provided consents to participate in the study.

Results

Descriptive Profile of the Study Participants

Figure 3.1 provides an overview of the spread of the respondents by regionality. A total of 476 participants (89%) resided in DP areas and 59 participants (11%) resided in LDP areas in WA. The sample's demographic profile was comparable; there was no significant group differences due to regionality. For example, over 80% of the respondents' children with ASD were boys regardless of regionality (Table 3.1).

Figure 3.1: Percentage of responses in each response category for the residential postcode question



*Densely Populated (DP) areas, **Less Densely Populated (LDP) areas

Table 3.1: Characteristics of the families of children with ASD for the total sample, the sample of participants living in DP areas and the sample of participants living in LDP areas of WA

Characteristics	Total sample		DP areas of WA sample		LDP areas sample	
	N= 535	%	*N*= 476	%	*N*= 59	%
Children's Age (month) Mean (standard deviation)	119.51 (50.5)		119.52 (50.8)		118.91 (48.8)	
						t = 0.86, *p* = 0.56
Children's Gender						
Male	442	82.9	397	83.8	45	76.3
Female	91	17.1	77	16.2	14	23.7
						X^2= 2.07, *DF* = 1, *p* = 0.15
Official ASD diagnosis						
Autism	289	55.7	253	54.3	36	63.2
HFA	113	21.8	107	23.2	6	10.5
AS	37	7.1	30	6.5	7	12.3
PDD-NOS	80	15.4	72	15.6	8	14
						X^2= 8.24, *DF* = 6, *p* = 0.22

Characteristics	Total sample		DP areas of WA sample		LDP areas sample	
Presence of cognitive impairments/intellectual disability						
Yes	147	27.8	133	28.2	14	24.1
No	382	72.2	338	71.8	44	75.9
						X^2= 0.43, *DF* = 1, *p* = 0.51
Presence of other diagnosed psychological/mental health						
Yes	114	21.5	101	21.4	13	22
No	416	78.5	370	78.6	46	78
						X^2= 0.01, *DF* = 1, *p* = 0.91
Presence of other medical diagnosis						
Yes	173	33	157	33.6	16	27.6
No	352	67	310	66.4	42	72.4
						X^2= 0.85, *DF* = 1, *p* = 0.35
Respondents' relationship to child						
Biological mother	430	80.7	379	80	51	86.4
Biological father	94	17.6	88	18.6	6	10.2
Grandparent	4	0.8	2	0.4	2	3.4
Foster parent	3	0.6	3	0.6	0	0
Step parent	1	0.2	1	0.2	0	0
Other	1	0.2	1	0.2	0	0
						X^2= 9.1, *DF* = 5, *p* = 0.1
Timing of when noticed 1st sign of something not right						
Less than 12 months	129	24.2	114	24.1	15	25.4
12 to 18 months	154	28.9	140	29.5	14	23.7
19-24 months	106	19.9	95	20	11	18.6
2 to 6 years	131	24.6	114	24.1	17	28.8
6 to 12 years	11	2.1	9	1.9	2	3.4
13 to 18 years	2	0.4	2	0.4	0	0
						X^2= 2.0, *DF* = 5, *p* = 0.84

Characteristics	Total sample		DP areas of WA sample		LDP areas sample	
Care-givers’ employment status						
Both fulltime	39	10.7	37	11.4	2	5.3
None employed	8	2.2	8	2.5	0	0
One fulltime and one part time	121	33.3	105	32.3	16	42.1
Only one fulltime	122	33.6	112	34.5	10	33.6
Both part time	14	3.9	13	4.0	1	2.6
Single parent full time	13	3.6	10	3.1	3	7.9
Single parent not employed	29	8	27	8.3	2	5.3
Single parent part time	17	4.7	13	4.0	4	10.5
						X^2= 9.6, *DF* = 8, p = 0.28
Household composition						
Two parent	406	77.6	359	77.4	47	79.7
Single parent	76	14.5	66	14.2	10	16.9
Extended family	4	0.8	3	0.6	1	1.7
Two parent and extended family	24	4.6	23	5	1	1.7
Single parent and extended family	10	1.9	10	2.2	0	0
Foster	3	0.6	3		0	0.6
						X^2= 3.9, *DF* = 5, p = 0.56

Chi-square and *t*-tests Analyses

Chi-square test for independence and *t*-test were conducted to identify IVs significantly associated with the regionality (DV). Associations at the nominated significance level ($p < 0.1$) were found between regionality (DV) and the following IVs: (1) types of school attended by the child with ASD (p = .014); (2) access to in-home respite services (p = .009); (3) effect of a child’s ASD symptoms on primary care-givers’ employment hours (p = .002); (4) number of employment hours reduced due to having a child with ASD (p = .047); (5) impact of having a child with ASD on primary care-givers’ ability to socialise (p = .042); (6) travel distance to medical facility (p = .005); (7) average weekly hours which a child with ASD attend Early

Intervention Therapy (*p* = .016); (8) frequencies of respite care utilisation (*p* = .003); (9) levels of social support primary care-givers receive (*p* = .032); and (10) parental perception of levels of family stress due to the impact of having a child with ASD (*p* = .003); (11) hours arranged for their other children, if any, without ASD to attend day care (*p* = .063); (12) average weekly hours the child with ASD spend with friends (*p* = .073); and (13) average monthly visits to non-medical services other than intervention or behavioural therapy (*p* = .071). These significant IVs were entered into the univariate analysis. The non-significant IVs include: (1) hours arranged for a child with ASD to attend day care centres and after school care; (2) evening and weekend babysitter hours arranged for a child with ASD; (3) hours arranged for their other children, if any, without ASD to attend after school care; (4) evening and weekend baby sitter hours arranged for their other children without ASD; (5) primary care-givers' weekly leisure hours; (6) average monthly number of ASD related medical visits; (7) average monthly number of non-ASD related medical visits; (8) distance to therapeutic services; (9) weekly average therapy interventions hours attended by a child with ASD who is older than 7 years; (10) average weekly education support hours which a child with ASD receive; (11) difficulty finding babysitters for a child with ASD; (12) if the family moved since their child was diagnosed with ASD; (13) types of people whom the primary care-givers receive support from; (14) presence of dual diagnosis of ASD and intellectual disability; (15) presence of dual diagnosis of ASD and mental health diagnosis; (16) presence of dual diagnosis of ASD and chronic illness; and (17) impact of interventions on children's Quality of Life. These non-significant IVs were excluded from further analysis.

Univariate Analysis

All significant IVs at the nominated level were tested in univariate analysis to select IVs which would be included in multivariate logistic regression analysis. The following IVs were found to be significant and therefore included in the multivariate logistic regression analysis: (1) types of school attended by the child with ASD (*p* = .032); (2) effect of a child's ASD symptoms on primary care-givers' employment hours (*p* = .026); (3) travel distance to medical facility (*p* = .012); and (4) parental perception of levels of family stress due to the impact of having a child with ASD (*p* = .031); (5) average monthly visits to non-medical services other than intervention or behavioural therapy (*p* = .019). The following non-significant IVs were excluded in the multivariate logistic regression analyses: (1) access to in-home respite services; (2) number of employment hours reduced due to having a child with ASD; (3) impact of having a child with ASD on primary care-givers' ability to socialise; (4) average weekly hours which a child with ASD attend Early Intervention Therapy; (5) frequencies of respite care utilisation; (6) levels of social support primary care-givers receive; (7) hours arranged for their other children, if any, without ASD to attend day care; and (8) average weekly hours the child with ASD spend with friends.

Multivariate Logistic Regression Analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant ($X^2 = 33.9$, $DF = 4$, $p < 0.001$). Four significant factors included explained 14% of the variability of the outcomes (Nagelkerke $R^2 = 0.14$). The overall accuracy of the model was 89.6%. The Wald statistic was used to identify statistically significant factors associated with families of children with ASD living in LDP areas and Exp (B) was used to predict the direction of prediction (Table 3.2).

Table 3.2. Variables associated with families of children with ASD living in LDP areas

LDP areas **Independent Variables**	***B***	**SE**	**Wald**	***p***	**Exp (B)**	**95 % CI for Exp (B)**	
						Lower	**Upper**
Reduced employment hours due to having a child with ASD (a two-parent household)	1.24	0.33	14.08	<.001	3.48	1.81	6.69
Reduced employment hours due to having a child with ASD (a single-parent household)	1.20	0.47	6.49	.011	3.32	1.31	8.39
Travel distance to medical facility	.23	0.86	7.51	.006	1.27	1.07	1.50
Family's very severe stress levels due to having a child with ASD based on parental perception	-1.51	0.61	6.09	.014	0.22	0.06	0.73

For the two IVs (overall family stress and overall employment hours) which were ordinal in nature, dummy variables were created to analyse the difference within each category of the variable. The analysis revealed three factors, including two categories in one of the IVs (overall employment hours), which significantly contributed towards living in LDP areas. These included:

1. Employment hours (two-parent household) due to having a child with ASD ($p < .001$) Participants living in LDP areas were 3.48 times more likely to reduce employment hours.
2. Employment hours (single-parent household) due to having a child with ASD ($p = .011$). Participants living in LDP areas were 3.32 times more likely to reduce employment hours.
3. Travel distance to medical facility (p = .006). Participants living in LDP areas were 1.26 times more likely to travel greater distance to access medical facility.

4. Parental perception of *very* severe stress levels resulting from having a child with ASD ($p = .014$). Participants living in LDP areas were 0.22 times less likely to report *very* severe stress levels.

The following factors did not significantly contribute to the multivariate model: (1) types of school the child with ASD attended; and (2) average monthly visits to non-medical services other than intervention or behavioural therapy. Although overall ratings were significant for the two IVs (overall family stress levels and overall employment hours), following the analysis using dummy variables, the subsequent categories within each variable were found to be statistically non-significant. These categories included: (1) ratings of mild stress levels resulting from having a child with ASD; (2) ratings of moderate stress levels resulting from having a child ASD; (3) ratings of severe stress levels resulting from having a child with ASD; (4) ratings of employment hours reduced due to having a child with ASD for both parents; (5) ratings of one parent unable to work due to having a child with ASD in a two-parent household; and (6) ratings of both parents unable to work due to having a child with ASD in a two-parent household.

Discussion

Family Daily Routines

The current study found that the parents in LDP areas, regardless of household composition, were more likely to report reduced employment hours due to having a child with ASD than their DP counterparts. This may be related to a lack of opportunities in obtaining flexible employment in those areas in Australia, where the major sources of employment are in agriculture, forestry, fishing and mining industries (Rural Industries Research and Development Corporation, 2009). The recent legislative change and the introduction of a variety of leave entitlements in Australia, such as a paternity leave, has resulted in more flexible and family friendly employment conditions (Australian Bureau of Statistics, 2009a, 2009b). However, there continues to exist notable difference between industries in providing flexible employment opportunities. For example, nearly half of the agriculture, forestry and fishing workers are required to be on call (Australian Bureau of Statistics, 2013d), which limits workers’ flexibility in daily planning. This contrasts with the employment conditions in the professional, scientific and technical service industries, where 70% of the workers are offered the flexibility of choosing their start and finish times; more than twice that of the mining industry workers (Australian Bureau of Statistics, 2009a). Given the variability in employment opportunities due to industry type, it is plausible to argue that a limited range of employment options and less flexible employment conditions in LDP areas adversely affect the ability of parents to participate in workforce while accommodating the needs of their child with ASD (National Rural Health Alliance INC., 2013).

This study did not find much difference in families’ engagement in daily routine between DP and LDP areas, apart from the finding in parental reduced employment hours. The results indicate that routines in families of children with ASD do not differ by regionality. However, IVs used in the current study did not include commonly examined family routine activities, such as mealtime and bedtime (Crespo et al., 2013; Evans & Rodger, 2008; Fiese et al., 2006; Marquenie et al., 2011; Mindell, Telofski, Wiegand, & Kurtz, 2009), morning routine (Clarke et al., 1999; Segal, 2004a) and family leisure activity (Downs, 2008). While previous research suggest that the unique characteristics of ASD impact on family routine engagement (Boyd et al., 2014; Marquenie et al., 2011), investigations into the experiences of families of children with ASD in LDP areas are limited. Hence, future study should include those commonly examined family routine activities to obtain a better picture of the unique experiences among families in LDP areas in engaging in daily routine.

Service Usage

We found that families of children with ASD living in LDP areas travelled significantly greater distance to access medical services, which may be a reflection of an uneven distribution of medical services between DP and LDP areas in Australia. In 2011, the per capita ratio of GPs and specialists working in LDP areas was found to be lower than those in DP areas (Australian Bureau of Statistics, 2013a). The geographical limitation unique to countries like Australia may be contributing to the fact that people with disability, including ASD, who reside in LDP areas access medical services less frequently than their DP counterparts (Australian Institute of Health and Welfare, 2015). However, children with ASD often require on-going medical and therapy support (Myers & Johnson, 2007) and parents are committed to meeting the needs of their children with ASD (Cashin, 2004; Hoogsteen & Woodgate, 2013a, 2013b). Having to travel long distances to medical services increases the time spent in transit. This could potentially add extra strain and cost to the life of families in LDP areas.

The current study did not find much difference in service usage between the two areas, apart from travel distance to medical facility. This finding may indicate a lack of services which caters for children with ASD in general, considering the low response rate (total of 125 out of 535 respondents) for this question. No significant difference between families living in DP and LDP areas were found in difficulty finding baby sitters for their child with ASD and many of the respondents reported ‘very to somewhat’ difficulty in finding baby sitters. Mothers of children with ASD have reported their unmet needs in receiving support in child care (Bromley et al., 2004). It is imperative to provide child care support services to those families, given the higher levels of stress among this population (Benson & Karlof, 2009; Eskow et al., 2011).

Perceived Stress Levels

Families in LDP areas were less likely to report *very* severe levels of stress in this study. Although increased parental role strain and related stress due to lack of services can be a common issue in LDP areas (Hoogsteen & Woodgate, 2013b), the advantage of living in these areas may be that families receive better support from within the community. Having adequate social support moderates the adverse effects of stress on health (Sawyer et al., 2010; Zablotsky, Bradshaw, et al., 2013). However, given the small odds ratio, we need to consider the possibility that service provision in DP areas may already include strategies which increase community connections in supporting parents of children with ASD.

Taking a community approach to support the families of children with ASD in LDP areas may foster positive parental perceptions of community acceptance of their child with ASD and their family (Hoogsteen & Woodgate, 2013a). These increased positive parental perceptions would be expected to encourage those families to socialise within their community, resulting in establishing further personal connections with others. Factors, such as the difficulty finding a family friendly environment which caters to the needs of the child with ASD; people's prejudicial attitudes towards children with ASD due to lack of knowledge; and the substantial parental efforts to educate others repeatedly by explaining their children's behaviour (Cashin, 2004; Woodgate et al., 2008), can lead the families of children with ASD to feel stressed in public spaces. However, people living in small communities in LDP areas may become familiar with the child with ASD more intimately. The increased awareness of the unique needs of the child with ASD could allow people to provide better support to the child and their families (Hoogsteen & Woodgate, 2013a). The opportunity to form closer community relationships in LDP areas may act as a protective factor for the families of children with ASD from experiencing higher stress levels.

Limitations

There are some limitations in the current study. First, this study was a secondary analysis of the previously collected data (Horlin et al., 2014). Although we used a specific question to measure families' stress due to having a child with ASD, validated measures for stress or family daily routines were not used. Caution therefore ought to be exercised while generalising the results. Second, the representation of the participants from LDP areas was low (11%). More targeted recruitment strategies to increase a better representation of LDP family participants is recommended. Third, the response rate observed was low (14%) (Horlin et al., 2014). This may be because the contact details of families registered with the DSC are maintained sporadically and as a consequence, a number of records contained incomplete or inaccurate entries. Additionally, due to the manner in which the DSC database is set up, the questionnaire was only addressed to the father of the registered clients. This would mean that mothers of separated couples did not receive the questionnaire. Given the children's mothers were the primary respondents (80%) in this study, overlooking this sample group would be expected to reduce the response rate. However, it should be noted that the non-respondent analysis suggested the sample was representative.

Conclusion

Overall, this current study did not find much difference in the nature of family routines and service usage due to families' residential location, except the three factors discussed. The results indicate: (1) underlying inequality of employment opportunities in LDP areas; (2) the scarcity of medical professionals in LDP areas; and (3) lower parental perception of family stress levels in LDP areas. A further exploration of the factors and associated issues with the geographical expansion in LDP areas, targeting employment and medical service provision, is required. The reason for lower stress levels in LDP areas should be further examined to benefit parents in DP areas. Detailed investigation into family routines by breaking down activities and by using a method which captures ‘lived experience’ of family, such as experience sampling method, may be useful to elicit the experiences of families of children with ASD. Future studies should also consider using valid family routine and stress measures, combined with qualitative methods, in order to guide the direction of research and practice in this area.

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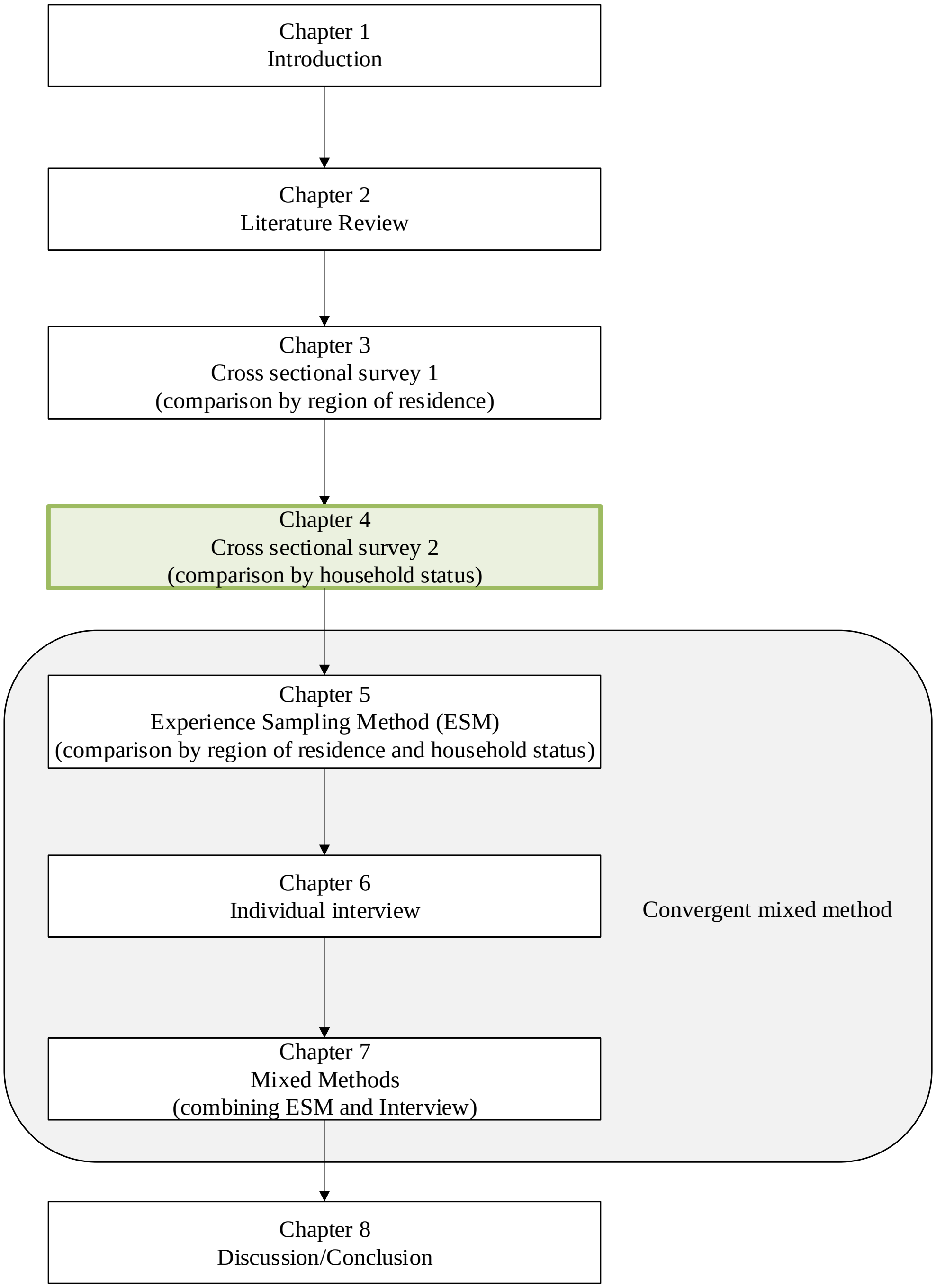
Chapter 4 Cross Sectional Study 2

(Published paper)



Title: Quality of life, coping styles, stress levels, and time-use in mothers of children with autism spectrum disorders: comparing single versus coupled households

This chapter compared quality of life (QoL), coping styles, stress levels and time-use among mothers of children with ASD by their household status. Following the gap identified by the cross-sectional survey 1 (Chapter 3), validated instruments were used to investigate QoL, coping styles and stress levels in this chapter. A 24-hour time-use table was used to collect the proportion of time spent in a typical weekday and weekend day. However, the findings highlighted the need to use other methods to investigate mothers' time-use, such as experience sampling method, to investigate the experiences of mothers in a more comprehensive manner[2].

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[2] This chapter has been published in Journal of Autism and Developmental Disorder (See Appendix E). Authors: Tomomi McAuliffe, Reinie Cordier, Sharmila Vaz, Yvonne Thomas and Torbjorn Falkmer

Abstract

This study aimed to examine the influence of differences in household status on the parental stress, coping, time use and quality of life (QoL) among mothers of children with autism spectrum disorders. Forty-three single and 164 coupled mothers completed the survey. Data were analysed using multivariate logistic regression. We found that single mothers were 1.05 times more likely to report lower levels of environmental QoL. Whilst they were 1.73 times more likely to use acceptance coping style, this association did not persist after adjusting for total number of children, household income and employment status. There was no difference in time use and stress between these mothers. Possible environmental issues for single mothers and implications for future research are discussed.

Keywords

ASD, single and coupled mothers, time use, quality of life, stress, coping

Introduction

Parenting a child with autism spectrum disorders (ASD) can be a challenging task (Nicholas et al., 2016). It is well documented that parents of children with ASD experience higher levels of stress than parents of children without ASD (Griffith et al., 2010; Montes & Halterman, 2007; Zablotsky, Bradshaw, et al., 2013). Limited social skills, challenging behaviour of the child with ASD (Bromley et al., 2004; Griffith et al., 2010) and low levels of family support (Bromley et al., 2004) are some of the factors associated with the increased parental stress levels.

Previous studies with families of children with ASD have developed knowledge on the parental experiences, such as parental stress levels (Griffith et al., 2010), coping styles (Marshall & Long, 2010), time use (Sawyer et al., 2010), and quality of life (QoL) (Dardas & Ahmad, 2014a). In the study of the parental experiences, the experiences of mothers of children with ASD are commonly examined (Ekas et al., 2010; Ekas & Whitman, 2010; Kuhaneck et al., 2010; Marshall & Long, 2010; Seymour et al., 2013). Mothers face an increased risk of ill health (Allik et al., 2006), and are required to assume multiple roles to cater for the unique demands of the child with ASD (Safe, Joosten, & Molineux, 2012). Studies that specifically examined the experiences of fathers are somewhat limited (Burrell, Ives, & Unwin, 2017; Cheuk & Lashewicz, 2016); however, some studies have compared the experiences between mothers and fathers of children with ASD (Allik et al., 2006; McStay et al., 2014; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). For example, there is emerging evidence to suggest mothers of children with ASD experience lower levels of QoL than fathers (McStay et al., 2014).

Previous studies have used various parental characteristics in investigating the experiences of parents of children with ASD. These characteristics include age (Gray, 2006; Pruitt, Willis, Timmons, & Ekas, 2016), gender (Allik et al., 2006; Lee, 2009; McStay et al., 2014; Mugno et al., 2007), employment status (Dardas & Ahmad, 2014a), and household income (Dardas & Ahmad, 2014a). In fact, a recent review on coping styles among parents of children with ASD reported that age and gender of parents are the most commonly discussed factors (Lai & Oei, 2014). Spousal relationship factors, such as spousal support (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), marital satisfaction (Higgins, Bailey, & Pearce, 2005), and marital quality (Harper, Dyches, Harper, Roper, & South, 2013), are other parental characteristics used to investigate the experiences of parents of children with ASD. Parents of children with ASD were found to experience spousal relationship issues when they used maladaptive coping strategies, such as escape-avoidance (Dunn et al., 2001).

Few studies have compared the experiences of parents of children with ASD using a parental characteristic of single versus coupled household status. Household status is common demographic information to be collected in the study of parents of children with ASD; however, it is not always used as the primary variable of interest (Mugno et al., 2007). One study reported insufficient statistical power to compare parental coping strategies based on the single versus coupled household status (Twoy et al., 2007). Some studies have used the household status in their statistical analyses (Benjak, 2011; Bromley et al., 2004; Reed, Sejunaite, & Osborne, 2016). For example, one study that compared subjective QoL between parents of children with ASD and parents of children without a disability in Croatia conducted a logistic regression analysis with an independent variable of single versus coupled household status (Benjak, 2011). However, the focus of the previous studies that used the variable of the household status was not to investigate the parental experiences due to single versus coupled household status. This current study, therefore, intends to fill the gap in the study of parents of children with ASD through analysing various parental experiences, such as stress levels, coping styles, time use, and QoL that relate to single versus coupled household status.

Mothers’ Experiences When There is a Child with ASD in Their Families

To date, parental experiences, such as stress levels, coping styles, time use and QoL have been examined among mothers of children with ASD (Benson, 2010, 2014; Dardas & Ahmad, 2014a, 2014b, 2015; Mugno et al., 2007; Sawyer et al., 2010). Families of children with ASD tend to assume traditional family roles where mothers commonly hold the primary caregiver’s role (Nealy, O'Hare, Powers, & Swick, 2012; Pepperell et al., 2016). As primary caregivers, mothers are more likely to experience parenting related difficulties. One study that examined child related stressors, availability of resources, and coping strategies among parents of children with ASD found that mothers experienced higher levels of stress than fathers (McStay et al., 2014). Although parents of children with ASD use various coping styles, such as acceptance, humour, and gaining hope from child’s improvement (Marshall & Long, 2010), some coping styles used may be counterproductive or maladaptive (Hall & Graff, 2011; Sivberg, 2002). A recent longitudinal study, which was conducted over a seven-year period, on maternal coping styles and adjustment among mothers of children with ASD found that increased use of maladaptive coping styles was related to increased stress proliferation and distress, and decreased parental efficacy (Benson, 2014). It is therefore important to examine the parental coping styles, in particular those of mothers, given that mothers are commonly the primary organisers of the family schedules (Larson, 2000a).

The role of being a mother is time intensive, especially when children have a disability (Olson & Esdaile, 2000). Compared with parents of typically developing children, parents of children with special needs spend longer time in childcare activities (Crowe & Florez, 2006; McCann et al., 2012). One study found that mothers of children with a disability engaged in childcare activities on average 13.1 hours more per week than mothers of children without a disability (Crowe & Florez, 2006). Parents of children with ASD were found to spend on average 43 hours per week in caring for their children (Järbrink et al., 2003). A consequence of increased childcare hours is a reduction of time available for other daily activities among parents, including personal leisure, work, and personal care (Brandon, 2007). Mothers feel physically and mentally exhausted by meeting this increased care needs, while not spending much time in personal care, such as sleeping (McGuire et al, 2004).

A recent systematic review found that the QoL of parents of children with ASD is lower than that of parents of typically developing children or the general population (Vasilopoulou & Nisbet, 2016). Various factors are associated with parents of children with ASD reporting lower QoL. These factors include increased challenging behaviours of the child with ASD (Dardas & Ahmad, 2014a; McStay et al., 2014; Tung et al., 2014), severity of ASD (Pozo et al., 2014), lower household income (Dardas & Ahmad, 2014a), decreased levels of social support (Pozo et al., 2014), parental distress (Dardas & Ahmad, 2014a), and parental coping style (Dardas & Ahmad, 2014a; Pozo et al., 2014). The complex interplay between these factors should, therefore, be considered when describing the QoL among parents of children with ASD. Parents of children with ASD are often required to adjust many aspects in their life, including their family interactions, family lifestyles, marital relationships, work arrangement, coping styles, and their perspective of life (Ooi et al., 2016). QoL is useful in capturing the complexity of the lives of these parents and should be considered in understanding the impact of having a child with ASD on parents (Dardas & Ahmad, 2014a).

Parental Experiences among Single Mothers

The family structure has changed over the years in Western society due to the decreased marriage rates, the increased divorce rates, and the increased number of cohabiting couples (The Organisation for Economic Co-operation and Development [OECD], 2012). One of the notable family structural changes is an increase of single parent families. In Australia, by 2031 the rate of the single-parent families is projected to increase by between 40% and 77% (Australian Bureau of Statistics, 2010). Other OECD countries, such as UK and Norway, have projected similar trends of an increase of single parent families (OECD, 2012). In 2015, there were 617,800 single parent families with dependants living with them in Australia and of those, 84% were led by single mothers (Australian Bureau of Statistics, 2016). This over-representation of single parent families that are led by mothers is predicted to remain unchanged over the next fifteen years (Australian Bureau of Statistics, 2010).

Single motherhood, in general, presents some unique challenges, for example, additional time pressure in managing daily family responsibilities (Compas & Williams, 1990; Sachs, Hall, & Pietrukowicz, 1995) and financial pressures (Cooper et al., 2008; Sachs et al., 1995). One study that compared the experiences of single and coupled first-time mothers of typically developing infants found that single mothers experienced higher levels of stress than their counterpart (Copeland & Harbaugh, 2010). Both global (Witvliet, Arah, Stronks, & Kunst, 2014) and Australian (Crosier et al., 2007) studies indicate that single mothers experience poorer physical and mental health outcomes compared to coupled mothers.

Single motherhood has been previously explored particularly within the area of social welfare and employment research (Cook, 2012b, 2012c; Herbst & Tekin, 2014; Wu, Wang, & Eamon, 2014); however, there is a paucity of research on single mothers of children with chronic health conditions, including children with a disability (Brown et al., 2008). Even fewer studies have been conducted with single mothers of children with ASD (Dyches et al., 2016). Given the challenges that single mothers face, combined with the unique factors identified among mothers of children with ASD, such as increased stress levels and lower QoL, there is a need to investigate the experiences of single mothers of children with ASD.

The Aim of the Study

The aim of the current study was to examine the influence of differences in household status (single versus coupled) on the stress levels, coping styles, time use and QoL among mothers of children with ASD. For the purpose of this study, we employed the definition of lone parent provided by the Australian Bureau of Statistics (2015b) to define single mothers. Single mothers in this study are those who have “no spouse or partner usually resident in the household but who forms a parent-child relationship with at least one child usually resident in the household” (Australian Bureau of Statistics, 2015b, para. 21).

Methods

Study Design

The present study was part of a larger cross-sectional study that investigated the experiences of families of children with ASD in Western Australia. Researchers at Curtin University conducted this study in collaboration with the Disability Services Commission of Western Australia (DSC) and South-West Autism Network (SWAN). The larger study examined a number of topics related to the experiences of families of children with ASD, with a cross-sectional survey that consisted of the following four sections: (1) demographic information of the family, (2) the process of ASD diagnosis and access to health services, (3) the impact of having a child with ASD on family life, and (4) possible behavioural difficulties related to the characteristics of ASD. The survey was pilot tested with a convenient sample for clarify of questions, the flow of content, and estimating completion timeframe. The survey was refined following the pilot testing.

Participants

A parent or a primary caregiver of a 2 to 18 year old child or young person diagnosed with ASD living in Western Australia was eligible to participate in this study. The participants were recruited through the existing internal lists of families of children with ASD who agreed to participate in future research held at Curtin University and the Telethon Kids Institute; service providers, such as DSC and SWAN; ASD related events held at Curtin University; health professionals working with families of children with ASD; and media release on radio.

Instruments

Four measures were used in this current study: (1) The World Health Organisation Quality of Life BREF (The WHOQOL Group, 1998), (2) Autism Parental Stress Index (Silva & Schalock, 2012), (3) The Brief COPE (Carver, 1997), and (4) time use estimate table. All four measures were included in section three of the survey (i.e., the impact of having a child with ASD on family life).

The World Health Organisation Quality of Life Brief (WHOQOL BREF). The WHOQOL BREF that is a short form of the WHOQOL-100 is a convenient and concise tool to use for studies in which QoL is of interest (The WHOQOL Group, 1998). It is possible to calculate four domains scores: physical, psychological, social relationships, and environment. Social relationships and environmental domains are often not included in other short version of QoL assessments (The WHOQOL Group, 1998). There are 26 items in total. Some examples of the items in the physical domain include pain and discomfort, energy and fatigue, mobility, and work capacity. In the psychological domain, items, such as positive and negative feelings, self-esteem, bodily image, and spirituality, are included. The social relationships domain includes personal relationships, social support, and sexual activity. In the environment domain, items, such as physical safety and security, home environment, financial resources, accessibility to services and its quality, and opportunities for leisure activity, are included (The WHOQOL Group, 1998). Two items are independent from these four domains: respondents' overall perception of QoL and their overall perception of health (The WHOQOL Group, 1996). A five-point Likert scale is used in WHOQOL BREF, and the respondents are asked to answer each item reflecting their experiences in the last two weeks (Skevington, Lofty, & O'Connell, 2004). Four domain scores are calculated using the mean score of each item within each domain, and in order to make the domain scores comparable with the WHOQOL-100, the mean scores are then multiplied by four (The WHOQOL Group, 1996). Each domain is reported to have acceptable internal consistency. The alpha levels reported for each domain are as follows: for the physical domain .82, for the psychological domain .81, for the social relationships domain .68, and for the environmental domain .80 (Skevington et al., 2004). Likewise, acceptable test-retest reliability of .66 for the physical domain, .72 for the psychological domain, .76 for the social relationships domain, and .87 for the environment domain over a two to four week period was reported (The WHOQOL Group, 1998).

Autism Parental Stress Index (APSI). The APSI has an overall parental stress scale and three subscales that measure stress levels of parents of a child with ASD, specifically identifying the areas with which parents require further support (Silva & Schalock, 2012). These three subscales include (1) the core autism symptoms, (2) comorbid behaviours, and (3) comorbid physical issues. The results of the APSI validation suggests good internal consistency for the overall scale (Cronbach’s alpha = .83). The acceptable internal consistency of .79 for the core autism symptoms; .76 for the co-morbid behaviours; and .67 for the co-morbid physical issue was reported. A good test-retest reliability of .88 was reported for the overall scale over a four-month period (Silva & Schalock, 2012).

Brief COPE. The 28-item Brief COPE was developed as a shorter version of the full COPE, and it measures 14 different coping styles (Carver, 1997). The 14 theoretically derived subscales that consist of two items per subscale represent different coping styles: (1) active coping, (2) planning, (3) positive reframing, (4) acceptance, (5) humour, (6) religion, (7) emotional support, (8) instrumental support, (9) self-distraction, (10) denial, (11) venting, (12) substance use, (13) behavioural disengagement, and (14) self-blame. The Brief COPE is a useful tool for researchers to assess a range of coping styles, whilst reducing participant response burden. Respondents are asked to rate each statement that describes a coping style on a 4-point scale that ranges from ‘I haven’t been doing this at all’ to ‘I’ve been doing this a lot. On average, adequate internal reliabilities (α ranged from .50 to .90) have been reported (Carver, 1997).

Time Use Estimate Table. This constituted a 24-hour format table that participants completed to describe their average weekday and weekend day by providing estimated hours on each of the 14 activities presented. We chose these 14 activities from previous publications on time use of mothers of children with a disability (Gevir et al., 2006; McCann et al., 2012). The fourteen activities listed in this study were (1) sleep, (2) grooming and personal hygiene, (3) meal preparations and clean up, (4) having a meal, (5) taking care of child, (6) travel time to and from school or work, (7) time spent at work, (8) personal leisure time, (9) house duties, (10) shopping, (11) having quiet time or down time, (12) visiting family/friends, (13) studying, and (14) voluntary work.

Procedures

The survey was made available in three different formats for completion: (1) an online version, (2) a telephone interview to complete the survey, or (3) a paper and pencil version to be returned via post. The online survey was available from January 2015 to December 2015. The paper and pencil version of the survey was distributed to prospective participants at several events, which were organised by the Curtin Autism Research Group (CARG) in 2015. Participants who completed the online survey (*n* = 150) provided consent to participate in this study by completing the survey. For those participants who completed the survey (*n* = 2) by telephone, a researcher read the scripted consent prior to starting the survey, and the participants’ response was recorded in the electronic data entry form. The participants who completed the paper and pencil survey (*n* = 55) were asked to return the signed consent form to the research team. We have conducted a sensitivity analysis with all variables that went into the univariate analysis between those participants who completed the online survey and those who completed the paper and pencil version. There were no meaningful differences between the two forms of data collection on any of the variables. Due to the procedure used to collect data, it was impossible to calculate how many potential participants who received the survey, opted not to participate.

All data were entered directly by participants online or the researchers entered data from the telephone and the paper and pencil versions online. These data were stored on Curtin University's Qualtrics Web Server, which was password protected. A total of 248 surveys were completed. We removed those double or triple entries made by the same participants (*n* = 22) and only kept their latest entry in this current study. We also removed the entries made by fathers (*n* = 16) and by grandparents (*n* = 3) as the targeted population of the current study was mothers. In total, 207 were completed by mothers, including biological, step and foster, and thus were deemed relevant to the current study. For the purpose of this study, those 207 participants were categorised into coupled mothers and single mothers.

Data Analyses

The Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp, 2013) was used to analyse data. The question on participant's household status was used to create a dichotomous variable, a coupled mother or a single mother. The participants chose their household status from the following seven options: (1) two-parent, (2) single parent, (3) extended family (grandparents), (4) two-parent plus extended family, (5) single parent plus extended family, (6) foster situation, and (7) other. The household status category of the coupled mother was formed by collapsing the two parent (*n* = 156) or the two-parent plus extended family options (*n* = 3). The household status category of the single mother was formed by combining the single parent (*n* = 39) and the single parent plus extended family options (*n* = 4). Those participants who chose the other option were included if further information to identify their household status (i.e. two-parent or single parent) was provided ($n = 5$). Those participants who chose the extended family option were not included in this current study. The newly created household dichotomous variable, a coupled mother or a single mother, was used as a dependent variable.

Although the structure of the coping styles with Brief COPE among parents of children with ASD has been previously explored (Benson, 2010; Hastings, Kovshoff, Brown, et al., 2005), both studies yielded different factor structures and had smaller sample size ($N = 113$; $N = 135$ respectively) than the current study ($N = 207$). Therefore, factor analysis was conducted to explore the structure of the coping styles that best fit to the current study participants. A principal component analysis of the 28 items using oblimn rotation was undertaken. The scree-test was used to determine the number of factors with the eigenvalue greater than 1.0 (Field, 2005; Osborne & Costello, 2009) and factor loading greater than 0.40. Eigenvalues greater than one indicated that the first five factors, which are listed in Table 4.1, explained 18%, 15%, 9%, 7%, and 6% of the variance respectively. The sixth and the seventh factors had eigenvalues of just over 1%, and they explained 5% and 4% of the variance respectively. Following the initial examination of the correlation matrix, the two items that form a subscale of substance use and another two items that form a subscale of use of religion were excluded, as their correlations were high ($r > 0.8$). The Kaiser-Meyer-Olkein measure indicated good sampling adequacy (KMO = .75) (Field, 2005). Bartlett's test of sphericity (X^2 (276) = 1724.67, $p = .001$) indicated that the correlation between each item was sufficient (Field, 2005). As a result, the five-factor solution explaining 56% of the total variance was used in the current study. Cronbach's alpha for each of the five-factor is reported in Table 4.1.

Unlike the previous two studies (Benson, 2010; Hastings, Kovshoff, Brown, et al., 2005) that reported four factors, our analysis yielded five factors with one item dropped. The dropped items was '*I have been turning to work or other activities to take mind off things',* which is an item for the self-distraction subscale. The result of the factor analysis is presented in Table 4.1.

Table 4.1: Factor loadings for analysis of Brief COPE items

Factor	Problem focused	Active avoidance	Positive coping	Limited use of relationship support	Acceptance
% variance	18.44	15.34	9.02	7.74	5.74
Cronbach's alpha	0.77	0.78	0.74	0.75	0.70
Coping taking action to try to make the situation better	**.722**	-.052	.028	-.001	.172
Coping concentrating my efforts on doing something about the situation I am in	**.700**	.081	.033	-.068	-.087
Coping trying to come up with a strategy about what to do	**.652**	.208	.041	-.046	.244
Coping thinking hard about what steps to take	**.578**	.117	-.036	-.028	**.450**
Coping blaming myself for things that happened	.147	**.738**	-.009	.028	-.035
Coping giving up the attempt to cope	-.205	**.735**	-.184	.048	.186
Coping criticizing myself	.151	**.721**	-.002	.119	-.102
Coping saying to myself this isnt real	.096	**.646**	.131	.120	-.340
Coping refusing to believe that it has happened	.231	**.615**	-.011	.040	**-.414**
Coping giving up trying to deal with it	**-.470**	**.543**	-.017	.109	.335
Coping saying things to let my unpleasant feelings escape	-.076	**.523**	-.122	-.370	-.123
Coping doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	-.260	**.409**	.233	-.245	.188
Coping turning to work or other activities to take my mind off things	.010	.349	.090	-.023	.172
Coping making jokes about it	-.080	.009	**.894**	.042	-.039
Coping making fun of the situation	-.161	.009	**.861**	.001	-.134
Coping trying to see it in a different light, to make it seem more positive	.325	.069	**.594**	-.050	.127
Coping looking for something good in what is happening	.211	-.150	**.536**	-.083	.195
Coping getting emotional support from others	-.075	-.058	-.047	**-.836**	.015

Factor	Problem focused	Active avoidance	Positive coping	Limited use of relationship support	Acceptance
Coping getting comfort and understanding from someone	-.043	-.231	.139	**-.726**	-.029
Coping getting help and advice from other people	.366	-.199	.100	**-.611**	-.064
Coping expressing my negative feelings	-.055	**.409**	.144	**-.570**	.002
Coping trying to get advice or help from other people about what to do	.359	.084	-.081	**-.566**	.040
Coping learning to live with it	.137	-.062	.097	.104	**.715**
Coping accepting the reality of the fact that it has happened	.234	-.099	.007	-.081	**.655**

Our factors somewhat resembled the result of Hastings, Kovshoff, Brown, et al. (2005) and hence their labels suited the current extracted factors. Factor one (problem focused) included all items of the planning and active coping subscales. This factor describes mothers' proactive coping styles to deal with stressors. Factor two (active avoidance) included all items of the self-blame, behavioural disengagement, denial and venting and one item from self-distraction subscales. This factor describes mothers' coping style to avoid stressors physically or emotionally. Factor three (positive coping) included all items of the humour and positive reframing subscales. This factor describes mothers' coping style to perceive stressors through their constructive lens. Factor four (lack of relational support) included all items of the emotional support and instrumental support and one item from venting subscales. This factor describes mothers' limited use of external support in dealing with stressors. Factor five (acceptance) included both items of the subscale of acceptance, and one item of the subscale of planning. This factor describes mothers' coping style to deal with stressors while adopting the situation.

A *chi*-square test was conducted to compare the relationship between single versus coupled household status and demographic variables. A univariate analysis was conducted to identify significant associations between single versus coupled household status and the scores for the WHOQOL BREF and the APSI, the extracted factors of the Brief COPE, and the number of hours reported in the time use estimate table. Binary logistic regression analyses were then performed with the significant variables to identify key factors associated with single mothers' stress levels, coping styles, time use, QoL, and demographic variables. A backward elimination method was used to develop the final model. In this method, all variables that were found significant in the univariate analysis were entered in the regression model initially and the least significant variable was removed one at a time until it reached the final model.

Results

Demographic Information of Participants

Table 4.2 provides an overall descriptive profile of the participants by single versus coupled household status. There were 43 single mothers (20.8%) and 164 coupled mothers (79.2%). Significant differences were found between single and coupled mothers on the following five demographic variables: (1) respondents' self-reported presence of cognitive impairment or intellectual disability with the child with ASD was higher among single mothers (*p* = 0.009), (2) total number of children was higher among coupled mothers (*p* = 0.011), (3) more single mothers were unemployed (*p* < 0.001), (4) household income was lower among single mothers (*p* < 0.001), and (5) single mothers had lower education levels (*p* = 0.027). No significant differences were found on any other demographic variables.

Table 4.2: Characteristics of the mothers and their children for the total sample, the sample of single mothers and the sample of coupled mothers

Characteristics	**Total sample**		**Single mothers**		**Coupled mothers**	
	N= 207	%	*N*= 43	%	*N*= 164	%
Children's Age (month) Mean (standard deviation)			10.23 (4.7)		9.95 (4.9)	
					t = 0.73, p = 0.78	

Characteristics	Total sample		Single mothers		Coupled mothers	
	N= 207	%	*N*= 43	%	*N*= 164	%
Children's Gender						
male	173	83.6	37	86	136	82.9
female	34	16.4	6	14	28	17.1
					X^2= 0.24, *DF* = 1, *p* = 0.62	
Official ASD diagnosis						
Autistic Disorder (Autism)	111	55.8	23	57.5	88	55.3
HFA, AS, PDD-NOS	88	44.2	17	42.5	71	44.7
					X^2= 0.06, *DF* = 1, *p* = 0.81	
Presence of cognitive impairments/intellectual disability						
Yes	55	27	18	42.9	37	22.8
No	149	73	24	57.1	125	77.2
					X^2= 6.79, *DF* = 1, *p* = 0.009*	
Children's age when noticed 1st sign of something not right						
Less than 3 years old	166	80.2	35	81.4	131	79.9
3 years old and older	41	19.8	8	18.6	33	20.1
					X^2= 0.49, *DF* = 1, *p* = 0.82	
Children's age when formally diagnosed						
Less than 4 years old	84	41	16	37.2	68	42
4 years old or older	121	59	27	62.8	94	58
					X^2= 0.32, *DF* = 1, *p* = 0.57	
Number of children with ASD						
1 child	189	91.3	40	93	149	90.9
More than 1	18	8.7	3	7	15	9.1
					X^2= 0.20, *DF* = 1, *p* = 0.65	
Total number of children						
1 child	32	15.5	12	27.9	20	12.2

Characteristics	**Total sample**		**Single mothers**		**Coupled mothers**	
	N= 207	%	*N*= 43	%	*N*= 164	%
2 or more children	175	84.5	31	72.1	144	87.8
					X^2= 6.44, *DF* = 1, *p* = 0.011*	
Employment status						
Employed	170	88.5	19	52.8	151	96.8
Unemployed	22	11.5	17	47.2	5	3.2
					X^2= 55.86, *DF* = 1, *p* < 0.001*	
Household income**						
Up to $51,999	46	22.9	31	73.8	15	9.4
$52,000 and over	155	77.1	11	26.2	144	90.6
					X^2= 78.01, *DF* = 1, *p* < 0.001*	
Mothers' education levels						
Did not complete school	25	12.1	5	11.6	20	12.2
Year 12	25	12.1	5	11.6	20	12.2
Post TAFE or Certificate	73	35.3	23	53.5	50	30.5
University	84	40.6	10	23.3	74	45.1
					X^2= 9.14, *DF* = 3, *p* = 0.027*	

**The cut-off point was set based on the median household income in Western Australia at the time of the study.

Univariate Analysis

Univariate analysis was conducted to identify independent variables significantly associated with single versus coupled household status. The following independent variables were found to be significant: (1) WHOQOL BREF physical domain (*p* = .003), (2) WHOQOL BREF psychological domain (*p* = 0.028), (3) WHOQOL BREF social relationships domain (*p* = 0.012), (4) WHOQOL BREF environment domain (*p* < 0.001), (5) WHOQOL BREF overall QoL (*p* = 0.001), (6) WHOQOL BREF health satisfaction (*p* = .039), (7) factor two (active avoidance) coping style (*p* = 0.001), (8) factor five (acceptance) as coping style (*p* = 0.008), (9) estimated hours completing house duties during the week (*p* = 0.04), (10) estimated hours visiting family or friends during the weekend (*p* = 0.049), (11) APSI the core autism symptoms (*p* = 0.013), (12) APSI comorbid behaviour (*p* = 0.027), (13) APSI comorbid physical (*p* = 0.014), and (14) APSI overall scores for parental stress levels (*p* = 0.002). These significant independent variables were entered into the multivariate logistic regression analysis. Apart from the two variables, estimated hours completing house duties during the week and visiting family or friends during the weekend, there were no significant difference between single and coupled mothers in their estimated time use. No significant difference was found with the variables of coping style factor three (positive coping) and factor four (lack of relational support). These non-significant independent variables were excluded in the multivariate logistic regression analysis.

Multivariate Logistic Regression Analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant ($X^2 = 29.29$, $DF = 4$, $p < 0.001$). The included factors explained 21% of the variance (Nagelkerke $R^2 = .21$). The overall prediction success rate of the model was 80.3%. The Wald criterion was used to identify factors that were significantly associated with single mothers, and Exp (B) was used to predict the direction of the outcomes. Table 4.3 and 4.4 shows the results of the multivariate logistic regression analysis.

Table 4.3: Variables associated with single mothers of children with ASD

Single mothers							
Independent Variables						**95 % CI for Exp (B)**	
	B	**SE**	**Wald**	***p***	**Exp (B)**	**Lower**	**Upper**
WHOQOL Environmental Domain	-0.57	.013	18.88	<.001	.945	0.92	0.97
Brief COPE factor five (acceptance)	0.55	.199	7.60	.006	1.73	1.17	2.55

Table 4.4: Variables associated with single mothers of children with ASD with demographic variables

Single mothers							
Independent Variables						**95 % CI for Exp (B)**	
	B	**SE**	**Wald**	***p***	**Exp (B)**	**Lower**	**Upper**
WHOQOL Environmental Domain	-0.57	.013	18.88	<.001	.945	0.92	0.97
Brief COPE factor five (acceptance)	.236	.286	.845	.358	1.30	.743	2.28
Total number of children	-1.30	.642	4.11	.043	.272	0.77	.958
Household income	-2.22	.618	11.82	.001	.119	0.35	.399
Employment status	2.21	.787	7.85	.005	9.08	1.94	42.50

The multivariate logistic regression analysis revealed two factors that significantly contributed towards being single mothers: (1) WHOQOL BREF environment domain ($p < 0.001$); and (2) Factor five, acceptance as a coping style ($p = 0.006$). The current results showed that single mothers were 1.05 times more likely to report lower levels of QoL in the environmental domain (OR = 1.05; 95% CI = 1.04, 1.09). Although factor five (acceptance) was found significant ($p < 0.05$) in the multivariate logistic regression analysis (OR = 1.73; 95% CI = 1.17, 2.25), which indicates single mothers were 1.73 times more likely to use acceptance as a coping style, this result did not persist after adjusted for total number of children, household income and employment status in the analysis. The WHOQOL BREF environmental domain remained significant ($p = 0.004$) following this adjustment.

The following factors did not significantly contribute to the multivariate model: (1) WHOQOL BREF Physical health domain, (2) WHOQOL BREF Psychological health domain, (3) WHOQOL BREF Social relationships domain, (4) estimated hours completing house duties during the week, (5) estimated hours visiting family or friends during the weekend, (6) overall scores for parental stress levels, and (7) factor two (active avoidance) coping style.

Discussion

The aim of this current study was to examine the influence of differences in single versus coupled household status on the stress levels, coping styles, time use and QoL among mothers of children with ASD. The finding revealed that single mothers experience lower QoL in the environmental domain, whilst they use an adaptive coping style (acceptance) more to deal with everyday stressors.

Maternal Quality of Life

In this current study, single mothers reported lower levels of QoL in the environmental domain than coupled mothers. Financial hardship is a common issue among single mothers (Crosier et al., 2007; Dyches et al., 2016; Sachs et al., 1995; OECD, 2012), in particular if they are from working class background (Rowlingson & McKay, 2005). One of the reasons for single mothers to experience financial hardship may be due to a lack of suitable jobs, including those with flexible employment opportunity, which prevents those single mothers from obtaining full time employment. A study that examined the work force participation of single parents across 30 European countries found that single mothers were less likely to be employed full time than their counterpart, particularly while their children were young (Riggeri & Bird, 2014). Other factors, such as a lack of suitable childcare services, may also prohibit single mothers' abilities to obtain full time employment (Broussard, Joseph, & Thompson, 2012). In a meta-synthesis of single mothers' experiences of transitioning from welfare to work, the issues of the affordability, accessibility, and practicability of childcare services were found to exacerbate the already difficult transition process among these mothers in USA and Canada (Cook, 2012a). Having access to suitable childcare support can be a challenging issue among mothers of children with ASD (Bromley et al., 2004). It is, therefore, speculated that this issue maybe even more pronounced among single mothers of children with ASD.

Mothers are generally able to increase working hours as children mature and start attending school, and the difference in full time employment rates between single and coupled mothers narrows (Riggeri & Bird, 2014). However, mothers of children with complex needs, such as ASD, may need to seek part-time employment as the demand to cater for their children's unique needs (McCann et al., 2012; Sawyer et al., 2010) may continue through to young adulthood (Smith et al., 2010). In fact, parents of children with ASD report that reduced working hours and the associated loss in income are the single largest contributing factor to the cost of having a child with ASD (Horlin et al., 2014).

In Australia, social security payments were the largest source of income for 61% of single parent families in 2003 to 2004 (Australian Bureau of Statistics, 2007). A legislative change in Australia, which shifted some single parents to lower social security payments, resulted in these single parent families facing increased risk of poverty (The Australian Council of Social Service, 2012). In the current study, the single mothers reported lower household income than coupled mothers ($p < 0.001$), and more single mothers were unemployed ($p < 0.001$). Financial insecurity derived from a lack of flexible employment opportunity and insufficient social security payment among single mothers may have contributed to their lowered perceptions of QoL in the environmental domain.

This current study did not find differences between single and coupled mothers in the physical, psychological, and social relationships domains of QoL. This result may indicate that the status of being a single versus coupled household with a child with ASD does not have much impact on their QoL. It is also possible that both groups of mothers experience lower QoL compared to the general population, but there was no marked difference between the two groups. Indeed, one study has found that parents of children with ASD had lower QoL in every domain compared with the general population (Tung et al., 2014). Given that the current study did not have a control group, future research should consider comparing the QoL of these mothers with that of a control group to thoroughly understand the relative influence of being a single versus coupled household with a child with ASD.

Acceptance coping style

Single mothers were found to use the acceptance coping style more than coupled mothers. This finding is similar to a study by Compas and Williams (1990) where single mothers of typically developing young adolescents were found to use the acceptance and positive reappraisal coping style. Single mothers often need to cope with daily stressors without the support of an intimate partner, unlike coupled parents who have an option to share parental burden while supporting each other (Gray, 2006). In fact, coupled mothers consider spousal support critical in coping with stressors (Kuhaneck et al., 2010). Coupled parents can access a dyadic coping strategy, where they combine individual skills and capacities to deal with daily stressors or to support their partner in managing stressors (Bodenmann, 1995). In positive dyadic coping, couples can express and share stressful situations, receive both practical and emotional support from their partner, request for help in managing the stressors, and use a collaborative approach to cope with the stressors (Falconier, Jackson, Hilpert, & Bodenmann, 2015). However, single mothers simply do not have access to spousal support. Instead, family and other social supports play a crucial role in managing stressors and sharing parental responsibilities for single mothers of children with a disability (Levine, 2009; Muir, Tudball, & Robinson, 2008). Some of these mothers consciously build and maintain their social support networks, in preparation for the future needs of their children (Levine, 2009). However, finding reliable social support can be challenging due to multiple factors, for example, having to travel large geographical distances to access the support networks and having to train and empower people who lack knowledge and skills in caring for the child with complex needs (Muir et al., 2008). It may be plausible that given the complexity to establish and maintain reliable social networks, for single mothers of children with ASD, dealing situations by using the acceptance coping style maybe an easier option. While a lack of spousal and social support may be forcing these mothers to adapt the acceptance coping style, other factors may also be able to explain the current result.

The use of acceptance coping style did not remain significant after adjusting for total number of children, household income, and employment status. Our results suggest that those three demographic variables are critical in influencing the coping styles that single mothers adopt. Complex interactions between parental characteristics should be considered as coping is a process and is influenced by personal and situational factors (Folkman & Moskowitz, 2004). Another possible explanation of this result is that both single and coupled mothers of children with ASD are resilient. There is emerging evidence to show that families of children with ASD are resilient (Bayat, 2007; Bekhet, Johnson, & Zauszniewski, 2012; Tunali & Power, 2002). Despite the unique daily challenges, such as lack of public or family understanding towards ASD (Higgins et al., 2005; Nealy et al., 2012) and challenging behaviour of the child (Bromley et al., 2004), mothers of children with ASD show extreme commitments in caring for their children (van Tongerloo, van Wijngaarden, van der Gaag, & Lagro-Janssen, 2015). One study that explored the experiences of mothers of preschool children with ASD found that mothers developed hope and positive optimism over the years and their positive perspectives contributed towards their resilience (Bultas & Pohlman, 2014). In a study that compared the psychological functioning and coping styles of the mothers of children with ASD (*n* = 364) and the mothers of children without ASD (*n* = 61,408), it was found that mothers of children with ASD were 1.8 times more likely to report that they were coping better with daily parenting issues (Montes & Halterman, 2007). Parents of children with ASD develop more adaptable coping styles, such as acceptance over the years (Ooi et al., 2016), and the coping style of acceptance has been found to be a mediating factor between stress and QoL among parents of children with ASD (Dardas & Ahmad, 2015). Parents are able to deal with stressors in a practical manner by accepting situations (Marshall & Long, 2010). Acceptance is an indicator of resilience (Bekhet et al., 2012) that helps to unite families, which further strengthen their family relationships (Bayat, 2007).

Time Use

This study did not find much difference in time use between single and coupled mothers. The current result may indicate that single versus coupled household status does not contribute to the difference in time use among mothers of children with ASD. A study conducted in Australia, found no statistically significant difference between single and coupled mothers in everyday time use (Craig & Mullan, 2012; Le & Miller, 2013). However, an earlier study that compared family life experiences between single and coupled mothers of children with a disability found that single mothers of children with a disability experienced more time pressures than coupled mothers (Schilling, Kirkham, Snow, & Schinke, 1986). In the current study, participants estimated hours for listed activities. Although time estimation method has previously been used with mothers of children with a disability (Padeliadu, 1998), it may not have fully captured the experiences of mothers or account for day-to-day variations. Future study should use more comprehensive data collection methods, such as an experience sampling method, to obtain more accurate information of mothers’ time use (Chen, Cordier, & Brown, 2015; Cordier, Brown, Chen, Wilkes-Gillan, & Falkmer, 2016).

Maternal Stress Levels

This study did not find difference in parental stress levels between single and coupled mothers, which was similar to a previous research finding for mothers of children with a disability (Schilling et al., 1986). The instrument used in this study, the APSI (Silva & Schalock, 2012), measures parental stress levels that are specifically related to the characteristics of ASD and do not measure other parental stress factors, such as lowered income. Therefore, the results of the current study indicate that parents of children with ASD, regardless of single versus coupled household status, experience similar levels of parenting stress related to managing the characteristics of ASD. The demographic characteristics of the single mothers in this current study were reflective of common parental stress factors among single mothers in general (Cooper, McLanahan, Meadows, & Brooks-Gunn, 2009). Our single mother participants had on average lower household incomes, higher unemployment rates and lower educational levels compared with coupled mothers. Future research comparing single and coupled mothers of a child with ASD should consider using other instruments that measure broader stressors, such as financial pressures and lack of employment opportunities, as single mothers may be more prone to these stressors than their counterpart (Cook, 2012a; Sachs et al., 1995).

Limitation

The current study has several limitations. The data collected were only from mothers who resided in Western Australia. Several recruitment strategies were employed in this study and the researchers did not have access to the actual number of surveys that were distributed or the pool of participants that were approached. Although we incorporated drop out analyses in the online version of the survey, none of the participants provided data. Hence, we were unable to determine whether the profile of the non-respondents differed from the participants and this limits our ability to calculate the true response rate. Therefore, caution should be taken when generalising the findings. The current study did not have a control group. The use of a control group would be useful to understand the impact of the single versus and coupled household status on parental experiences. The focus of the current study was to compare the broader parental experiences between single versus coupled mothers, rather than the impact of the unique characteristics inherent to ASD. However, factors, such as communication difficulties and limited social skills, have been found to be associated with parental QoL (Baghdadli et al., 2014). Future studies examining parental experiences should consider these aspects. Lastly, the method used to collect time use data may have allowed participants to over or underestimate their time, which may have resulted in an inaccurate reflection of their time allocation. For example, in a previous study, time spent on childcare was overestimated when time estimate format was used to collect data (Järbrink et al., 2003). However, due to the design of this current study, we were unable to use other methods, such as daily diary entry, to collect data.

Conclusion

This current study discussed possible environmental issues surrounding single mothers of children with ASD, including a lack of flexible employment opportunity, insufficient social security payment and the resultant financial disadvantage. The environmental factors that are associated with single mother's QoL should be further explored with a focus on the economic aspect. Prior to adjusting for demographic variables, our results demonstrated that single mothers use acceptance coping style more in managing stressors. These differences should be further investigated, in particular the reason for the use of this adaptive coping style among single mothers in order to understand the underlying factors that may assist coupled mothers in turn. We did not find much difference in time use and maternal stress levels between these two mothers. However, time pressure is a common issue in single motherhood and previous studies have identified unique parental stressors among single mothers. The use of different methods, such as experience sampling method and the use of other stress measures, maybe beneficial in comparing single and coupled mothers whilst highlighting the vital differences.

Ethical approval

The study was approved by the Curtin University Human Research Ethics Committee (HR123/2014) and all procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in this study.

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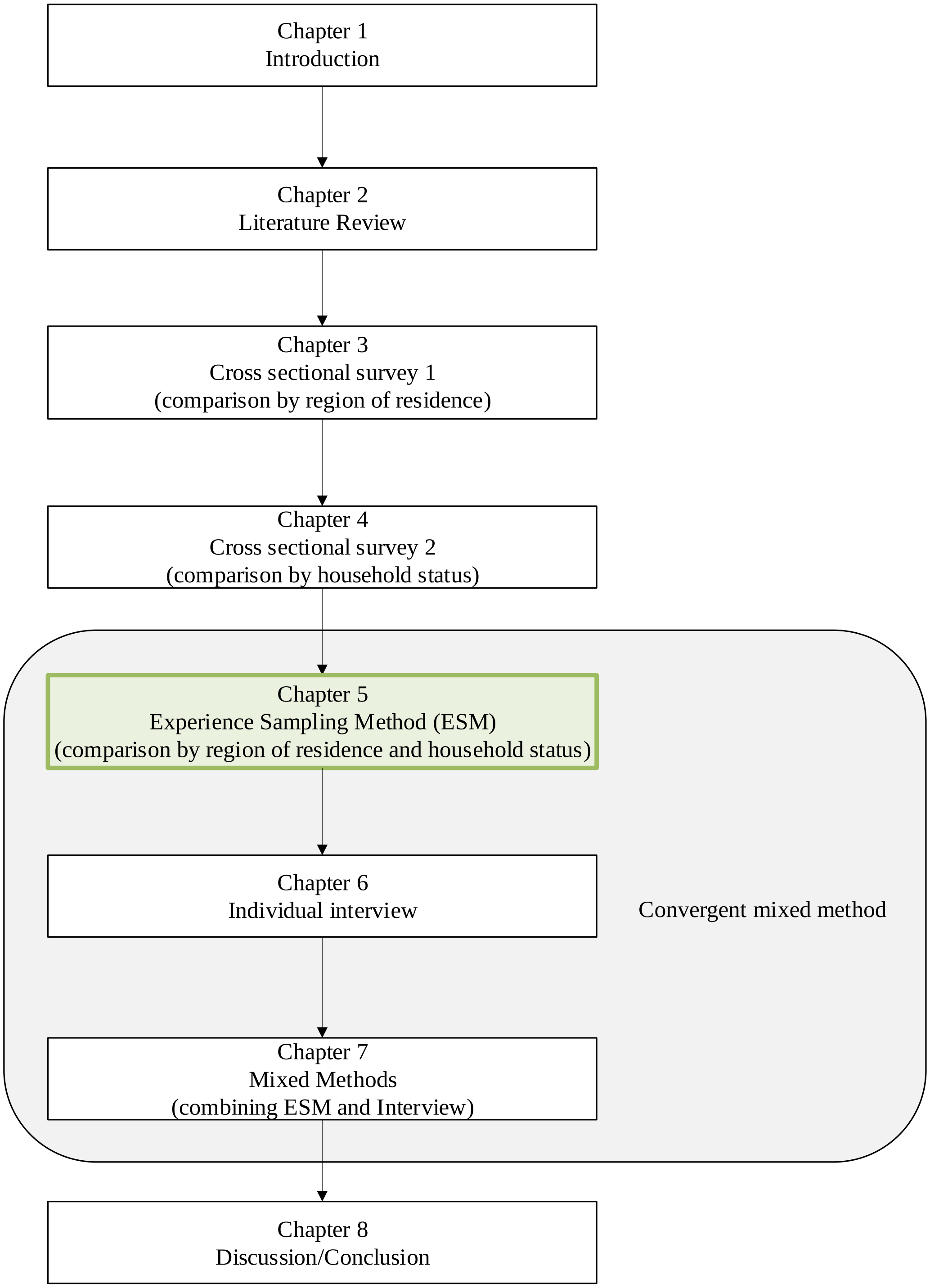
Chapter 5 Experience Sampling Method

(Paper submitted for publication)



Title: In-the-moment experiences of mothers of children with autism spectrum disorder: A comparison by household status and region of residence

This chapter comprises a study that investigated in-the-moment experiences of mothers of children with ASD by using experience sampling method (ESM) to illuminate a more accurate understanding of how these mothers construct family routines. The results were compared by mothers' household status and region of residence. The results of Chapter 3, 4 and 5 highlighted the need to depict the meaning involved in constructing family routines among mothers of children with ASD by employing other methods, such as interviews[3].

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[3] This chapter is currently under review for publication. Authors: Tomomi McAuliffe, Reinie Cordier, Yu-Wei Chen, Sharmila Vaz, Yvonne Thomas and Torbjorn Falkmer

Abstract

Purpose: This study compared the *in-the-moment* experiences among mothers of children with autism spectrum disorder by their household status (i.e., single versus coupled) and region of residence (i.e., regional versus major city area).

Methods: An experience sampling method was employed to collect data, and a total of 40 mothers used an iOS device to record activity types and *in-the-moment* experiences for one week during school term. Mann-Whitney *U* test and multilevel analysis were conducted to compare the experiences of these mothers.

Results: The analyses found the following results: 1) mothers spent most time in childcare and least time in self-care activities; 2) coupled mothers were more likely to feel supported; 3) coupled mothers were less likely to feel supported in domestic tasks; 4) mothers from major city were more likely to feel challenged in self-care activity; and 5) mothers from major city were more likely to feel supported in productivity tasks.

Conclusion: The difference found between single and coupled mothers, as well as mother from regional and major city areas was limited. However, the findings highlight gaps in the provision of appropriate support needs for these mothers.

Keywords

Lone mothers, time-use, real-life experience, everyday experience, ecological momentary assessment, mothers of children with disability, caregiver

Introduction

The 2015 Survey of Disability, Ageing and Carers (SDAC) identified that there were 856,100 primary carers in Australia with females constituting 68.1% (Australian Bureau of Statistics, 2015a). This tendency that the primary carers are mainly females is also observed in other countries, such as the United Kingdom and Sweden (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). As a consequence, nearly 90% of parents who are primary carers for their children are mothers (Australian Bureau of Statistics, 2015a). The trend that mothers are more likely to assume this carer role has remained unchanged since 2012 (Australian Bureau of Statistics, 2012). In families of children with autism spectrum disorders (ASD), the trend is similar with the majority of primary carers being mothers (Pepperell et al., 2016).

Previous research suggests that mothering is an intensive role (Larson, 2000b; Medina & Magnuson, 2009). Mothers who assume the main role to manage household responsibilities (Nealy et al., 2012) often face difficulties in balancing the demands between childcare and domestic tasks (Larson & Miller-Bishoff, 2014). Some factors, such as having young children (Le & Miller, 2013) or children with disabilities (Crowe & Florez, 2006; Crowe & Michael, 2011; Larson & Miller-Bishoff, 2014; Olson & Esdaile, 2000), increase the intensity of parenting activities. For example, parents of children with ASD are documented to spend on average 43 hours per week in childcare activities (e.g., assisting children’s personal care) (Järbrink et al., 2003). Previous research suggests that providing care for children with ASD is a challenging experience (Ekas & Whitman, 2010; Nicholas et al., 2016) and parents of children with ASD experience higher levels of stress than other groups of parents (Griffith et al., 2010; Zablotsky, Bradshaw, et al., 2013). Child-related factors, such as emotional, functional and behavioral problems of the child with ASD, are associated with increased caregiver stress (Hastings, Kovshoff, Ward, et al., 2005; Karst & Van Hecke, 2012; Lecavalier et al., 2006). However, emerging evidence suggests that parent-related factors, such as perceived sense of control, are related to psychological well-being among parents of children with disability, such as ASD (Falk et al., 2014; Lloyd & Hastings, 2009; Siman-Tov & Kaniel, 2011).

To investigate the demands that mothers of children with disability experience, their time-use and daily patterns have been commonly examined (Crowe & Florez, 2006; Crowe & Michael, 2011; Gevir et al., 2006; McCann et al., 2012). Childcare, domestic tasks, work, resting or sleeping, self-care and leisure time for parents, such as socializing, are commonly examined in previous time-use studies (Crowe & Florez, 2006; Gevir et al., 2006; Luijkx, van der Putten, & Vlaskamp, 2017; McCann et al., 2012). Mothers of children with disabilities have been found to spend most of their time in childcare (Crowe & Florez, 2006; Luijkx et al., 2017), and this tendency remains the same even their children grow older (Crowe & Michael, 2011). To compensate increased time in childcare, parents of children with disability typically reduce hours spent in personal activities, such as leisure, self-care, and socializing (Brandon, 2007; Crowe & Michael, 2011; Luijkx et al., 2017; Murphy, Christian, Caplin, & Young, 2007). This reduced time in personal activities may have a negative impact on parental psychological well-being (Larson & Miller-Bishoff, 2014; Luijkx et al., 2017).

Various data collection methods have been used to investigate the time-use among parents of children with disability. These include: 1) daily diary entry (Brandon, 2007; Luijkx et al., 2017; Smith et al., 2010; Thomas, Hunt, Hurley, Robertson, & Carter, 2011), 2) time estimation (Järbrink et al., 2003), and 3) instruments to record daily activities and parental perceptions, such as satisfaction (Crowe & Florez, 2006; Crowe & Michael, 2011; Gevir et al., 2006; Rassafiani et al., 2012). Although these methods are valuable, they may be prone to recall bias (Hektner, Schmidt, & Csikszentmihalyi, 2007) and can be burdensome for parents of children with disability who commonly experience increased time pressure (Curran et al., 2001). Moreover, these traditional methods do not allow researchers to investigate *in-the-moment* experiences of parents and their related emotions while engaging in activities.

Unlike the traditional methods, such as daily diary entry, that take a retrospective approach, an experience sampling method (ESM) survey allows researchers to collect the *in-the-moment* experience of participants (Hektner et al., 2007; Shiffman, Stone, & Hufford, 2008). Although this method is underutilized in the field of disability (McKeon, McCue, Skidmore, Schein, & Kulzer, 2018), through ESM, researchers can identify patterns of activities and explore participants' feelings while engaging in activities (Chen, Bundy, Cordier, Chien, & Einfeld, 2016; Cordier et al., 2016; Farnworth, Mostert, Harrison, & Worrell, 1996). Use of ESM can potentially minimize recall bias (Hektner et al., 2007; Shiffman et al., 2008) and requires less cognitive demand than those traditional methods due to short completion time (Chen et al., 2016). ESM has not been widely used with mothers (Dunton et al., 2017; O'Connor et al., 2017); however, it has been employed to examine time-use with a variety of populations (Larson, 1989; Lee & Waite, 2005; Park, Holloway, Arendtsz, Bempechat, & Li, 2012). Previous research that examined the emotional experiences in managing multiple roles among public health nurses reports good usability of this method (Tak-Ying Shiu, 1999).

There is a scarcity of research on the experiences of single mothers of children with ASD (Dyches et al., 2016). Previous studies commonly investigated whether mothers' time-use differ depending on the presence of children's disability (Crowe & Florez, 2006; Crowe & Michael, 2011) or children's diagnosis (Gevir et al., 2006). However, empirical studies that compared the time-use of mothers based on their household status (i.e., single versus couple) are limited (McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017). Receiving support, such as spousal support, is an essential coping strategy in managing daily life among mothers of children with disability (Kuhaneck et al., 2010). However, single mothers of children with disability face increased time pressure to manage family care responsibilities without day-to-day spousal support (Schilling et al., 1986). Lack of knowledge on the everyday experiences of single mothers of children with ASD, such as time-use and *in-the-moment* experiences, warrants a need to investigate this population to identify similarities and differences with their counterparts.

Similarly, the experiences of mothers of children with ASD who live in regional and remote areas have also been largely overlooked. The high population density in Australian capital cities means more services are generally available in these areas (Australian Bureau of Statistics, 2013a). Subsequently, families of children with disability who live in those areas may have difficulty in accessing therapy services on a daily basis (Farmer & Reupert, 2013). The geographical landscape and its impact on everyday experiences should, therefore, be considered in countries, such as Australia. A longitudinal study that examined Australian children's activity participation and their time-use over a five-year period found that region of residence (i.e., regional versus major city) was significantly associated with the types of activities in which children engaged (Mullan, 2013). Emerging evidence suggests that people's lifestyle differs due to region of residence, as such there is a need to investigate the experiences of mothers who live in regional areas.

The current study investigated *in-the-moment* experiences of mothers of children with ASD in daily activities. The aim of this current study was to compare the everyday experiences of mothers of children with ASD by their household status (i.e., single versus couple) as well as region of residence (i.e., regional versus major city) in their everyday *in-the-moment* experiences (i.e., time-use and related feelings).

Methods

Participants

Convenience sampling was used to recruit 40 mothers who had children aged 2-19 years with ASD, living in Western Australia. The first author contacted prospective participants to partake in this study through email and phone. Participants were recruited through the wide network of community organizations. We adopted the definition of the Australian Bureau Statistics to define single mothers for this study. Single mothers were defined as those who have "no spouse or partner usually resident in the household but who forms a parent-child relationship with at least one child usually resident in the household" (Australian Bureau of Statistics, 2015b, para. 21). In order to compare the experiences of mothers between the two households, the variable of single versus coupled household status was created based on the participants' responses for the question 'what is your household composition?' in the demographic survey. Participants were asked to choose their household composition from four options, 1) two-parent, 2) single parent, 3) two-parent plus extended family, and 4) single parent plus extended family. Those participants who chose 'two-parent' were categorized into coupled mothers and those participants who chose 'single parent' or 'single parent plus extended family' were categorized into single mothers. No one chose two-parent plus extended family. There were 20 single mothers and 20 coupled mothers in the current study. More single mothers were unemployed ($p = .002$), and their household income was lower ($p < .001$) than coupled mothers. There were no other significant differences between the two groups of mothers by household status.

This study classified participants' region of residence (i.e., regional versus major city area) based on the Australian Statistical Geography Standards (ASGS) remote structure (Australian Bureau of Statistics, 2013b). Participants' postcodes in the demographic survey were used to create the variable of regional versus major city area. We recoded participants' postcodes using the ASGS remote structure that has five remoteness areas (RAs). RAs are based on road distances to the nearest service centers and the five categories are as follows: 1) major city, 2) inner regional, 3) outer regional, 4) remote, and 5) very remote (Australian Bureau of Statistics, 2013b). There were no participants who were from outer regional, remote or very remote areas in this current study. Thirty mothers lived in major city areas, and 10 mothers lived in regional areas. All children of the mothers who lived in regional areas were male, while there were 21 male and nine female children in major city area ($p < .05$). There were no other significant differences between mothers living in regional areas and those living in major city areas. Table 5.1 presents a comparison of participants' characteristics by household status and region of residence.

Table 5.1: Characteristics of the mothers and their children for the total sample, the sample of single mothers, the sample of coupled mothers, the sample of mothers who reside in major city area and the sample of mothers who reside in regional area

Characteristics			**Household status**				**Region of residence**			
	Total Sample		**Single mothers**		**Coupled mothers**		**Major city area**		**Regional area**	
	$N = 40$	%	$n = 20$	%	$n = 20$	%	$n = 30$	%	$n = 10$	%
Children's Age (year) Mean (standard deviation)			11.9 (4.0)		12.1 (3.5)		12.0 (3.6)		12.0 (4.0)	
					$t = -0.11$, $p = 0.92$				$t = -0.02$, $p = 0.99$	
Children's Gender										
Male	31	77.5	16	80	15	75	21	70	10	100
Female	9	22.5	4	20	5	25	9	30	0	0
					$X^2 = 0.14$, $DF = 1$, $p = 0.70$				$X^2 = 3.88$, $DF = 1$, $p = 0.05$*	
Official ASD diagnosis										
Autistic Disorder (Autism)	17	42.5	9	45	8	40	12	40	5	50
HFA, AS, PDD-NOS* **	23	57.5	11	55	12	60	18	60	5	50
					$X^2 = 0.10$, $DF = 1$, $p = 0.75$				$X^2 = 0.31$, $DF = 1$, $p = 0.58$	
Presence of cognitive impairments/intellectual disability										
Yes	9	22.5	3	15	6	70	7	23.3	2	20
No	31	77.5	17	85	14	30	23	76.7	8	80
					$X^2 = 1.29$, $DF = 1$, $p = 0.27$				$X^2 = 0.48$, $DF = 1$, $p = 0.83$	
Children's age when noticed 1st sign of something not right										
Less than 3 years old	34	85	15	75	19	95	26	86.7	8	80
3 years old and older	6	15	5	25	1	5	4	13.3	2	20
					$X^2 = 3.14$, $DF = 1$, $p = 0.77$				$X^2 = 0.26$, $DF = 1$, $p = 0.61$	
Number of children with ASD										
1 child	39	97.5	19	95	20	100	29	96.7	10	100
More than 1	1	2.5	1	5	0	0	1	3.3	0	0
					$X^2 = 1.02$, $DF = 1$, $p = 0.31$				$X^2 = 0.34$, $DF = 1$, $p = 0.56$	
Total number of children										
1 child	10	25	7	35	3	15	9	30	1	10
2 or more children	30	75	13	65	17	85	21	70	9	90
					$X^2 = 2.13$, $DF = 1$, $p = 0.14$				$X^2 = 1.60$, $DF = 1$, $p = 0.21$	
Employment status										
Employed	27	67.5	9	45	18	90	21	70	6	60
Unemployed	13	32.5	11	55	2	10	9	30	4	40
					$X^2 = 9.23$, $DF = 1$, $p = 0.002$**				$X^2 = 0.34$, $DF = 1$, $p = 0.56$	
Household income** **										
Up to $51,999	20	50	17	85	3	15	15	50	5	50
$52,000 and over	20	50	3	15	17	85	15	50	5	50
					$X^2 = 19.6$, $DF = 1$, $p < 0.001$**				$X^2 = 0.00$, $DF = 1$, $p = 1$	
Mothers' education levels										
Did not complete school	3	7.5	2	10	1	5	1	3.3	2	20
Year 12	9	22.5	5	25	4	20	7	23.3	2	20
Post TAFE or Certificate	12	30	8	40	4	20	9	30	3	30
University	16	40	5	25	11	55	13	43.3	3	30
					$X^2 = 4.03$ $DF = 3$, $p = 0.29$				$X^2 = 3.15$ $DF = 3$, $p = 0.37$	

*approaching significance, **$p < 0.05$, ***High functioning autism (HFA), aspersers syndrome (AS), and pervasive developmental disorder non specified (PDD-NOS), ****The cut-off point was set based on the median *household income in Western Australia at the time of the study.*

ESM Survey

An iOS application, Participation in Everyday Life Survey Application (PIEL$^{©}$ survey) was used to conduct the ESM survey. This application was developed to assist researchers to collect ESM data (Jessup, Bian, Chen, & Bundy, 2012b). Participants' responses and time when they responded were stored in the application. We designed the survey to explore mothers' feelings that are related to everyday activities in which they participate. The survey included fourteen questions in the following areas: 1) the specific place (i.e., 'where were you when you were beeped at'), 2) the specific activity (i.e. 'what was the main thing you were doing'), and 3) 'in the moment' feelings experienced by participants (i.e., perceived levels of engagement, stress, challenge, support, and sense of control). Activities included in the survey were selected based on the previous time-use studies (Crowe & Florez, 2006; Crowe & Michael, 2011; Gevir et al., 2006). Multiple options were provided to answer the specific place and activity; participants could only choose one response. The ESM survey questions can be found in Table 5.2. Following a pilot testing with a convenient sample of four mothers of typically developing children to check for feasibility, the wording of the questions were revised to improve clarity.

Table 5.2: ESM survey questions

Questions	Responses
Where were you when you were beeped at?	a. Home b. Work c. Shopping centre d. Café e. Restaurant f. Medical/Healthcare facility g. Therapeutic facility h. Extended family/friend's house i. Children's School/After school activities place j. Other
What was the main thing you were doing?	a. Resting/Nothing b. Childcare related activity c. Work and Training related activity d. House work related activity e. Self-care related activity f. Leisure related activity g. Personal well-being related activity h. Other
When you were beeped, were you feeling…	Disengaged ↔ Engaged
When you were beeped, were you feeling…	Stressed ↔ Calm
How challenging was the activity?	Not at all ↔ Very much
Did you feel supported by others in performing this activity?	Not at all ↔ Very much
Did you feel in control of the situation?	Not at all ↔ Very much

Procedures

We asked participants to download the PIEL© survey application (Jessup et al., 2012b) to their iOS device, such as iPhone. If participants used Android devices, we lent an iPod touch. We provided a 30 to 60 minutes training session with individual participants on the PIEL© survey application. Participants were asked to carry their device for seven consecutive days during school terms due to concerns that mother's activity pattern and therefore time-use may be different during school holidays. The application signaled seven times a day randomly between the waking hours of 7.30 am and 9 pm for the participants to respond to the survey. Participants were required to record the main activity they were engaged in at the time of signal and if they engaged in a second activity, they were asked to record it as such. Participants were instructed to respond to as many surveys as possible and answer all questions, except when it was not convenient to them.

Ethics approval was granted by Curtin University Human Research Ethics Committee (HR123/2014-01) and all procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed written consent was obtained from all individual participants included in this study.

Data analyses

The analysis of time-use per activity. The SPSS version 22 (IBM Corp, 2013) was used to compare time-use per specific activity categories by single versus coupled household status and regional versus major city region of residence. For this analysis, the proportion of responses that each participant reported doing particular activity to represent the time-use was calculated (Hektner et al., 2007). Six activity categories were created (see Table 5.3). When participants chose resting or nothing, it was categorized as resting/nothing. Any activity items related to childcare regardless of direct involvement with their children were included in the category of childcare, such as meal routine for children and planning future events or activities for children. The category of domestic tasks included items, such as laundry and cleaning. The category of productivity included paid work, volunteering, and study. The category of self-care included activity items that participants engaged in to care for themselves, such as personal hygiene and attending medical appointment for self. The category of personal leisure included activities that participants engaged in for their enjoyment only, such as engaging in a hobby and catching up with friends. Some of the data from the categories were not normally distributed. For uniformity reason, the nonparametric Mann-Whitney *U* test was performed to compare time-use of mothers by their single versus coupled household status and regional versus major city region of residence.

Table 5.3: Proportion of time spent per activity items

Activity participated		**Percentage of time spent**											
				Household status					**Region of residence**				
		All participants (n = 40)		**Single mothers (*n* = 20)**		**Coupled mothers (*n* = 20)**			**Regional area (*n* = 10)**		**Major city (*n* = 30)**		
Items	**Categories**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	***p* value**	**Mean**	**SD**	**Mean**	**SD**	***p* value**
What was the main thing you were doing?													
Resting or nothing	Resting/nothing	9.8	6.9	12.0	6.7	7.1	6.7	0.02*	12.5	7.5	8.6	6.8	0.18
Supervising children	Childcare	8.4	7.0	7.7	6.8	9.1	7.3	0.60	8.1	7.2	8.5	7.0	0.94
School related activity		7.8	5.8	8.6	6.2	6.8	5.4	0.29	5.4	5.0	8.6	5.9	0.10
Meal routine for children		3.5	4.1	4.2	4.8	2.9	3.2	0.53	1.9	1.7	4.0	4.5	0.27
Sleep routine for children		2.2	3.1	2.2	3.0	2.3	3.2	1.00	1.6	2.4	2.5	3.3	0.46
Grooming or hygiene for children		1.8	2.7	2.5	3.0	1.1	2.2	0.10	1.6	2.4	1.9	2.8	0.91
Organising medical or therapy appointments for children		1.6	3.8	2.1	2.8	1.2	4.6	0.02*	2.7	6.5	1.3	2.4	0.78
Attending medical or therapy appointments for children		2.3	3.3	2.1	2.8	2.5	3.8	0.98	3.1	3.8	2.0	3.1	0.38
Planning future events or activities for children		2.4	4.6	3.7	5.9	1.0	2.2	0.12	0.6	1.3	2.9	5.2	0.19
Work related activity	Productivity	16.6	19.6	12.8	16.7	20.5	21.9	0.16	20.5	23.7	15.4	18.3	0.54
Study related activity		3.7	8.6	3.6	10.1	3.7	7.1	0.50	0.3	0.9	4.8	9.7	0.16
Volunteering		3.7	8.6	2.1	4.9	2.2	4.2	0.61	2.2	5.5	2.2	4.2	0.49
Household shopping	Domestic tasks	2.2	4.5	2.8	3.5	1.7	2.6	0.31	2.2	2.9	2.3	3.2	0.96
Cooking		2.3	3.1	5.8	5.7	4.9	4.6	0.64	5.3	5.9	5.4	4.9	0.88
Cleaning		5.3	5.1	5.3	4.3	7.1	5.0	0.23	7.8	4.7	5.7	4.7	0.23
Finance or banking		6.2	4.7	1.1	2.0	0.8	1.7	0.68	0.4	1.1	1.1	2.0	0.27
Laundry		0.9	1.9	1.8	3.0	3.1	4.2	0.30	3.9	4.4	1.9	3.3	0.15
Eating	Self-care	2.5	3.7	3.3	3.4	3.6	5.0	0.68	4.6	4.4	3.1	4.2	0.23
Grooming or personal hygiene		4.2	4.4	4.0	5.0	4.7	5.7	0.61	3.6	5.0	4.6	5.5	0.51
Religious or spiritual activity		0.9	1.8	0.8	2.5	0.3	0.9	0.61	0.3	0.9	0.6	2.1	0.74
Attending support group		0.4	1.2	0.9	1.8	0.4	1.2	0.24	0.0	0.0	0.9	1.7	0.09
Watching TV	Personal leisure	3.4	4.2	3.3	3.4	3.6	5.0	0.15	4.6	4.4	3.1	4.2	0.70
Reading		4.4	5.3	3.3	3.3	4.8	5.0	0.43	5.5	2.9	3.6	4.6	0.03*
Catching up with family or friends		0.7	1.3	0.5	1.2	0.7	1.4	0.52	0.7	1.6	0.6	1.2	0.86
Personal shopping for mothers		4.0	4.3	1.0	2.2	1.4	2.6	0.61	0.7	2.3	1.4	2.4	0.37
Hobby		0.6	1.3	1.1	2.0	0.7	1.6	0.59	0.6	1.4	0.9	1.9	0.75
Exercising		0.4	1.2	2.4	1.3	0.3	1.0	0.96	0.7	1.5	0.3	1.0	0.23

*Mann-Whitney *U* test: $p < 0.05$

The analysis of ESM data. The ESM data collected have a hierarchical structure with multiple surveys (level 1) nested within each participant (level 2). This creates dependency of surveys within the same participants (Leeuw & Meijer, 2008; Snijders & Bosker, 2012). We therefore used multilevel analyses to examine the associations between activities and *in-the-moment* feelings as this analytical approach account for this dependency (Snijders & Bosker, 2012). Multilevel analyses allow researchers to investigate the relationships between variables at different levels and the possible moderating effects of level 2 variables on level 1 variables (Hox, 2010; Snijders & Bosker, 2012). If variability between and within different levels is not accounted for, misleading conclusions may be drawn (Snijders & Bosker, 2012). Thus, multilevel analysis is better suited to analyze ESM data than conventional ordinary least squares (OLS) (Nezlek, 2001) in increasing statistical power (Bell, Morgan, Schoeneberger, Kromrey, & Ferron, 2014). The process of calculating statistical power for multilevel analysis is complicated due to the complexity of model estimation as well as the need to determine sample size at different levels (Hox, 2010; Snijders & Bosker, 2012). However, a previously suggested guideline is a minimum sample of 30 for both level 1 and 2 (i.e., a total of 900 surveys with 30 participants) (Kreft & De Leeuw, 1998). Given that recent studies that analyzed ESM data using multilevel analysis had sample sizes of between 25 and 40 participants (Chen, Bundy, Cordier, Chien, & Einfeld, 2017; Jean, Swendsen, Sibon, Fehér, & Husky, 2013; Powell et al., 2009; Roelofs, Peters, Patijn, Schouten, & Vlaeyen, 2004; Short, Allan, Stentz, Portero, & Schmidt, 2018), a sample size of 40 with over 1300 data points in the current study would be considered acceptable. Hierarchical Linear and Nonlinear Modelling software (HLM 6.08) (Raudenbush, Bryk, Cheong, Congdon, & du Toit, 2011) was used to conduct the multilevel analyses.

Two steps of multilevel linear analyses were conducted. First, multilevel linear analyses were used to examine the relationships between activities and the dependent variables of five different *in-the-moment* feelings, including perceived levels of challenge, engagement, stress, support, and control. Independent variables included in level 1 were six categories of activity; resting/doing nothing was used as a reference. Participants' demographic characteristics were also included in the analysis as level 2 independent variables: single versus coupled household status, and regional versus major city region of residence. In addition, the level 2 independent variables included other variables that have been found to be associated with the everyday experiences of parents of children with disability: 1) cognitive impairment of the child, 2) age of the child with ASD, and 3) total number of children (Craig & Bittman, 2008; Larson & Miller-Bishoff, 2014; Le & Miller, 2013; Patton, Ware, McPherson, Emerson, & Lennox, 2018). A fixed regression coefficient (*β*) and standard errors (SE) were used to evaluate the associations between dependent and independent variables.

In the second step, we examined the possible moderating effects of participants' characteristics (single versus coupled household status and regional versus major city region of residence) on the relationships of activities (level 1 independent variables) and *in-the-moment* feelings (dependent variables). The interactions between level 1 and level 2 independent variables were added to the original analyses. Similar to the first step, we also included three potential confounding variables (i.e., children with a cognitive impairment, children's age, and total number of children) as level 2 variables in the analysis. A significant moderating effect of single versus coupled household status, regional versus major city region of residence, as well as three confounding variables (level 2 variables) on the relationships between activities (level 1 independent variables) and *in-the-moment* feelings (dependent variables) were evaluated using significance in cross-level interaction. We removed cross-level interactions between level 1 independent variables and level 2 confounding variables that showed no significant association with dependent variables to establish the final model (Hox, 2010; Snijders & Bosker, 2012). For all analyses, the critical α-level was set at .05.

Results

Time-use and participants' characteristics

In accordance with previous research that used ESM (Chen et al., 2016), participants' ESM surveys were included if their response rate was more than 33 percent. This means that participants had to respond to at least 17 out of 49 surveys. The average response rate of the ESM survey was 68% (range: 37% to 90%). The analysis included 1,333 surveys. Overall, participants spent most time on childcare (30%) and spent the least amount of time on self-care (9%). Table 5.3 provides an outline of the proportion of time spent per activity for all participants and by different groups: single versus coupled household status and regional versus major city. The proportion of time spent in resting/doing nothing and organizing medical or therapy appointments for children was greater for single mothers (*Mdn* = 11.9; 0.0 respectively) than coupled mothers (*Mdn* = 4.9; 0.0 respectively), *U* = 112.5; 130.0, *p* = .02; .02. There was no other significant difference between single and coupled mothers. The proportion of time spent in reading was greater for mothers living in regional areas (*Mdn* = 6.1), compared with those living in major city areas (*Mdn* = 2.6), *U* = 81.5, *p* = .03. There was no other significant difference between these two groups of mothers.

Multilevel analyses

Relationships between activity and in-the-moment feelings. Overall, mothers were less likely to feel supported when engaging with childcare and domestic tasks. However, they were more likely to feel supported while participating in leisure activities. They were also more likely to feel challenged when engaging in childcare and productivity activities, but less likely to feel in control with the same two activities. We also found that participants were more likely to feel engaged while participating in productivity and leisure activities; however, more likely to feel stressed with childcare, productivity, and domestic tasks (Table 5.4).

Table 5.4: Results of multilevel analysis for activities and in-the-moment feelings

Variables	**Felt supported**	**Felt challenged**	**Felt in control**	**Felt engaged**	**Felt calm or stressed**
	Coefficient (SE)	**Coefficient (SE)**	**Coefficient (SE)**	**Coefficient (SE)**	**Coefficient (SE)**
Level 1					
Childcare	-0.11 (0.04)*	0.21 (0.05)**	-0.12 (0.04)**	0.01 (0.05)	-0.22 (0.04)**
Productivity	-0.03 (0.05)	0.40 (0.05)**	-0.11 (0.03)**	0.12 (0.05)*	-0.21 (0.04)**
Domestic tasks	-0.23 (0.04)**	0.06 (0.04)	-0.04 (0.03)	-0.01 (0.06)	-0.15 (0.04)**
Self-care	-0.05 (0.04)	0.04 (0.05)	0.03 (0.04)	0.08 (0.05)	-0.06 (0.04)
Leisure	0.11 (0.04)**	0.05 (0.04)	0.07 (0.04)	0.21 (0.04)**	0.06 (0.03)*
Level 2					
Household	0.22 (0.07)**	-0.03 (0.05)	0.03 (0.05)	0.06 (0.05)	0.04 (0.05)
Region of residence	-0.11 (0.07)	-0.03 (0.04)	-0.04 (0.06)	-0.09 (0.05)	-0.04 (0.07)
Cognitive impairment	-0.01 (0.07)	-0.01 (0.07)	0.04 (0.05)	-0.05 (0.06)	-0.00 (0.05)
Age of child	0.00 (0.07)	-0.02 (0.04)	0.02 (0.05)	0.06 (0.05)	0.04 (0.05)
No. of children	-0.08 (0.08)	0.04 (0.05)	-0.10 (0.05)	-0.05 (0.05)	-0.06 (0.05)

*$p < 0.05$, **$p < 0.01$

Relationships between participants' characteristics and in-the-moment feelings. Coupled mothers were more likely to feel supported than single mothers. There were no other significant differences among these mothers by their single versus coupled household status and regional versus major city region of residence. This result did not change after adjusting for the three confounding variables (Table 5.4).

Moderating effects of participants' characteristics on the in-the-moment feelings in activity participation. Single versus coupled household status moderated the relationship between feeling supported and domestic tasks ($\beta = -0.19$, $SE = 0.08$, $p < .05$). This means that coupled mothers were less likely to feel supported in domestic tasks than single mothers. Regional versus major city region of residence had a moderating effect on the relationship between feeling challenged and self-care activity ($\beta = 0.20$, $SE = 0.09$, $p < .05$). This means that those mothers who lived in major city areas felt more challenged while engaging in self-care activities. No other moderating effects of participants' characteristics on the *in-the-moment* feelings in activity participation were found. After adjusting for the confounding variables, these results remained overall the same with one exception. Regional versus major city region of residence was found significant, demonstrating a moderating effect on the relationship between feeling supported and productivity ($\beta = 0.16$, $SE = 0.08$, $p < .05$). This means that those mothers who lived in major city areas felt more supported while engaging in productivity activities.

The confounding variables had a number of significant findings. Cognitive impairment of the child had a moderating effect on the relationship between feeling stressed and childcare ($\beta = -0.20$, $SE = 0.08$, $p < .05$). Children's age had a moderating effect on the relationship between feeling supported and productivity, self-care and leisure ($\beta = 0.20$, $SE = 0.08$, $p < .05$; $\beta = 0.16$, $SE = 0.08$, $p < .05$; $\beta = 0.15$, $SE = 0.06$, $p < .05$ respectively). Children's age also had a moderating effect on the relationship between feeling engaged and productivity as well as domestic tasks ($\beta = 0.21$, $SE = 0.09$, $p < .05$; $\beta = 0.24$, $SE = 0.12$, $p < .05$ respectively). Lastly, total number of children had a moderating effect on the relationship between feeling engaged productivity as well as leisure ($\beta = 0.24$, $SE = 0.08$, $p < .01$; $\beta = 0.15$, $SE = 0.07$, $p < .05$ respectively).

Discussion

The current study aimed to investigate the *in-the-moment* feelings in daily activities among mothers of children with ASD to examine if their household status (i.e., single versus coupled) or region of residence (i.e., regional versus major city area) were associated with their everyday experiences. In the following sections, we aim to discuss the following three points: 1) overall participants' experiences, 2) comparison of participants by single versus coupled household status, and 3) comparison of participants by regional versus major city region of residence.

Overall participants' experiences in time-use and in-the-moment feelings

The current study found that engaging in childcare was overall a negative experience among all mothers. The participants felt more challenged and stressed, and less supported and in control while engaging in childcare activities. This finding is in line with previous research that suggests parenting a child with a developmental disability, including ASD, is a challenging task (Hastings, 2002; Seymour et al., 2013). Perceived control is an important construct to consider when investigating the experiences of parents of children with ASD (Frantzen et al., 2016). Past studies that examined the relationships between perceived control over life events and mental health among parents of children with disability, including ASD, found that when mothers perceived they did not have control over an event, for example childcare related activities, they were more likely to experience mental health issues, such as increased stress and depression (Falk et al., 2014; Lloyd & Hastings, 2009; Siman-Tov & Kaniel, 2011). Conversely, when mothers felt they were in control in managing children's behavior, they were found to hold positive perceptions of their children (Lloyd & Hastings, 2009). A sense of control during childcare is important, as it is one of the key factors that promote resilience among families of children with ASD (Bekhet et al., 2012). Inevitably, the focus in the majority of parenting programs for parents of children with ASD is on facilitating perceived parental control through teaching behavior management of the child or communication techniques with the child (Schultz, Schmidt, & Stichter, 2011). However, previous research suggests that given the characteristics of ASD, such as rigidity, and related parental stressors, learning to control situations may be counterproductive (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007). It is unknown if the participants in this study had completed such parenting programs previously. Nevertheless, the results indicate a need to support mothers of children with ASD in promoting perceived control through employing alternative parenting approaches. Further research is warranted to examine parental sense of control in the everyday experiences among mothers of children with ASD.

Parenting a child with ASD is an intensive task that requires high levels of vigilance and commitment (Hoogsteen & Woodgate, 2013a; Woodgate et al., 2008). Mothers are required to constantly engage in both direct childcare activities, such as assisting a child during meal time (Evans & Rodger, 2008), and indirect childcare activities, such as coordinating children's therapy appointments (Hodgetts et al., 2014). In the current study, the category of childcare included both direct and indirect childcare activities. It is, therefore, unknown if the identified negative experiences were more related to direct or indirect childcare activities. However, previous research suggests that indirect childcare activities, such as negotiating with service providers and advocating for the child, is a challenging task for mothers of children with ASD (Gevir et al., 2006; Green, 2007; Hodgetts et al., 2014; Shepherd, Landon, & Goedeke, 2017). Moreover, indirect childcare activities can be time-consuming that they may lead to mothers having less time available for personal activities (Gevir et al., 2006; Green, 2007). Previous studies found that mothers of children with a disability create extra time by reducing their own time to meet the childcare demands (Brandon, 2007; Murphy et al., 2007; Smith et al., 2010). The current study found a similar trend, that is, mothers spent more time in childcare and less time engaging in their own activities, such as self-care and personal leisure. Although this prioritization in childcare over personal activities may be a reflection of parental commitments to provide the optimal care for their children, parents of children with disability have reported feelings that they do not spend enough time engaging in personal leisure activities (Larson & Miller-Bishoff, 2014). Previous research suggests that mothers prioritize their time based on meaningfulness of activities (Gevir et al., 2006). Therefore, future studies that examine time-use of mothers of children with ASD should incorporate qualitative means to investigate the meaning of everyday experiences. Particularly, exploring mothers' perspectives on personal time-use may be important in identifying key factors that can support these mothers to engage in activities that address their own needs.

Comparison between single and coupled mothers

Overall, coupled mothers were more likely to feel supported while participating in everyday activities. This result is to be expected given coupled mothers have access to spousal support, unlike single mothers who need to carry all family responsibilities. Spousal support promote parental resiliency (Kapp & Brown, 2011), and previous studies that explored coping strategies among mothers of children with ASD found that receiving support from their partner was critical for mothers in managing everyday responsibilities (Kuhaneck et al., 2010; Searing, Graham, & Grainger, 2015; Tunali & Power, 2002). Although the benefits of receiving informal support from other sources, such as extended family, have been well documented for parents of children with ASD (Marsack & Samuel, 2017; Murphy et al., 2007; Tint & Weiss, 2015), there is a tendency that levels of informal support received by these parents are generally low (Bromley et al., 2004). It is also not uncommon for parents of children with ASD to receive negative reactions from their potential sources of informal support on the caring needs for the child with ASD (Ooi et al., 2016; Woodgate et al., 2008). A study that examined social support and psychological wellbeing of mothers of adolescents and adults with ASD found that receiving negative informal support, such as criticizing parenting styles, was associated with lower levels of wellbeing among these mothers (Smith et al., 2012). Therefore, spouses who share everyday experiences might be perceived as a more valuable source of support among parents of a child with ASD (Higgins et al., 2005).

Interestingly, the current study found that coupled mothers were less likely to feel supported while completing domestic tasks. The current result may be a reflection of a tendency that families of children with ASD have traditional parental role allocations, where mothers hold primary household responsibilities (Hartley et al., 2014). Consequently, their spouses may not actively contribute to domestic tasks and mothers' perceived levels of support in this area are lowered. Our results may also indicate a gap between the coupled mothers' expectations for their spouses to share some of the domestic responsibilities and the levels of support received. The current study found that mothers did not feel challenged while engaging in domestic tasks. However, previous studies suggest that these tasks are hassles and not enjoyable (Erlandsson & Eklund, 2003; Gevir et al., 2006). Perhaps coupled mothers expected their spouse to participate in those troublesome, but not challenging, domestic tasks. However, their expectations were not met; hence, the perceived levels of support were lower than that of single mothers. Perceived support entails a person's belief around the availability of support, as well as levels of supportiveness of their social environment (Pierce, Sarason, & Sarason, 1992). A higher level of perceived support has been found to be related to decreased burden (Stuart & McGrew, 2009) and lower stress levels among parents of children with ASD (Zaidman-Zait et al., 2017). It should be noted that the current study did not investigate the types of support, such as instrumental support, that the mothers received (Gottlieb & Bergen, 2010). However, received support is an element of the complex construct of perceived support (Haber, Cohen, Lucas, & Baltes, 2007). Therefore, future studies should investigate both types of received support and perceived support when examining the everyday experiences of mothers of children with ASD.

Unlike the previous results that found single mothers spent significantly less time in childcare activities than coupled mothers (Kendig & Bianchi, 2008), the current study found no significant differences between single and coupled mothers, except time spent in resting or nothing and organizing medical or therapy appointments for children. These findings are similar to the results of an Australian study that found comparable time allocations in everyday activities across different types of households, including single and coupled mothers (Le & Miller, 2013). Perhaps no difference in time-use between single and coupled mothers indicates that single mothers carry the same burden of responsibility as their counterparts alone (Le & Miller, 2013). Although some single mothers may receive instrumental support for everyday activities from their children's fathers, such as childcare payments, previous research suggests that single mothers of children with disabilities experience limited support networks that share caring responsibility (Chou & Kröger, 2014). The frequency and degree of fathers' involvement in the lives of children with ASD are unknown in the current study; however, the results suggest the involvement of children's fathers that counterbalance single mothers' burden is limited. Indeed, a study that investigated support networks of single mothers of children with disability found that the main source of support for mothers was their female family members or friends, not their children's fathers (Correa, Bonilla, & Reyes-MacPherson, 2011). However, support from family or friends that share everyday responsibilities of single mothers, such as in childcare, may not be readily available for all single mothers (Kröger, 2010). Receiving adequate social support that alleviates adverse health issues (Sawyer et al., 2010; Zablotsky, Bradshaw, et al., 2013) is particularly important to single mothers, as earlier research suggests that they experience more negative health outcomes than coupled mothers (Crosier et al., 2007). Understandably, the main foci in literature on the involvement of fathers following separation are child factors, such as children's cognitive development and self-esteem (Bastaits, Ponnet, & Mortelmans, 2012; Choi & Pyun, 2014). Our results indicate that, where possible, for health professionals to involve separated fathers in therapeutic processes to improve the outcomes for both single mothers and children with ASD.

We did not find any other significant differences in time-use and *in-the-moment* feelings between single and coupled mothers. The results may indicate that regardless of household status, experiences among mothers of children with ASD are similar. Perhaps other factors, such as the age of the child (Craig & Bittman, 2008; Larson & Miller-Bishoff, 2014), presence of intellectual disability (Patton et al., 2018), and number of children (Brandon, 2007; Craig & Bittman, 2008), may be more relevant to the mothers' everyday experiences. This study found that those mothers who had children between the ages of 5 and 11 years felt more engaged during productivity and domestic tasks than those mothers who had children older than 11 years. Previous research suggest that the childcare demands for mothers of younger school-aged children with disability are higher than that of mothers of older school-aged children with disability (Crowe & Florez, 2006; Crowe & Michael, 2011). Productivity tasks, such as paid work, can provide respite for parents of children with disability from their childcare responsibilities (Larson & Miller-Bishoff, 2014). Perhaps the result demonstrates on-going high childcare demands among mothers of younger children, and hence the mothers felt more engaged in completing other activities than childcare, such as productivity, that provided a sense of 'relief' from their responsibilities.

Comparison between regional versus major city area

The current study found that mothers who lived in major city areas were more likely to feel challenged when engaging in self-care tasks than their counterparts. Perhaps mothers who lived in major city areas felt that they did not have enough time for themselves due to lifestyle demands associated with city life. Conversely, mothers who lived in regional areas may receive better support in a tight-knit community. Emerging evidence suggests that those mothers who live in regional areas have access to supportive social networks that meet the needs of their children with ASD (Hoogsteen & Woodgate, 2013b). The availability of social support may allow mothers who live in regional areas to find it easier to participate in personal activities, such as self-care and personal leisure, than their counterparts. In support of this notion, the current study found that mothers who lived in regional areas spent longer time in reading than their counterparts. Future investigations into levels and types of support received by mothers will shed further light into the complexities of time-use in contrasting their experiences by region of residence.

Another finding was that those mothers who lived in major city areas were more likely to feel supported when engaging in productivity tasks. The result may be attributed to flexible employment opportunities in major city areas that support mothers' participation in productivity tasks. Parents of children with ASD, who lived in regional areas, reduced their employment hours due to childcare needs more than those parents who lived in major city areas (McAuliffe, Vaz, Falkmer, & Cordier, 2016). Flexible employment arrangements that assist these mothers in everyday level should be further advocated.

We did not find any other significant differences in the time-use and everyday experiences between mothers who lived in regional areas and those who lived in major city areas. The findings may indicate that regardless of regional versus major city region of residence, the experiences of mothers of children with ASD are similar. Nonetheless, this paper is one of the first studies that compared the time-use and *in-the-moment* feelings among mothers of children with ASD by region of residence. Additional research should be conducted to further explore the differences and similarities between these two groups of mothers.

Limitation

There are several limitations in this current study. The participants were recruited in Western Australia only, and all regional participants were from inner regional areas. Caution should be taken to generalize the results to other contexts. The current study also had a relative small sample size, and participants did not respond to all surveys; however, it should be noted that the results of this study are based on the analysis of over 1300 survey entries. Although previous research that used ESM show that it is a reliable method to study individual time-use (Chen et al., 2016), the current method did not allow researchers to collect data, such as actual hours spent on each activity. Further, those activities conducted outside the set hours of 7.30 am and 9 pm were not recorded. This time limitation may have contributed to the low leisure activity hours recorded by the participants. Caution should be taken when interpreting the results of cognitive impairment as a confounding variable, as it was based on maternal report and there was a small number of mothers who had children with cognitive impairment (*n* = 8) compared to the mothers of children without cognitive impairment (*n* = 32). It should be noted, however, that the overall results remained largely the same after adjusting for confounding variables. The category of childcare did not differentiate time spent for children with or without ASD. Future study should consider using other methods, such as qualitative study, along with the ESM to further elucidate the experiences of these mothers when participating in childcare. Diagnosis of ASD was based on maternal self-report. However, it should be noted that the demographic survey included a page with a diagnostic checklist of DSM-IV-TR/ICD10 symptoms of ASD (Matson et al., 2008) to validate that child meets diagnostic criteria at the time of completing the study. Lastly, the inclusion of a control group of mothers of typically developing children in future studies would allow researchers to elicit the specific impact of household status and region of residence on the time-use and *in-the-moment* feelings in everyday experiences among these mothers.

Conclusion

This study was one of the first studies to compare the *in-the-moment* experiences of single mothers of children with ASD with coupled mothers, as well as comparing mothers of children with ASD from major cities with mothers from regional areas, extending the current knowledge on the everyday experiences of mothers; often overlooked sub-populations. Some of the differences between these groups of mothers found in the current study highlight the importance of providing appropriate support. Single mothers carry similar levels of responsibilities as coupled mothers with limited support networks. In order to support these mothers, health professionals could consider involving their children’s fathers in therapeutic process. While coupled mothers may receive spousal support, the levels or types of support provided to these mothers may not be sufficient. The nature of the supports that coupled mothers received should be examined further to improve potential benefits for these mothers. We did not find any other differences that were noteworthy between these groups of mothers, building evidence to support that regardless of household status or region of residence, the experiences of these mothers are similar. Perceived control is one of the key constructs in parenting experiences, hence, this should be promoted among all mothers. However, given the characteristics of ASD, alternative parenting programs may need to be further promoted among these mothers. Engaging in childcare activities can be a time-consuming task for these mothers that result in reducing time available for themselves. Future studies should investigate the reasoning behind these mothers’ everyday time-use by utilizing other methods, such as qualitative studies, to explore new avenues in supporting them to engage in personal activities.

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Declaration of Interest

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Data availability

The ESM data used to support the findings of this study have not been made available due to the condition approved by the Curtin University Human Research Ethics Committee.

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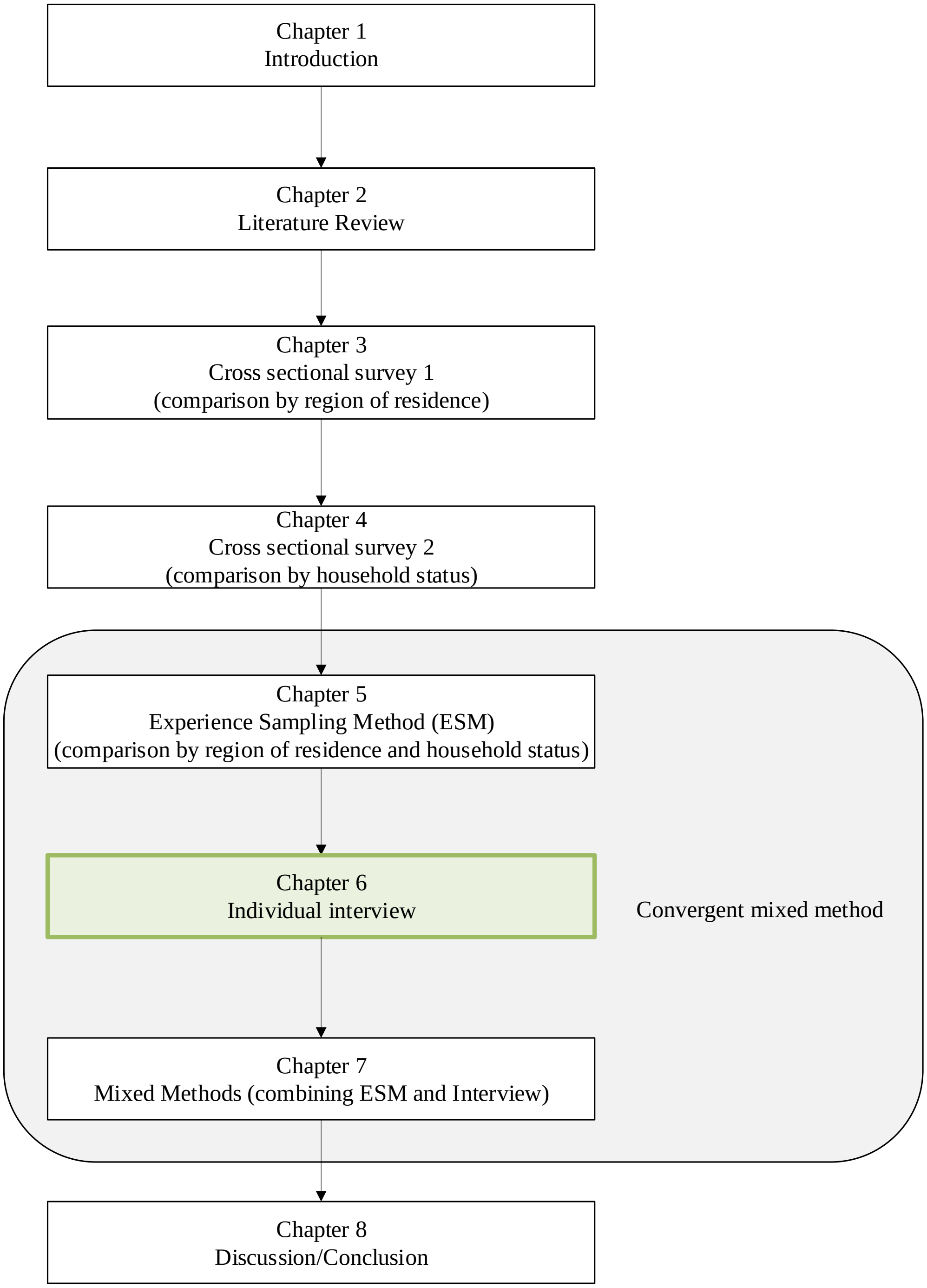
Chapter 6 Individual Interview Study

(Published paper)



Title: The experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing

Chapter 6 comprises a study that explored meanings mothers of children with ASD find in constructing family routines through conducting individual interviews. The themes identified in this chapter described mothers' perceived meaningfulness when constructing family routines in relation to their health and wellbeing. The results of Chapter 5 and 6 together confirmed the need to investigate family routines in a more comprehensive approach, such as mixed methods, to further depict the complexity of family routines[4].

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[4] This chapter has been published in Australian Occupational Therapy Journal (See Appendix F). Authors: Tomomi McAuliffe, Yvonne Thomas, Sharmila Vaz, Torbjorn Falkmer, and Reinie Cordier

Abstract

Introduction: Families of children with autism spectrum disorder (ASD) use family routines to provide predictability and structure to support occupational engagement of their family members. Mothers assume the major role to orchestrate occupations in constructing family routines, which may impact their health and wellbeing. However, the experiences of mothers in managing family routines and their health and wellbeing have not been the main focus in previous research. Thus, this study explored the experiences of mothers of children with ASD in managing family routines and their perceptions of the impact of family routines on their health and wellbeing. **Methods:** An interpretive phenomenological approach was used. Twenty mothers of children with ASD, aged between 28 and 56 years, participated in semi-structured interviews. Data were transcribed verbatim and each transcript was analysed. **Results:** Five themes that summarise mothers' perceptions towards health and wellbeing when managing family routines emerged: 1) Keeping on track keeping healthy; 2) My life is busy, because I do everything for everyone else; 3) Keeping on track all the time is tiring or frustrating; 4) Looking after my family by looking after myself; and 5) I am not perfect and it's OK. **Conclusion:** This study highlighted the substantial efforts required in constructing family routines that may be at the cost of mothers' health and wellbeing. However, mothers may be able to cope with everyday demands in managing family routines by changing their perspectives. By integrating 'me-time' activities in family routines, mothers may be able to support their own health and wellbeing. Mothers' values and needs are reflected in family routines; hence, thorough understanding of family routines may be key to support mothers' occupational engagement.

Introduction

The parents of children with autism spectrum disorder (ASD) use family routines to provide expectations and predictabilities in everyday life (Larson, 2006). Family routines allow parents to integrate the needs of the child into family life (Larson, 2006) by accommodating the unique ASD characteristics, such as rigid and repetitive interests and activities (American Psychiatric Association, 2013) and sensory preferences, that commonly interfere with the occupational participation of the child (Schaaf et al., 2011). As such, family routines serve to promote healthier coping mechanism among families of children with ASD (Kapp & Brown, 2011). However, appropriately designing family routines to suit the unique support requirements of the child with ASD is often challenging (Boyd et al., 2014).

In studies of family routine, the two related terms (i.e., family routines and rituals) are commonly discussed. The term ‘routines’ refer to patterned and continually repeated activities that have instrumental functions, whereas the term ‘rituals’ represent meaning arising from the patterned engagement (Fiese et al., 2002; Marquenie et al., 2011). However, confusion exists in literature as these terms are used interchangeably, due to overlaps between the two terminologies (Denham, 2003). For example, mealtime provides instrumental functions, as well as meanings to family (Evans & Rodger, 2008). While the differences presented in previous literature (Fiese et al., 2002) should be acknowledged, the current study uses the term ‘family routines’ to encompass the elements of rituals (i.e., meaning derived from routines). Our decision to use this terminology is similar to a previous literature review on family routines among families of children with ASD that used ‘routines’ as the overarching term due to the conceptual relatedness between the two terminologies (Boyd et al., 2014).

Routines provide a foundation for family life and allow members to engage in meaningful occupations, such as mealtime (Bagatell et al., 2014). Mothers play a major role in orchestrating occupations to construct family routines (Bagatell, 2016; Larson & Miller-Bishoff, 2014) that develop connection between members and establish identity as a family unit (Evans & Rodger, 2008). While family routines provide stability (Schaaf et al., 2011), structure, and order in the family environment (Fiese, 2007), the management of family routines is a complex process that requires considerable maternal efforts (Larson & Miller-Bishoff, 2014).

Empirical studies that explored mothers' own experiences in orchestrating family routines among families of children with disability are limited (Kellegrew, 2000; Larson, 2000b), while the entire family experiences (Bagatell, 2016; Schaaf et al., 2011) and the impact of the disability characteristics on family routines have been examined commonly through mothers' perspectives (Bagatell et al., 2014). Family routines and its management impact the health and wellbeing of family (Fiese, 2007). For example, families of children with ASD commonly experience increased stress levels during dinnertime routine (Marquenie et al., 2011). However, maternal health and wellbeing in relation to management of family routines among mothers of children with disability, including ASD, has not been widely investigated (Larson & Miller-Bishoff, 2014). This lack of research can be an issue given mothers of children with ASD commonly assume the major role of managing family routines (Larson, 2006), and previous research suggest that managing family routines can be stressful for mothers of children with disability (Larson & Miller-Bishoff, 2014). Therefore, family routines and the health and wellbeing of mothers of children with ASD should be the focus of research for health professionals, including occupational therapists. The current study, therefore, aimed to explore the experiences of mothers of children with ASD in managing family routines in relation to their perceptions towards their health and wellbeing.

Method

Research approach

A phenomenological approach that allows researchers to explore the experiences of participants was employed (Creswell & Poth, 2017). While there are various types in phenomenological approaches, this study used interpretative phenomenological analysis (IPA) to understand individual participants' experiences in their context. Some criticise IPA for lacking connection to the theoretical foundation of phenomenology (Giorgi, 2010). However, others argue that IPA is well founded in theories and thus an appropriate approach to investigate lived experiences of individuals (Smith, Flowers, & Larkin, 2009).

IPA is widely used in the fields of health science research (Finlay, 2011). IPA allows researchers to explore the perspectives and experiences of participants, and not only describe them but also develop meanings in a thematic form (Larkin, Watts, & Clifton, 2006). In the process of exploration, it is acknowledged that the interpretation includes both participants' and researchers' views (Finlay, 2011). This is because IPA uses a 'double hermeneutic' process: while participants make sense of their own experiences, researchers attempt to make sense of participants' sense-making experiences (Smith et al., 2009). Therefore, in IPA, researchers take dynamic roles in the process of interpreting participants' perspectives (Smith et al., 2009).

Participants

Purposive sampling methods were employed to recruit twenty mothers who have children with ASD, between the ages of 2 and 19 years, and lived in Western Australia (WA). Following the ethical approval from the Curtin University Human Research Ethics Committee (HR123/2014-01), the first author contacted prospective participants by email and phone. The flyers of the study were also disseminated to community organisations. Prospective participants were given opportunities to ask questions prior to confirming their intentions to participate in the study. The information sheets were provided, and informed consents were obtained from all participants prior to the interview. The demographic information of the participants is presented in Table 6.1.

Table 6.1: Participants' demographics

†Based on mothers' reports ‡Not disclosed

Participant number	**Age of mothers**	**Household status**	**Mother's education**	**Age of the child with ASD**	**Gender of the child with ASD**	**Presence of cognitive impairment of the child†**
1	41	Single	Post TAFE or Certificate	18	Male	Yes
2	47	Couple	Post TAFE or Certificate	9	Male	Yes
3	38	Single	Year 12	11	Male	No
4	ND‡	Couple	Post TAFE or Certificate	15	Female	Yes
5	56	Couple	Year 10	20	Female	No
6	43	Couple	Year 12	7	Male	No
7	51	Couple	University	13	Male	No
8	45	Couple	University	10	Female	Yes
9	47	Single	Post TAFE or Certificate	7	Male	Yes
10	55	Single	University	16	Female	No
11	43	Single	Year 12	9	Male	No
12	42	Single	University	14	Male	No
13	34	Single	Post TAFE or Certificate	12	Male	No
14	40	Couple	University	14	Male	No
15	ND‡	Couple	Year 12	11	Male	No
16	38	Couple	Year 12	11	Male	No
17	40	Single	Post TAFE or Certificate	12	Male	No
18	39	Couple	University	5	Male	No
19	28	Single	Year10	8	Male	No
20	ND‡	Single	Year 12	10	Male	No

Data collection

In line with the principles of IPA (Smith & Osborne, 2008), a semi-structured interview was used as it allows researchers to collect meaningful and important accounts of individual participants (Larkin et al., 2006). The interviews were conducted face-to-face at participants' homes or telephonically, depending on the participants' preferences and availabilities. The first author who is an occupational therapist conducted all the interviews. As discussed, the term 'family routines', rather than 'rituals', was used throughout the interview. Given a similarity between the study aim of Larson and Miller-Bishoff (2014) and that of the current study, we adopted their explanation of family routines: "Routines are organised, sequenced activity patterns that occur at specific time and in specific space. This tight and intricate sequencing allows the family to organise the individual and shared activities necessary to sustain health, well-being and connectedness among family members" (Larson & Miller-Bishoff, 2014, p. 1). The semi-structured interview schedule that was developed by the first two authors and reviewed by the last author was used to guide the interview. Five main open-ended questions were developed to explore participants' perspectives and experiences as mothers in managing family routines and their views on a relationship between routine management and their health and wellbeing, and creating meaning of their experiences (Table 6.2).

Table 6.2: Semi-structured interview guide used in this study

	Main questions	Follow up questions
1	Please tell me about an ordinary week day or weekend day with your family	
2	What does maintaining family routines mean to you as a mother?	Are there any specific routines more meaningful to you or your family than others?

	Main questions	Follow up questions
3	What is your role in keeping family routines?	What skills do you believe you need to have in managing family routines?
		How does the characteristics of autism impact on your ability to manage family routines?
4	What helps you managing family routines?	What do you do to look after yourself so that you can manage family routines?
		Do you think maintaining family routines is important for your wellbeing?
5	What restricts or limits you from being able to manage family routines	What support would you like to receive in managing family routines?
6	Is there anything you would like to add?	

At the end of each interview, participants were provided with an opportunity to add any points that they felt important in relation to the topic but were not explored during the interview. The interview duration ranged between 60 and 90 minutes. Each interview was audio recorded digitally and transcribed verbatim.

Analysis

NVivo 11 (QSR International Pty, 2015) was used to manage and process data in this current study. A computer software, such as NVivo, aids researchers in managing large data sets (Leech & Onwuegbuzie, 2011), and improves efficiency and transparency in the process of analysis (Hoover & Koerber, 2011). However, it is important to note that researchers are the ones who conduct the analysis in qualitative research, not the software (Leech & Onwuegbuzie, 2011).

There are variations and flexibilities in the IPA analysis process (Finlay, 2011). The current study adapted previously recommended IPA steps (Smith & Osborne, 2008) as a guide. The first and second authors separately read and re-read one interview transcript first, whilst making notes of points that were related to the research aim, and these points were discussed between the two authors. This process was repeated until the first two authors agreed with the analysis process. Following the agreement, the first author analysed other transcripts and initial notes were transformed into themes. The first author used codebooks in NVivo to record descriptions of emerged themes, and these codebooks were shared with the second author. Themes were reviewed until the first two authors reached consensus. The dialogue engaged by the first two authors in interpreting participants' perspectives and experiences was a lengthy process, due to the large volume of data.

The first author analysed all the data and engaged in reflexivity throughout the process by describing her own thoughts, values, and experiences using the memo and annotation functions of NVivo, while referring to the field notes that were recorded after each interivew. It should be noted that our intention to engage in reflexivity was not to reduce our own perceptions that were formed prior to the analysis process, like bracketing (Creswell & Poth, 2017), but rather for the researchers to be grounded in the interview transcripts whilst acknowledging own interpretations (Morse, 1991). The second author guided the first author who was not familiar with the IPA analysis throughout the process, exploring nuances in interpreting the data. This guidance acted as a practice of rigour in IPA (Smith et al., 2009). The participants were not asked to validate the findings because: 1) IPA involves 'double hermeneutics' (Smith et al., 2009), and 2) the validation process may have caused undue burden for the participants who were time-poor.

Results

Five themes that demonstrate mothers' experiences and perceptions in managing family routines in relation to their perceived health and wellbeing emerged from the analysis: 1) Keeping on track keeping healthy; 2) My life is busy, because I do everything for everyone else; 3) Keeping on track all the time is tiring or frustrating; 4) Looking after my family by looking after myself; and 5) I am not perfect and it's OK. Pseudonyms were used in each participant's quote.

Theme 1: 'Keeping on track keeping healthy'

Mothers discussed the benefits of family routines for themselves, the child with ASD, and their entire family. Family routines acted as a framework for their family to put in a structure and provide predictability in everyday life.

> *I like knowing what's happening and I like planning what's happening…I find it comforting as well, following those routines. I think we (my family) all probably do now* (Participant 8).

Most mothers agreed that because of family routines, their children with ASD felt secure. The sense of security offered to the child with ASD through structured lifestyle had a cascade effect on other family members. Participant 17 said, "*…without those routines…there would be more meltdowns and more conflict in the family…So for his well-being and…the well-being of the rest of the family it is extremely important."*

Family routines also provided practical benefits to mothers, such as completing tasks on time. Some mothers discussed that their actions to manage family routines had become "*second nature*" to them. No family routines meant chaotic life for mothers. *"I'd be constantly chasing my kids to…be 'ready' in the morning…, and I would be rushing to work…I need to do a multitude of things before the kids go to bed"* (Participant 7).

Some mothers discussed the benefits of family routines in nurturing their spirituality. As the mothers were the ones who designed and managed family routines, they could reflect their values, identities and needs on their family routines.

> *To maintain those routines and I see…that was what being a 'good mother' is…being able to cook for my family and make sure…they have good relationships with each other…That's why I can find it extraordinarily stressful when some of those things 'fall apart'. Because I think it really does go to the core of who 'I' am* (Participant 8).

Theme 2: My life is busy, because I do everything for everyone else

This theme is about the participants' experiences of carrying large responsibilities to manage family routines. Mothers' lives were busy, and they had to juggle multiple roles. Participant 3 said, *"You have to prioritise what you can and can't do. Because you don't always have time for everything."* In managing family routines, mothers were "*everything*". Without them, there were no family routines. Mothers provided various titles in describing their role in managing family routines, for example "*project manager", "president",* and *"a captain of the ship".* These titles demonstrate mother's insights that they were central in managing family routines. Mothers used multiple skills to manage busy family life, such as evaluating, planning, accommodating, being patient and resilient. Mothers had to be patient with not only the child with ASD, but also their spouse, other family members, and service providers, in the process of family routine management. *"Patience with other people. Because it's me who runs the show…I'm the one who runs around and does everything else"* (Participant 6).

Interestingly, some mothers did not seem to have taken this role of family routine management willingly, but rather it was out of necessity and social expectations. *"Somebody has to lead all of this and follow things up and make sure things are done. Otherwise things will just coast along"* (Participant 15). Socially constructed gendered roles and expectations for domestic responsibility resulted in a sentiment of resentment with some mothers who had little time for leisure occupations. "*I wouldn't mind a bit of help…but…, you do 80% and they (men) do 20%... they (men) get to go surfing but women still…don't get to go surfing"* (Participant 10).

Theme 3: 'Keeping on track all the time is tiring or frustrating'

Due to the large responsibilities, routine management became too much at times and mothers frequently reported being tired. Participant 13 said, *"It's stressful it's very stressful trying to keep up on top of things."* Participant 20 echoed this sentiment and said, "*I'm tired all the time…the motivation for me to…do these sorts of things (managing family routines)…I don't have it."*

Another aspect of this theme is a process that some mothers went through to get used to living a structured lifestyle. This process was more difficult and frustrating for those mothers who identified themselves as a 'free-flow' person, compared with those who identified themselves as a 'structured' person before having their children.

> *It's taken me many years to be 'comfortable' with it [structured lifestyle]. There's no point in 'fighting' it, because yes, I'm not autistic and I don't have to 'live' that way. But my son is autistic and he does* (Participant 12).

The mothers went through a lengthy process in finding a practical balance between meeting their children's needs (i.e., predictability in life) and their own needs (i.e., more spontaneous lifestyle). Participant 10 said, "*I didn't ever let Julie stay on something…despite the shrieks and protests…I would find something that would have a link to the things [she] loved…it's an evolution…it's a slow sort of incremental process…"* Participant 12 shared her experience:

> *…it's a matter of trying to bring in my character and the kind of activities that I enjoy and the kind of things that I feel are important. But through the structure and filter of autism world that makes it comprehensible to him (the child with ASD).*

Theme 4: 'Looking after my family by looking after myself'

All mothers acknowledged the importance of looking after themselves. They discussed the benefits of having 'me-time' activities for their health and wellbeing, and many mothers in this study were actively ensuring to have some time-off from their responsibilities. *"...I will take the book and read my book. That's my 'time-out.' Yes, and they (children) know…If they disrupt it, then they can hear it!"* (Participant 1).

Mothers were creative in securing their own time, for example grabbing moments whenever possible to engage in 'me-time' activities. Participant 3 said, *"...when Jackson's playing soccer, I schedule a 5 kilometre walk while he's doing soccer."* Participant 9 used everyday activities to have 'me-time' moments, "*...my break is getting on my ride-on lawnmower...and I actually like just sitting on it for an hour!...I don't know why but it just seems like meditation to me."* Some mothers scheduled their own time-off activities in every day routines.

> *Now, my 'me time' is 9.30pm. I go to bed at 9.30pm usually every night. That's my little routine. I'll put the television on and I have my tablet and I play my games and that's my de-stress* (Participant 5).

Mothers recognised the need to re-charge their energy, so they can continue to fulfil their roles in managing family routines. However, mothers frequently discussed difficulty in overcoming a sense of guilt in engaging in 'me-time' activities. "*I was always thinking they (children) have to be with me all the time…it wasn't fair to have someone look after them (children)…"* (Participant 19).

Most mothers recognised the central role they played in providing support to the family and, in particular, to the child with ASD. This was the main motivator incorporating their time-off into family routines. All participants acknowledged the importance of looking after themselves to fulfil their commitment to supporting their children.

> *We do have to kind of come first. Because if you think about it, what would happen if we weren't there?...the focus is all on them (children). But it's the parents – without that base, what happens with the child? Do they not suffer? They do* (Participant 2).

Theme 5: 'I am not perfect and it's OK'

Mothers discussed the importance of allowing themselves not to be perfect in fulfilling their roles in managing family routines. Participant 6 said, *"It's very important to…not try and be 'Wonder-woman' just be who 'I' am."* Participant 5 used the metaphor of an engine to explain that role of mothers in managing family routines was not about perfection, but about continuity and sustainability.

> *But sometimes the engine is not here, something's going to happen…but that's ok. You tend to it and...you fix it and then it's good to go again. It's like there's so many moving parts – that when it does break down…That's OK. Because that's life.*

In allowing themselves not to be perfect, some mothers recognised their limited capacity to cope with all the demands. Mothers had to let go of some tasks, so they could attend to another task. "*So I think there's an element of saying "Okay, I'm looking after Jodie. That's all I'm doing"…not trying to multi-task"* (Participant 8).

In realising that they do not have to be perfect, mothers learned to ask for help. In the process of learning, mothers had to overcome an internal conflict. *'It feels like something that I should be able to do. So you really have to get past – it's not a failing as a mother"* (Participant 12). Participant 2 echoed:

> *I've been 'there' and I was the type of person who never 'asked' for help. I used to put it all on myself. It's about yourself. It's about saying to yourself that "I can do it all" when you can't.*

Discussion

The current study explored the experiences and perceptions of mothers of children with ASD in managing family routines and its impact on their own health and wellbeing. Unlike previous research in the area of family routines that examined the experiences of the entire family (Bagatell, 2016), this study focused on the personal experiences of mothers.

The demands of constant family routine management may come at a cost to mothers' health and wellbeing

The findings highlight the vital role that mothers have in orchestrating occupations to construct family routines and thus support the results of previous research (Larson, 2006; Larson & Miller-Bishoff, 2014). Many of the participants were responsible for managing family routines, and without their contributions, their family would struggle in maintaining a structured life. Similar to previous research that examined the entire experiences of the family, the results show that family routines benefitted each and every family member, including mothers themselves (Schaaf et al., 2011). The benefits of a structured lifestyle, in turn, ensured that routines were sustained and became 'second nature' to the mothers involved in this study. Perhaps the cognitive demands that mothers experience in orchestrating occupations to construct family routines were somewhat reduced because of the sequenced patterns that occur every day. However, this study found that mothers considered the construction of family routines as an arduous occupation. This experience may be taxing for mothers given previous research suggesting that the lives of families of children with disabilities can be disorganised due to logistic challenges, such as complex scheduling with therapeutic services (Faw & Leustek, 2015). One of the consequences of these maternal efforts may be a cost to mothers' health. Indeed, the participants discussed feelings of exhaustion. This may be of concern as fatigue can be debilitating for parents' abilities to orchestrate family routines to meet the demands of family members (Larson & Miller-Bishoff, 2014). In contrast to previous research which suggest that family routines support the health of the family (Fiese et al., 2002) and provide a platform to participate in meaningful occupations (Bagatell et al., 2014), the present study demonstrates that the mother's responsibility for managing family routines is a potential risk to their own health and wellbeing (Bagatell, 2016). Thus, appropriate support should be provided for mothers in managing family routines, not only for their own benefits, but also for their families.

We found that some mothers adopted the role of family routine management because of the necessity to meet everyday demands or social expectations placed upon females. The findings indicate some mothers were hesitant to assume the pivotal role in managing family routines, even though the participants were committed in supporting their children and family. This hesitation may be derived from the participants' dissatisfaction with the traditional household labour division that is commonly found among families of children with ASD (Hartley et al., 2014). Previous research found that when parents of children or adolescents with ASD were not satisfied with their household labour division, they experienced higher levels of stress than those parents who were satisfied with the arrangement (Hartley et al., 2014). Therefore, health professionals, such as occupational therapists, should not overlook the perceived reasons in assuming the key role in managing family routines that may be related to household labour division issues and gender expectations, when considering the health and wellbeing of these mothers.

How mothers cope with the demands in managing family routines

An important finding of the study was that by accepting their own limitations and allowing themselves to be imperfect, mothers found a way to cope with the everyday demands of managing family routines. A study that investigated the relationship between psychological wellbeing and family routines among parents of children with disability found that the parents felt overwhelmed in meeting all family members' needs, and felt a sense of inefficacy as parents when they were unable to meet those demands (Larson & Miller-Bishoff, 2014). Therefore, embracing imperfections in completing everyday tasks and acknowledging own limitations may be helpful; however, it may not come automatically or be an easy process. We found that mothers had to overcome a sense of failure as a mother in allowing themselves to be imperfect. Perhaps this sense is attributed to the previous finding that mothering is a significant occupation (Larson, 2000a), and thus overcoming this sense would be challenging for any parent. Nonetheless, developing this particular psychological stance through changing perspectives (VanLeit & Crowe, 2002) by allowing themselves to be imperfect to cope with the demands in managing family routines may benefit mothers of children with ASD in supporting their own health and wellbeing.

The study highlighted the importance of engaging in 'me-time' activities for mothers as a way to address their own health and wellbeing. The participants were found to be actively participating in 'me-time' activities, contrary to previous research that found that parents of children with disability did not prioritise their own needs, such as health issues, due to perceived lack of time (Murphy et al., 2007). We found that the mothers' commitment to support children and family motivated, and even freed them to participate in 'me-time' activities. However, similar to a previous study (Gahagan, Loppie, Rehman, Maclellan, & Side, 2007), some of our participants experienced a sense of guilt when engaging in 'me-time' activities. The findings demonstrate the paradox of the occupational role of mothers, where mothers provide support for others over and beyond their own needs, yet they need to stay ‘healthy’ by looking after themselves to fulfil this meaningful role. The findings indicate that use of family routines may be helpful for mothers of children with ASD in striking a balance to integrate their ‘me-time’ activities into their everyday life. ‘Me-time’ activities have been found as a healthy coping strategy to deal with daily demands among parents of children with disabilities (Larson & Miller-Bishoff, 2014). Therefore, ‘me-time’ activities should be promoted among mothers of children with ASD to enable them in fulfilling their mothering role in managing family routines that, in turn, support their children and family.

Family routines nurturing mothers’ spirituality

An interesting finding of the study was that family routines reflected mothers’ beliefs, values and needs; hence, nurturing their own spirituality. While previous literature suggest that routines encompass cultural values and beliefs of families (Boyd et al., 2014; Denham, 2003), the finding extends the knowledge of spirituality embedded in family routines by considering mothers’ individual beliefs, values, and needs, adding to the previously identified spirituality, such as parenting values that are related to the needs of children as well as that of parents (E. Larson & Miller-Bishoff, 2014). Spirituality is an element commonly considered in occupational therapy theoretical frameworks, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E;Townsend & Polatajko, 2007). Spirituality, such as values and needs, are central to the CMOP-E and provide meaning to occupations (Townsend & Polatajko, 2007), while assisting individual occupational engagement (Strong & Gruhl, 2011). Organising daily activity patterns to meet the family’s needs is considered as a way to achieve life balance (Matuska & Christiansen, 2009). A sense of balance that is derived from living in accordance to ones’ own values leads to wellbeing (Pentland & McColl, 2009). Therefore, thorough understanding of family routines that entail mothers’ spirituality may lead occupational therapists to obtain crucial information that assist occupational engagement and promote wellbeing among mothers of children with ASD.

Limitation

Due to the nature of IPA, the results of this study are reflections of specific participants’ experiences in their situations (i.e., mothers of children with ASD who live in Western Australia) at the time of data collection (Larkin et al., 2006). Hence, the current results have a low transferability. However, IPA allowed us to explore the experiences and perceptions of this particular group of mothers more deeply, which was the aim of this study. Although the first author met each participant prior to the interview date, it is possible that there was limited disclosure of information, due to potential lack of rapport. Lastly, family routines are complex because multiple factors are intrinsically unique to each family, such as the socio-cultural backgrounds of families (Larson & Miller-Bishoff, 2014). Other research methods, such as mixed method, should be considered in obtaining more comprehensive experiences of mothers in managing family routines.

Conclusion

This study highlighted that mothers are pivotal in managing family routines and without their efforts, their family would have limited family routines that provide a structured lifestyle. Their responsibilities are large, and hence, the related challenges may come at the cost of the health and wellbeing of mothers of children with ASD. The psychological stance that allows themselves to be imperfect, while acknowledging their own capacity, may be beneficial to cope with the demand in managing family routines. Further, reasons for these mothers to assume their roles in managing family routines, such as social expectations placed upon female, should not be ignored, as the issues of household labour divisions may be a source of stress among parents of children with ASD. The importance of 'me-time' as a coping strategy has been discussed previously. Mothers' commitments to care for their children and family underpin their motivations to participate in 'me-time' activities. Engaging in such activities assists parents to deal with daily demands. Thus, use of family routines to encourage these mothers to participate in 'me-time' activities may be valuable in promoting their health. Family routines that reflect mothers' beliefs, values and needs nurture their spirituality. Therefore, understanding family routines may be key for occupational therapists in assisting occupational engagement among mothers of children with ASD, as well as fostering their health and wellbeing.

Key Points for Occupational Therapy

- Managing family routines is a major role for mothers of children with ASD
- Family routines can be used to explore mothers' occupational engagement and promote their health and wellbeing
- Family routines nurture mothers' spirituality that provide meaning and assist occupational engagement

Declaration of Authorship

TM conducted the data collection, performed the analysis and interpreted the data, and drafted the final manuscript. YC assisted the analysis, interpretation of the data and drafting the manuscript. RC assisted the analysis, and drafting the manuscript. SV assisted drafting the manuscript. TF assisted the data collection and drafting the manuscript. All authors read and approved the final manuscript. The authors declare that there is no conflict of interest. The authors conducted this research project, independent of the founder and those view expressed are not necessarily those of the founder's. All researchers take full responsibility for the integrity of the work.

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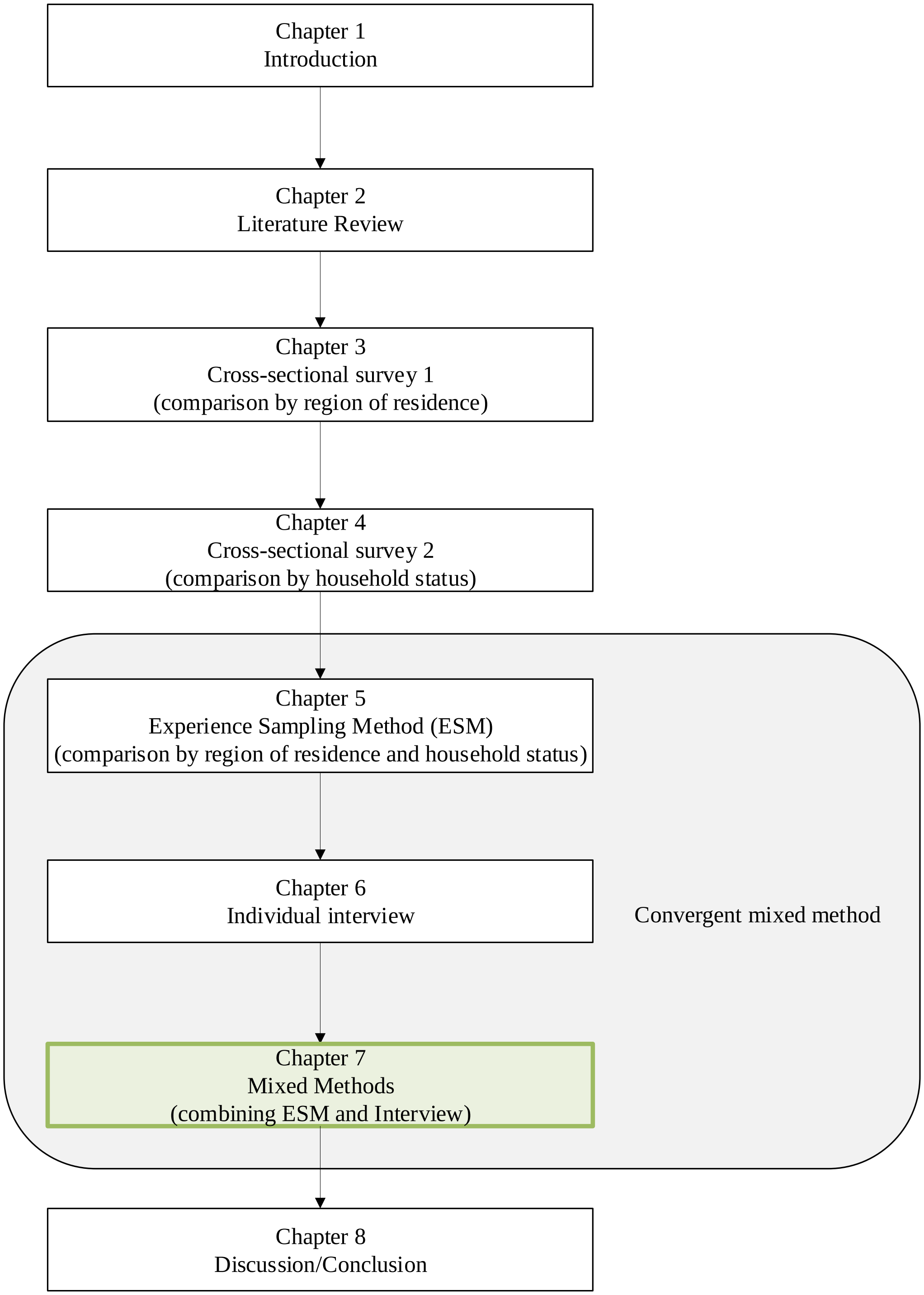
Chapter 7 Mixed Method Study

(Paper submitted for publication)



Title: Complexity in family routines: A study of the perspectives of mothers of children with autism spectrum disorder

This chapter comprises a mixed method study that synthesised the ESM (Chapter 5) and individual interview (Chapter 6) data. A convergent approach was employed where the ESM and the interview data were collected and analysed separately before two sets of results were integrated to develop meta-inferences[5]. The mixed method design used in this study elicited the complexity involved in constructing family routines from mothers' perspectives.

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[5] This chapter is currently under review for publication. Authors: Tomomi McAuliffe, Reinie Cordier, Yvonne Thomas, Sharmila Vaz and Torbjorn Falkmer

Abstract

Background: Mixed methods are not commonly employed in investigating family routines. However, the process of constructing family routines is complex due to multiple factors and its transactional nature. Thus, the mixed methods that allow researchers to develop in-depth understanding of complex phenomena should be utilised.

Aim: To understand complex phenomena and generate new ideas by explicating the experiences of mothers of children with autism spectrum disorder (ASD) with family routines.

Methods: A convergent mixed method approach was employed. The results of the experience sampling method (ESM) (*N* = 40) and the interview (*N* = 20) were integrated by using joint display.

Results: The five themes emerged and revealed in-depth understandings of family routines for mothers of children with ASD: 1) mothers' intrinsic motivation and sense of control in childcare; 2) work provides opportunities for personal achievement and respite; 3) dissonance between expected and practical support in domestic tasks; 4) self-care as sacrificed activity, and 5) internal and external permission to have 'me-time'.

Conclusions: Family routines allow mothers to obtain or maintain a sense of control; however, addressing their own needs within family routines is still challenging. Health professionals should acknowledge the needs of these mothers to spend time on themselves.

Keywords: ASD, mothers, routines, health, wellbeing, parenting

Introduction

Family routines provide stability and predictability in daily life for children with autism spectrum disorder (ASD) in supporting their unique characteristics, such as rigid and repetitive behaviours (Schaaf et al., 2011). Generally, well-constructed family routines that support the needs of family are considered to support family health and wellbeing (Churchill & Stoneman, 2004; Markson & Fiese, 2000). However, previous studies suggest that the process to construct family routines can be costly to the health and wellbeing of mothers who assume main responsibilities (Larson & Miller-Bishoff, 2014; McAuliffe, Thomas, Vaz, Falkmer, & Cordier, 2018).

The process of constructing family routines is complex due to several reasons; involvement of multifaceted factors, such as the nature of children's disability and parental health issues (Churchill & Stoneman, 2004; Muñiz et al., 2014) and the transactional nature of routines (Sameroff & Fiese, 2000). Each family member needs to contribute to the process in developing family routines through reciprocal interactions (Boyd et al., 2014; Fiese et al., 2002). This interactions occur repeatedly and continuously while family members make momentary commitments, creating a transactional process to develop family routines (Boyce et al., 1983; Fiese et al., 2002; Sameroff & Fiese, 2000).

To date, previous studies investigating family routines commonly employed either quantitative methods, such as use of Family Routines Inventory (FRI) to identify most frequently occurring routines (Jensen et al., 1983), or qualitative methods, such as conducting interviews to explore parental perceptions of the entire family experiences (Bagatell et al., 2014). While each method has its unique contribution, given the complexity of the nature of family routines and the manner in which routines are constructed (Larson & Miller-Bishoff, 2014), use of single method alone may not fully capture its complex nuances. In fact, a literature review on family routines among families of children with complex needs has suggested more mixed-methods be used to further understand this complex phenomena (Crespo et al., 2013).

The current study used previously analysed time-use (quantitative) and interview (qualitative) data (McAuliffe, Cordier, et al., 2018; McAuliffe, Thomas, et al., 2018) to explore complexities in the experiences of mothers of children with ASD in relation to family routines. Time-use studies provide in-depth information of family routines in investigating daily activity patterns (Koome et al., 2012). However, many of the past time-use studies have not extended their findings to establish a link with family routines (Crowe & Michael, 2011; Gevir et al., 2006). Although previous interview studies that investigated family routines among families of children with ASD described their unique experiences, such as difficulties in developing and maintaining family routines due to unpredictable behaviour of the child and child-centric nature of routines (Evans & Rodger, 2008; Larson, 2006; Marquenie et al., 2011), other data should be used to corroborate these findings. Therefore, the use of mixed methods by combining the time-use and interview data may provide more accurate understanding of the experiences of mothers of children in constructing family routines.

In the disability context, mixed methods have not been widely utilised to examine family routines (Crespo et al., 2013; Larson & Miller-Bishoff, 2014). By using mixed methods, the depth of understandings is further enhanced, in particular when investigating complex phenomena (Teddlie & Tashakkori, 2003). Thus, using mixed methods to investigate family routines that are complex in nature would allow researchers to obtain a more complete picture, thereby enhancing researchers’ interpretations (Collins, Onwuegbuzie, & Sutton, 2006). Based on the typology of mixed method purpose proposed by Newman, Ridenour, Newman, and

DeMarco (2003), the purpose of this mixed methods study was to understand complex phenomena and generate new ideas by explicating mothers' experiences with family routines in the context of families of children with ASD.

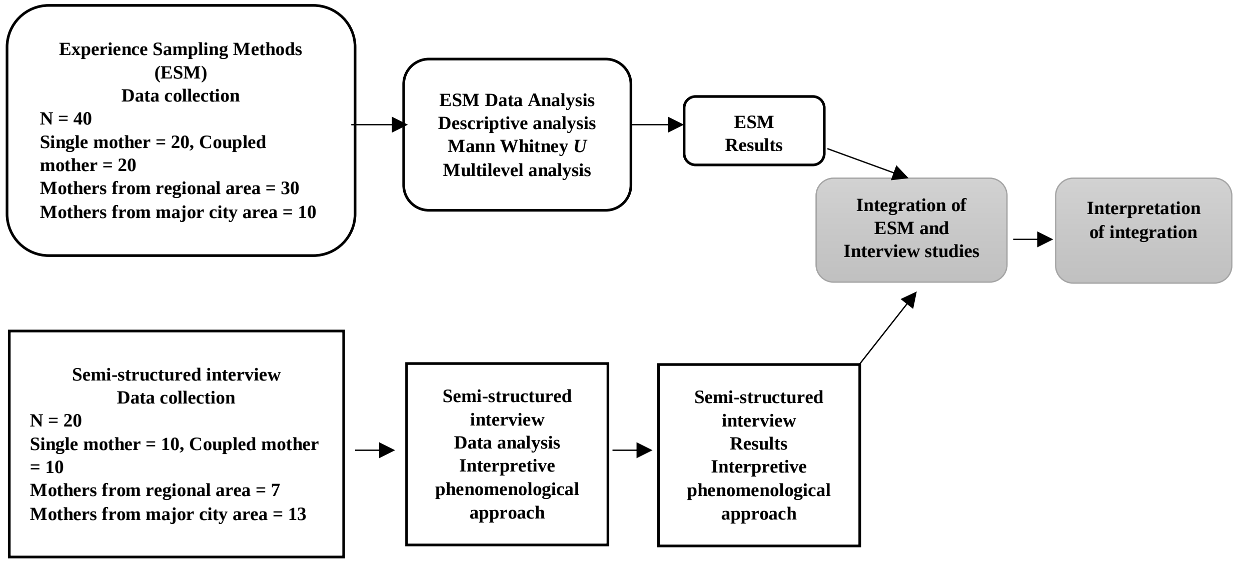
Additionally, the current study investigated the differences and similarities between single versus coupled mothers (i.e., household status) as well as mothers from regional versus major city areas (i.e., region of residence). The homogeneity of participants in the previous family routine studies that mainly focused on mothers who are coupled and from major city areas is of concern (Evans & Rodger, 2008; Marquenie et al., 2011). The focus on this particular population group has resulted in a lack of representation of single mothers and mothers from regional areas, particularly in the disability research. This lack of representation has limited the accurate understanding of the experiences of family routines among those overlooked population. Therefore, where applicable, the current study considered participants' household status and region of residence to fill the gap in the field of family routines.

Material and Methods

Research design

A convergent mixed-methods approach was used in this study (Creswell & Plano Clark, 2011), combining experience sampling methods (ESM) (quantitative) and semi-structured interviews (qualitative) (Figure 7.1). ESM data were used to investigate the relationships between mothers' time-use and their in-the-moment feelings and the moderating effects of their characteristics (i.e., household status and region of residence) on those relationships. The interview data were used to explore mothers' perceptions of their roles in managing family routines in relation to their health and wellbeing.

Figure 7.1: Research design



By combining the two methods, we aimed to achieve significant enhancement through thorough interpretation of data (Collins et al., 2006). According to the typology developed by Leech and Onwuegbuzie (2009), this study is classified as partially mixed concurrent equal status design. Data collection and analysis for the ESM and interview occurred concurrently, while the integration of the two results occurred following the analyses (Leech & Onwuegbuzie, 2009). Through integration of quantitative and qualitative findings, a more complete and nuanced picture can be presented instead of the sum of the two studies (Fetters & Freshwater, 2015). There are various ways to present mixed methods research, and this study followed a guideline recommended by Leech et al. (2011). The ESM and interview studies are either currently under review or published elsewhere, therefore, detailed information of each study is not included in this paper (McAuliffe, Cordier, et al., 2018; McAuliffe, Thomas, et al., 2018). However, to improve readability and interpretation of data, the ESM and interview studies are briefly described to guide readers.

Participants

Mothers who have children between the ages of 2 and 19 years old with ASD, living in Western Australia, were eligible to participate in this study. Participants were recruited through a network of community organisations. Single mothers were defined as, “those who have no spouse or partner usually resident in the household but who forms a parent-child relationship with at least one child usually resident in the household.” (Australian Bureau of Statistics, 2015b para 21). The Australian Statistical Geography Standards remote structure classifies participants’ region of residence by five remoteness areas (RAs) (Australian Bureau of Statistics, 2013b). Participants’ postcodes were used to determine the following five RA categories: 1) major city, 2) inner regional, 3) outer regional, 4) remote, and 5) very remote (Australian Bureau of Statistics, 2013b). All participants were either from major city or inner regional areas.

A purposive sample of forty participants participated in the ESM study; 20 were single and 20 were coupled mothers. Of those 40, 30 mothers were from major city areas and 10 were from regional areas. The semi-structured individual interviews were conducted with 20 participants who participated in the ESM study. Of those 20 participants, 10 were single and 10 were coupled mothers; 13 mothers were from major city area and 7 mothers were from regional areas. Written informed consent was obtained from all participants. Table 7.1 presents participants and their children’s characteristics for both the ESM and the interview studies.

Table 7.1: Characteristics of mothers and children– single mothers, coupled mothers, mothers who reside in major city areas, and mothers who reside in regional areas for experience sampling method study

Study	**Experience Sampling Method**		**Interview**	
	Total sample		Total sample	
Characteristics	*N* = 40	%	*N* = 20	%
Children's Age (year) Mean (standard deviation)	13.29 (3.7)		11.58 (3.7)	
Children's Gender				
Male	31	77.5	16	80
Female	9	22.5	4	20
Official ASD diagnosis				
Autistic Disorder (Autism)	17	42.5	11	55
HFA, AS, PDD-NOS*	23	57.5	9	45
Presence of cognitive impairments/intellectual disability†				
Yes	9	22.5	6	30
No	31	77.5	14	70
Mothers' Age (year) Mean (standard deviation)	44.81 (7.1)		43.24 (7.0)	
Household status				
Single mother	20	50	10	50
Coupled mother	20	50	10	50
Region of residence				
Major city	30	75	13	65
Regional city	10	25	7	35
Mother's employment status				
Employed	27	67.5	13	65
Unemployed	13	32.5	7	35
*Household income***				
Up to $51,999	20	50	11	55
$52,000 and over	20	50	9	45
Mothers' education levels				
Did not complete school	3	7.5	2	10
Year 12	9	22.5	5	25
Post TAFE or Certificate	12	30	6	30
University	16	40	7	35
Total number of children				
1 child	10	25	5	25
2 or more children	30	75	15	75

*High functioning autism (HFA), aspergers syndrome (AS), and pervasive developmental disorder non specified (PDD-NOS) **The cut-off point was set based on the median household income in Western Australia at the time of the study. † Based on mother's reports

ESM

An iOS application, Participation in Everyday Life Survey Application (PIEL$^{\copyright}$ survey) was used to collect data (Jessup, Bian, Chen, & Bundy, 2012a). ESM captures 'in-the-moment' experiences of participants that, otherwise, may go unnoticed through traditional methods, such as daily diary entry (Hektner et al., 2007). The survey was designed to obtain information about the mothers' emotions and the activities they participated in. Initially, the first author visited the participants to provide a training session on the application. For those participants who used Android devices, an iPod touch was provided. We asked participants to carry their devices for one week during school terms. The application randomly prompted participants to complete the survey seven times a day between 7.30 am and 9.00 pm. The five activity areas were included in the survey based on the previous time-use studies (Crowe & Florez, 2006; Crowe & Michael, 2011): 1) childcare; 2) domestic tasks; 3) productivity; 4) mothers' self-care; and 5) mothers' leisure activities. Participants were asked to record the main activity (i.e., one of the five activity areas) they engaged when prompted. The survey also included five emotions: 1) perceived levels of engagement, 2) stress, 3) challenge, 4) support, and 5) sense of control. Participants were asked if they experienced any of these five emotions, and to what extent, while participating in one of the five activity areas. They were instructed to complete as many surveys as possible when convenient. More detailed information of the ESM survey can be found in McAuliffe, Cordier, et al. (2018).

Interview

We used interpretive phenomenological analysis (IPA) approach as it allows researchers to investigate individual lived experiences while developing meaningful themes, rather than just describing participants account narratively (Smith et al., 2009). As IPA takes a 'double hermeneutic' process, it was acknowledged that the interpretation included both participants' and researchers' views (Finlay, 2011). After the week of ESM participation, the first author conducted semi-structured interviews, either face-to-face or telephonically, depending on the participants' availabilities to collect their individual account of the experiences of family routines in relation to their health and wellbeing. The semi-structured interview guide was developed and reviewed by the first three authors. There were five open-ended questions in the guide that started with a broad question *'Please tell me about an ordinary week day or weekend day with your family'.* Further details of the interview guide can be found in McAuliffe, Thomas, et al. (2018). The interviews were between 60 and 90 minutes in duration. All interviews were recorded and transcribed verbatim. Ethics approval was obtained through Curtin University Human Ethics Committee (HR123/2014-01) for both ESM and interview studies and all procedures performed were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Analysis

In convergent design, the analyses of quantitative and qualitative data are conducted separately before integrating them to form "meta-inferences" (Teddlie & Tashakkori, 2009 p.266). The researchers explain and interpret both data to obtain new conclusions (Greene, 2007). To guide the readers, the analyses of ESM and interview data are briefly presented before discussing the mixed method analysis. The detailed analyses of the ESM and the interview data can be found in McAuliffe, Cordier, et al. (2018); McAuliffe, Thomas, et al. (2018), respectively.

Analysis of ESM data. There is a hierarchical structure in the ESM data with multiple surveys (level 1) nested within each participant (level 2), creating dependency of surveys within the same participants (Snijders & Bosker, 2012). Multilevel analysis was used to investigate the relationships between variables at different levels and the possible moderating effects of level 2 variables on level 1 variables (Hox, 2010), using Hierarchical Linear and Nonlinear Modelling software (HLM 6.08) (Raudenbush et al., 2011). This particular analysis accounts for the unique dependency of the ESM data (Snijders & Bosker, 2012) and is therefore better suited to analyse ESM data than conventional ordinary least squares (OLS) (Nezlek, 2001). The dependent variables were five feelings investigated (i.e., levels of engagement, stress, challenge, support and sense of control). Level 1 independent variables were five activity areas (i.e., childcare, domestic tasks, productivity, mothers' self-care, and mothers' leisure activity). Level 2 independent variables were participants' characteristics (i.e., single versus coupled household status and region of residence). To investigate time-use of mothers per specific activities, SPSS version 22 (IBM Corp, 2013) was used. The mean proportion of responses of each participant was calculated, which represented mother's time-use (Hektner et al., 2007). Mann-Whitney *U* test was used to compare mothers by their household status and region of residence.

Analysis of interview data. The interview data were analysed using NVivo 11 (QSR International Pty, 2015). The analysis followed the IPA steps described by Smith and Osborne (2008), including read and re-read interview transcripts, to develop themes. The first and third authors worked collaboratively to identify and review tentative themes through ongoing dialogue and reflexivity before reaching consensus. Reflexivity allowed the first author to be grounded in the interview data while acknowledging own interpretations (Morse, 1991). The third author guided the first author throughout the analysis process, and this guidance supported practice of rigour (Smith et al., 2009).

Mixed methods analysis. Greene (2007) identified five phases of mixed methods analysis: 1) Data cleaning, 2) Data reduction, 3) Data transformation, 4) Data correlation and comparison, and 5) Analyses for inquiry conclusions and inferences. Depending on the types of data or approach researchers take, all or some of the phases can be included in the analysis process (Onwuegbuzie et al., 2007). The study included four of the five phases of Greene (2007), including data cleaning, data reduction, data correlation and comparison, and analyses for inquiry conclusions and inferences. The data set for the ESM study was reviewed to examine valid responses, and spelling errors of the interview transcripts were amended (data cleaning). As discussed in the ESM analysis section (2.5.1), the mean proportion of response was calculated using descriptive statistics, and for the interview data, the initial themes were developed (data reduction). The results from the two studies (i.e., ESM and interview) were compared and contrasted to develop further understanding of the experiences of mothers of children with ASD (data correlation and comparison). As the goal of this mixed method study was to understand complex phenomena and generate new ideas, the study adapted the approach of joint displays that allows researchers to develop new understandings from the two separate quantitative and qualitative results (Fetters, Curry, & Creswell, 2013). This approach visually presents the process of data synthesis that allow readers to gain better insight of the mixed methods results and has increasingly gained popularity among health science research (Guetterman et al., 2015; Johnson et al., 2017). A table was initially used in the process to organise the two results in joint displays (Creswell, Klassen, Plano Clark, & Smith, 2011; Fetters et al., 2013). In this process, we identified the findings of both ESM and interview data that either supported or differed from the other findings. As the process of mixing and interpreting both quantitative and qualitative data to develop inferences is largely cognitive process of the researchers (Greene, 2007), schemas that compared and contrasted the ESM and interview data are presented to show the progression of the results integration to the readers (conclusion and inferences; Figures 7.2 to 7.6). The first author attempted the initial integration and the results were reviewed by the second, third and fourth authors. The dialogue between four authors continued until consensus was reached for the integrated results.

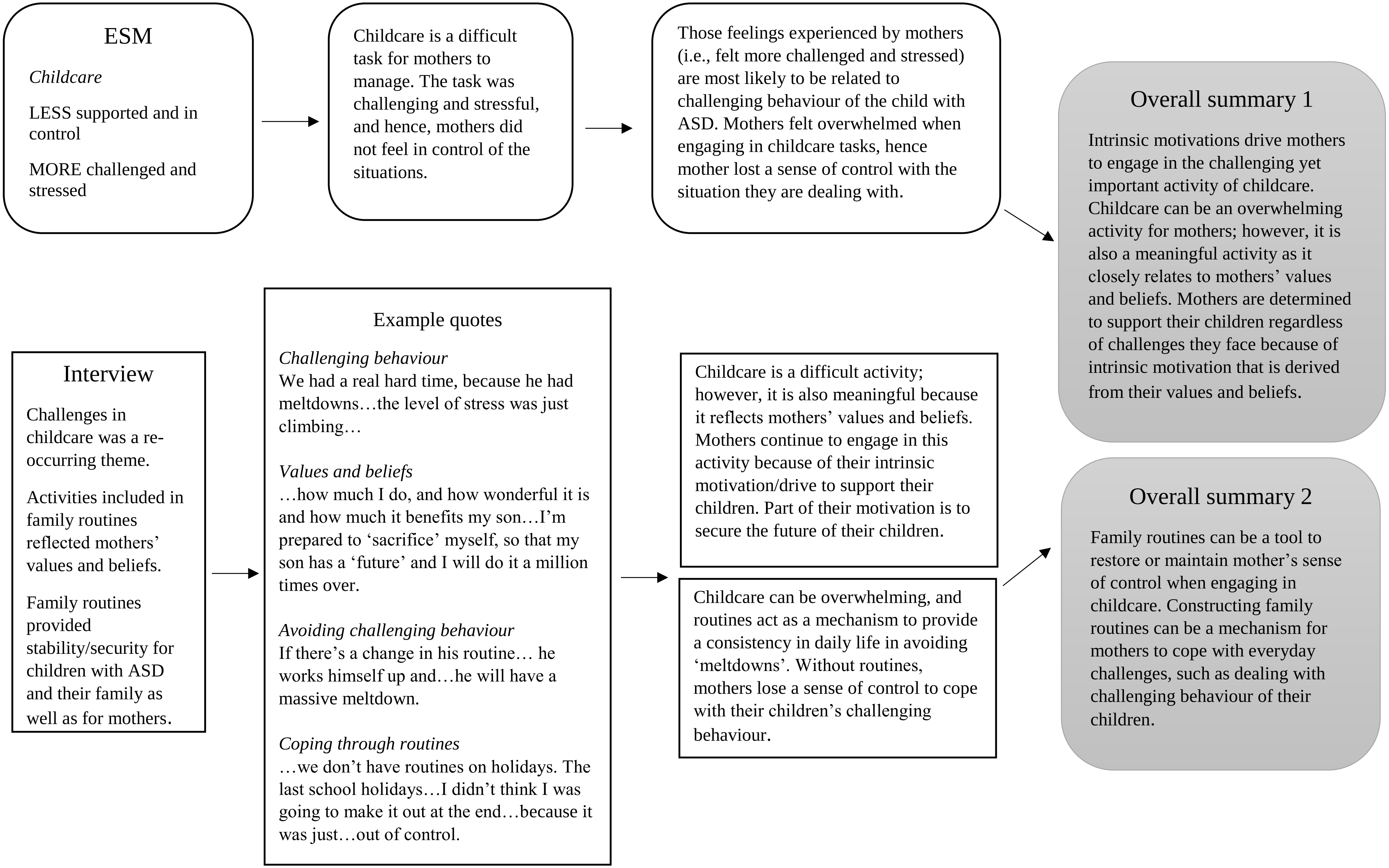
Results

Presenting quantitative and qualitative results separately reduces the benefits of the mixed method approach (Andrew & Halcomb, 2007). In the following section the focus will be the results from the mixed method analysis as per the purpose of the study. Following the integration of the ESM and interview data, five themes emerged: 1) Mothers' intrinsic motivation and sense of control in childcare; 2) Work provides opportunities for personal achievement and respite; 3) Dissonance between expected and practical support in domestic tasks; 4) Self-care as sacrificed activity, and 5) Internal and external permission to have 'me-time'.

Theme 1: Mothers' intrinsic motivation and sense of control in childcare

Building on the initial findings of the ESM and interview studies, the study identified this theme that discussed two aspects of childcare activities. The first one explains the reason why mothers continue to participate in childcare activities that are perceived as difficult. The ESM findings indicated that mothers felt more challenged and stressed when engaging in childcare; however, the participants continued to engage with this activity every day. Childcare reflected mothers' values and belief, hence, it was a meaningful activity for mothers. Mothers were intrinsically motivated to support their children regardless of the challenges they experienced. Another aspect of this theme is a potential function for family routines to restore or maintain mothers' sense of control while engaging in childcare. In the interviews, mothers reported feeling overwhelmed when dealing with challenging behaviour of the child with ASD, which resulted in a decreased sense of control. However, family routines acted as a mechanism to deal with challenging behaviour of the child by providing consistency in everyday life. In turn, mothers were able to restore or maintain a sense of control. Figure 7.2 explains the process in developing this theme.

Figure 7.2: Theme 1 Mothers’ intrinsic motivation and sense of control in childcare



ESM

Childcare

LESS supported and in control

MORE challenged and stressed

Childcare is a difficult task for mothers to manage. The task was challenging and stressful, and hence, mothers did not feel in control of the situations.

Those feelings experienced by mothers (i.e., felt more challenged and stressed) are most likely to be related to challenging behaviour of the child with ASD. Mothers felt overwhelmed when engaging in childcare tasks, hence mother lost a sense of control with the situation they are dealing with.

Overall summary 1

Intrinsic motivations drive mothers to engage in the challenging yet important activity of childcare. Childcare can be an overwhelming activity for mothers; however, it is also a meaningful activity as it closely relates to mothers’ values and beliefs. Mothers are determined to support their children regardless of challenges they face because of intrinsic motivation that is derived from their values and beliefs.

Interview

Challenges in childcare was a re-occurring theme.

Activities included in family routines reflected mothers’ values and beliefs.

Family routines provided stability/security for children with ASD and their family as well as for mothers.

Example quotes

Challenging behaviour
We had a real hard time, because he had meltdowns…the level of stress was just climbing…

Values and beliefs
…how much I do, and how wonderful it is and how much it benefits my son…I’m prepared to ‘sacrifice’ myself, so that my son has a ‘future’ and I will do it a million times over.

Avoiding challenging behaviour
If there’s a change in his routine… he works himself up and…he will have a massive meltdown.

Coping through routines
…we don’t have routines on holidays. The last school holidays…I didn’t think I was going to make it out at the end…because it was just…out of control.

Childcare is a difficult activity; however, it is also meaningful because it reflects mothers’ values and beliefs. Mothers continue to engage in this activity because of their intrinsic motivation/drive to support their children. Part of their motivation is to secure the future of their children.

Childcare can be overwhelming, and routines act as a mechanism to provide a consistency in daily life in avoiding ‘meltdowns’. Without routines, mothers lose a sense of control to cope with their children’s challenging behaviour.

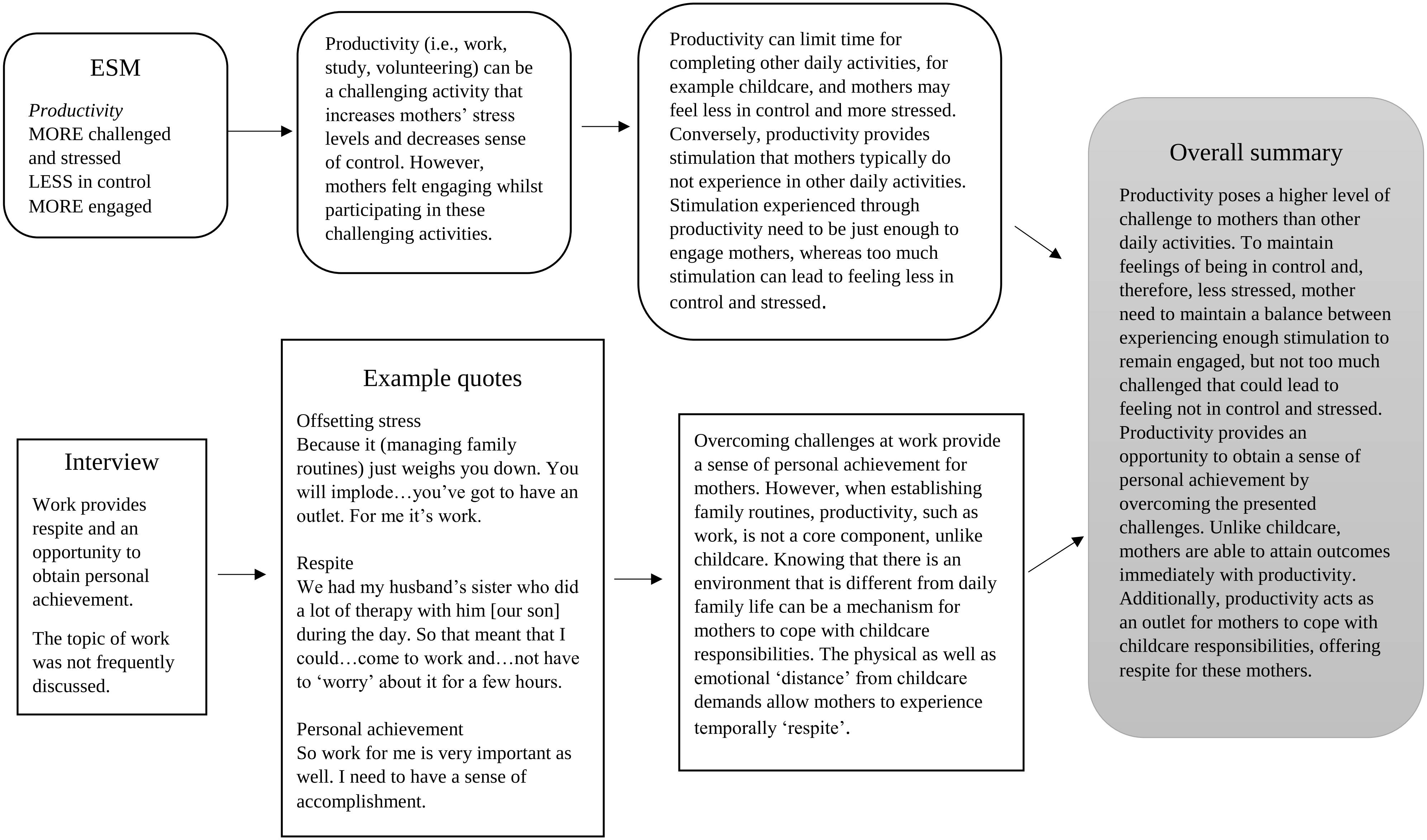
Overall summary 2

Family routines can be a tool to restore or maintain mother’s sense of control when engaging in childcare. Constructing family routines can be a mechanism for mothers to cope with everyday challenges, such as dealing with challenging behaviour of their children.

Theme 2: Work provides opportunities for personal achievement and respite

This theme describes mothers' experiences in participating in productivity, such as work, which foster personal achievement and provide a chance to have a break from daily responsibilities, including childcare (Figure 7.3). The ESM results showed that mothers felt more stressed and challenged and less in control with productivity; however, they felt more engaged. Interestingly, in the interview, mothers discussed gaining a sense of achievement when overcoming the challenges presented at work. Productivity provided stimulating and the 'just-right' challenges for mothers. However, mothers perceived that it was possible for them to overcome those challenges, which, in turn, fostered their sense of internal control and achievement. Mothers also discussed that having an environment away from family life, such as a work place, assisted them to cope with their daily responsibilities. Work was an outlet for some mothers that provided physical, as well as emotional distance from childcare, acting as respite for these mothers.

Figure 7.3: Theme 2 Work provides opportunities for personal achievement and respite



ESM

Productivity
MORE challenged and stressed
LESS in control
MORE engaged

Productivity (i.e., work, study, volunteering) can be a challenging activity that increases mothers' stress levels and decreases sense of control. However, mothers felt engaging whilst participating in these challenging activities.

Productivity can limit time for completing other daily activities, for example childcare, and mothers may feel less in control and more stressed. Conversely, productivity provides stimulation that mothers typically do not experience in other daily activities. Stimulation experienced through productivity need to be just enough to engage mothers, whereas too much stimulation can lead to feeling less in control and stressed.

Interview

Work provides respite and an opportunity to obtain personal achievement.

The topic of work was not frequently discussed.

Example quotes

Offsetting stress
Because it (managing family routines) just weighs you down. You will implode…you've got to have an outlet. For me it's work.

Respite
We had my husband's sister who did a lot of therapy with him [our son] during the day. So that meant that I could…come to work and…not have to 'worry' about it for a few hours.

Personal achievement
So work for me is very important as well. I need to have a sense of accomplishment.

Overcoming challenges at work provide a sense of personal achievement for mothers. However, when establishing family routines, productivity, such as work, is not a core component, unlike childcare. Knowing that there is an environment that is different from daily family life can be a mechanism for mothers to cope with childcare responsibilities. The physical as well as emotional 'distance' from childcare demands allow mothers to experience temporally 'respite'.

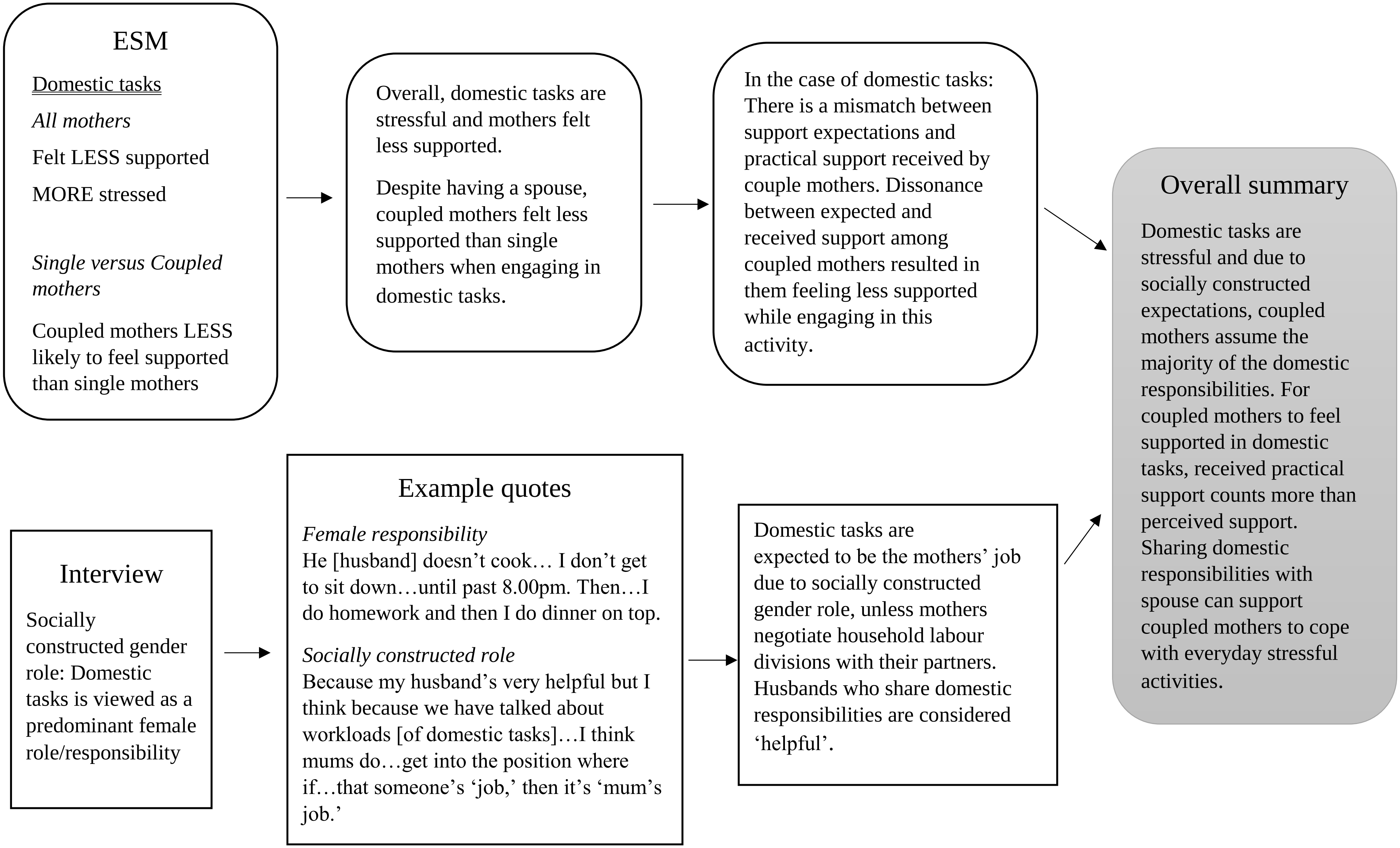
Overall summary

Productivity poses a higher level of challenge to mothers than other daily activities. To maintain feelings of being in control and, therefore, less stressed, mother need to maintain a balance between experiencing enough stimulation to remain engaged, but not too much challenged that could lead to feeling not in control and stressed. Productivity provides an opportunity to obtain a sense of personal achievement by overcoming the presented challenges. Unlike childcare, mothers are able to attain outcomes immediately with productivity. Additionally, productivity acts as an outlet for mothers to cope with childcare responsibilities, offering respite for these mothers.

Theme 3: Dissonance between expected and practical support in domestic tasks

This theme only applies to coupled mothers (not single mothers) (Figure 7.4). The ESM results indicated that coupled mothers were found to be less likely to feel supported in domestic tasks than their counterparts. However, the interview data helped to clarify that mothers regarded their spouses ‘helpful’ when their spouses shared domestic responsibilities. Combining the two results, dissonance between expected and received support among coupled mothers in domestic tasks was revealed. Mothers often had to negotiate household responsibilities with their spouses to receive support due to the socially constructed expectations that assume domestic tasks to be mothers’ responsibilities. The ESM and interview results together confirmed that receiving practical support was more important for coupled mothers to feel supported in domestic tasks than perceived support. Domestic tasks were perceived to be stressful; however, in coping with everyday demands, coupled mothers felt supported if household responsibilities were shared.

Figure 7.4: Theme 3: Dissonance between expected and practical support in domestic tasks



ESM

Domestic tasks

All mothers

Felt LESS supported

MORE stressed

Single versus Coupled mothers

Coupled mothers LESS likely to feel supported than single mothers

Overall, domestic tasks are stressful and mothers felt less supported.

Despite having a spouse, coupled mothers felt less supported than single mothers when engaging in domestic tasks.

In the case of domestic tasks: There is a mismatch between support expectations and practical support received by couple mothers. Dissonance between expected and received support among coupled mothers resulted in them feeling less supported while engaging in this activity.

Interview

Socially constructed gender role: Domestic tasks is viewed as a predominant female role/responsibility

Example quotes

Female responsibility
He [husband] doesn't cook… I don't get to sit down…until past 8.00pm. Then…I do homework and then I do dinner on top.

Socially constructed role
Because my husband's very helpful but I think because we have talked about workloads [of domestic tasks]…I think mums do…get into the position where if…that someone's 'job,' then it's 'mum's job.'

Domestic tasks are expected to be the mothers' job due to socially constructed gender role, unless mothers negotiate household labour divisions with their partners. Husbands who share domestic responsibilities are considered 'helpful'.

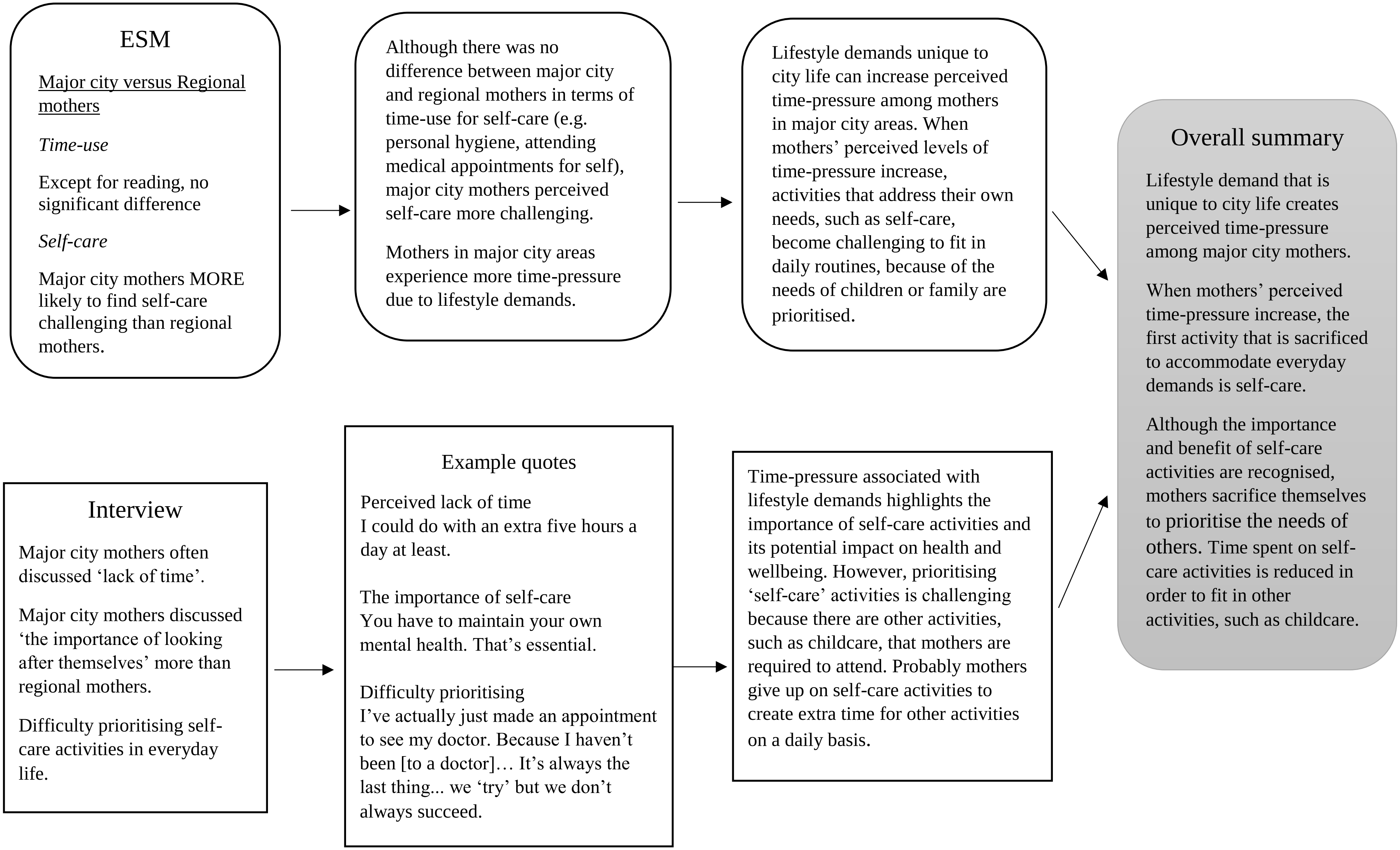
Overall summary

Domestic tasks are stressful and due to socially constructed expectations, coupled mothers assume the majority of the domestic responsibilities. For coupled mothers to feel supported in domestic tasks, received practical support counts more than perceived support. Sharing domestic responsibilities with spouse can support coupled mothers to cope with everyday stressful activities.

Theme 4: Self-care as a sacrificed activity

Mothers living in major city area, more so than mothers living in regional areas, often did not prioritise self-care due to time-pressures in meeting everyday demands. Although there were few differences between these two groups of mothers in terms of proportion of time spent on daily activities, the ESM findings showed that mothers from major city area were more likely to feel challenged when engaging in self-care activities than mothers from regional areas. Interestingly, during the interviews, ‘lack of time’ was often discussed by mothers living in major city areas. Lifestyle demands unique to city life created perceived time-pressure among mothers from major city area and the first activity sacrificed in family routines to accommodate the needs of others was self-care. Increased time-pressure highlighted the importance of self-care activities among mothers to maintain health and wellbeing; however, prioritising this activity was challenging for many mothers, due to prioritising their family’s needs over their own. Figure 7.5 presents the process in developing theme.

Figure 7.5: Theme 4 Self-care as sacrificed activity



ESM

Major city versus Regional mothers

Time-use

Except for reading, no significant difference

Self-care

Major city mothers MORE likely to find self-care challenging than regional mothers.

Although there was no difference between major city and regional mothers in terms of time-use for self-care (e.g. personal hygiene, attending medical appointments for self), major city mothers perceived self-care more challenging.

Mothers in major city areas experience more time-pressure due to lifestyle demands.

Lifestyle demands unique to city life can increase perceived time-pressure among mothers in major city areas. When mothers' perceived levels of time-pressure increase, activities that address their own needs, such as self-care, become challenging to fit in daily routines, because of the needs of children or family are prioritised.

Interview

Major city mothers often discussed 'lack of time'.

Major city mothers discussed 'the importance of looking after themselves' more than regional mothers.

Difficulty prioritising self-care activities in everyday life.

Example quotes

Perceived lack of time
I could do with an extra five hours a day at least.

The importance of self-care
You have to maintain your own mental health. That's essential.

Difficulty prioritising
I've actually just made an appointment to see my doctor. Because I haven't been [to a doctor]… It's always the last thing... we 'try' but we don't always succeed.

Time-pressure associated with lifestyle demands highlights the importance of self-care activities and its potential impact on health and wellbeing. However, prioritising 'self-care' activities is challenging because there are other activities, such as childcare, that mothers are required to attend. Probably mothers give up on self-care activities to create extra time for other activities on a daily basis.

Overall summary

Lifestyle demand that is unique to city life creates perceived time-pressure among major city mothers.

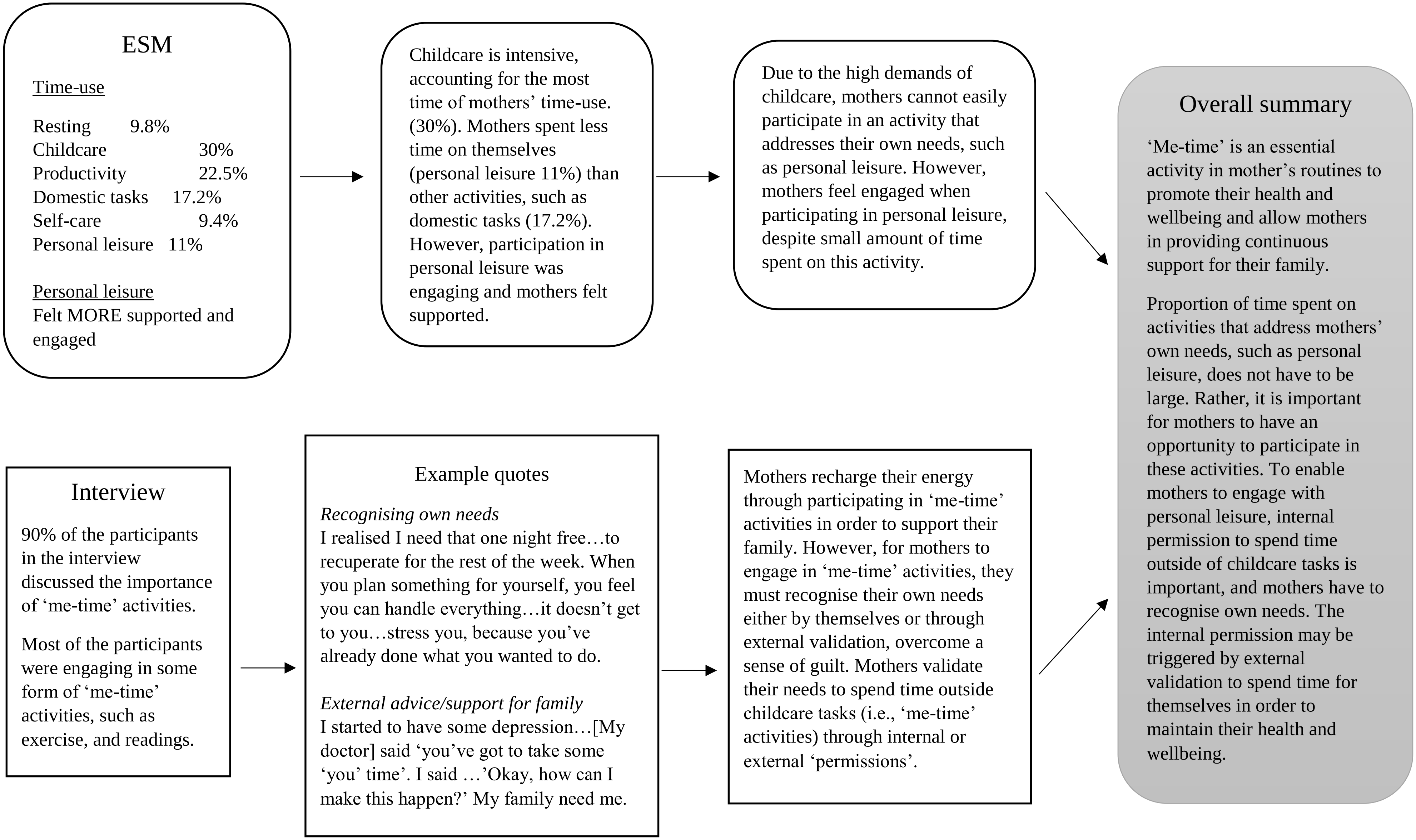
When mothers' perceived time-pressure increase, the first activity that is sacrificed to accommodate everyday demands is self-care.

Although the importance and benefit of self-care activities are recognised, mothers sacrifice themselves to prioritise the needs of others. Time spent on self-care activities is reduced in order to fit in other activities, such as childcare.

Theme 5: Internal and external permission to have ‘me-time’

This theme pertained to all mothers’ experiences, regardless of their household status or region of residence (Figure 7.6). Mothers discussed the importance of having ‘me-time’ during interviews, such as engaging in leisure activities to maintain their health and wellbeing. Mothers reported that they were motivated to participate in such activities to support their families. Mothers’ commitments to support family members, especially their children, were supported by ESM results, where these mothers spent most time in childcare (30 %). However, when engaging in personal leisure activities, mothers felt more supported and engaged. Although in the interview, the value of personal leisure activities were discussed, the ESM study found that the mothers spent less time in leisure activities (11%), compared to other activities, such as domestic tasks (17.2%). Collectively the findings indicate that the proportion of time spent on ‘me-time’ activities does not have to be long. Instead, having the opportunity to participate in these activities is more important for these mothers. Spending time on activities with a focus on having their own needs is not an easy decision for mothers to make, due to a sense of guilt. Mothers must allow themselves to have ‘me-time’, and this permission can be triggered externally. People, such as health professionals, can affirm the needs of mothers to spend time on themselves, providing external validation. Mothers are able to have ‘me-time’ with an internal permission that is supported through external validation.

Figure 7.6: Theme 5 Internal and external permission to have ‘me-time’



ESM

Time-use

Resting	9.8%
Childcare	30%
Productivity	22.5%
Domestic tasks	17.2%
Self-care	9.4%
Personal leisure	11%

Personal leisure

Felt MORE supported and engaged

Childcare is intensive, accounting for the most time of mothers’ time-use. (30%). Mothers spent less time on themselves (personal leisure 11%) than other activities, such as domestic tasks (17.2%). However, participation in personal leisure was engaging and mothers felt supported.

Due to the high demands of childcare, mothers cannot easily participate in an activity that addresses their own needs, such as personal leisure. However, mothers feel engaged when participating in personal leisure, despite small amount of time spent on this activity.

Interview

90% of the participants in the interview discussed the importance of ‘me-time’ activities.

Most of the participants were engaging in some form of ‘me-time’ activities, such as exercise, and readings.

Example quotes

Recognising own needs

I realised I need that one night free…to recuperate for the rest of the week. When you plan something for yourself, you feel you can handle everything…it doesn’t get to you…stress you, because you’ve already done what you wanted to do.

External advice/support for family

I started to have some depression…[My doctor] said ‘you’ve got to take some ‘you’ time’. I said …’Okay, how can I make this happen?’ My family need me.

Mothers recharge their energy through participating in ‘me-time’ activities in order to support their family. However, for mothers to engage in ‘me-time’ activities, they must recognise their own needs either by themselves or through external validation, overcome a sense of guilt. Mothers validate their needs to spend time outside childcare tasks (i.e., ‘me-time’ activities) through internal or external ‘permissions’.

Overall summary

‘Me-time’ is an essential activity in mother’s routines to promote their health and wellbeing and allow mothers in providing continuous support for their family.

Proportion of time spent on activities that address mothers’ own needs, such as personal leisure, does not have to be large. Rather, it is important for mothers to have an opportunity to participate in these activities. To enable mothers to engage with personal leisure, internal permission to spend time outside of childcare tasks is important, and mothers have to recognise own needs. The internal permission may be triggered by external validation to spend time for themselves in order to maintain their health and wellbeing.

Discussion

This convergent mixed method study aimed to understand the complexity of family routines and generate new ideas by investigating the experiences of mothers of children with ASD through the integration of the ESM and interview studies. Where appropriate, we considered the differences among these mothers based on their single versus coupled household status, as well as regional versus major city areas of residence to expand the current knowledge in the field of family routines. Unlike previous family routine studies (Bagatell, 2016; Marquenie et al., 2011), this study employed mixed methods to elucidate the complexity behind constructing family routines. By combining the ESM and interview results, the study generated in-depth understanding of the complexities these mothers experience and revealed the meanings underpinning in constructing family routines.

One of the main findings of this study was that family routines had a function of restoring or maintaining mothers' sense of internal control. Having a sense of control is an important element in maintaining parental wellbeing (Larson & Miller-Bishoff, 2014). This result suggests that the sense of 'regularity', provided through family routines, assisted these mothers to manage challenging behaviours of the child, while catering to the needs of their children, which, in turn, fostered their sense of control. In the past, parenting strategies to gain a sense of internal control often focused on direct behavioural management of the child (Schultz et al., 2011). However, in line with previous research (Lucyshyn et al., 2015), this study suggests that use of family routines can aid mothers in managing challenging behaviours of children with ASD. The results also extend to the potential benefits for mothers of children with ASD to restore or maintain a sense of control with childcare activities through the use of family routines. A lack of control has been found to be associated with reduced self-rated health and subjective wellbeing among mothers of typically developing children (Erlandsson & Eklund, 2004). Health professionals should, therefore, consider potential benefits of family routines for mothers of children with ASD, as these mothers are at risk of experiencing lower health-related quality of life than mothers of children with disability (Lee et al., 2009).

Subsequently, the finding raises a question on how best to support these mothers to construct functional family routines that facilitate their sense of control. Construction of family routines is a complex process due to multiple factors, such as parental health, children's disability, work, and health service provisions (Fiese et al., 2002; Larson & Miller-Bishoff, 2014). This complexity is attributed to a transactional nature of family routines, where the input from each family member influences one another and their environments (Sameroff, 2009; Sameroff & Mackenzie, 2003). Mothers are required to navigate through this complex transactions of parents, children and their environments to construct functional family routines. However, past research commonly focused on factors that are related to parents and children, in particular in the context of disability (Marquenie et al., 2011; Schaaf et al., 2011). Therefore, more focus should be given to environmental factors to identify an optimal way to support mothers in constructing family routines.

Another interesting finding was mothers' intrinsic motivation to engage in childcare. Mothers continuously engaged in this daily activity despite childcare being considered challenging. This highlights the dedication demonstrated by mothers of children with ASD to ensure optimal support for their children, as a sign of resilience. Perhaps mothers' resilience stems from the values and beliefs they hold for the childcare activities, which, in turn, provided a purpose for these mothers to continuously engage in these activities, regardless of having to deal with a multitude of challenges. Resilience relates to a construct of autonomous motivation in parenting; parents engage in parenting activities because they consider these activities as meaningful and interesting, regardless of the challenges they present (Jungert et al., 2015). How these mothers have developed or maintained autonomous motivation despite some of the common difficulties associated with raising a child with ASD, such as challenging behaviour, is unknown (Falk et al., 2014). However, autonomous parenting motivation in parents of typically developing children is positively associated with parental role satisfaction and competence, general life satisfaction and positive mood (Jungert et al., 2015). Given previous evidence suggests that greater levels of resilience is associated with better maternal wellbeing (Halstead, Ekas, Hastings, & Griffith, 2018), there is a need to further investigate parenting motivation that can increase our understanding of parental resiliency. Mothers continuously engage in the childcare because of their values and beliefs, and this may be a strength health professionals should recognise when working with mothers of children with ASD. Embracing mothers' strengths by recognising their contributions to the outcome of their children is an important consideration for practice of health professionals.

The current study found that mothers sacrificed their time in self-care activities to meet everyday demands. Mothers from major city areas in particular faced this challenge. This may be attributed to the perceived lifestyle difference between living in major city and regional and remote areas. In regional or remote areas, the lifestyle may be more 'relaxed', offering a better quality of life than living in major city areas (Halfacree, 2008). This lifestyle difference may have increased perceived time-pressure among mothers from major city areas. Another possible explanation is that mothers in major city areas actually experience time-pressure, due to the unique lifestyle, such as increased traffic congestion. Nevertheless, further exploration of the differences in perceived time-pressure among these mothers may provide a better insight into their everyday experiences.

Increased time-pressure due to high childcare demands is a common issue identified among mothers of children with a disability (Crowe & Michael, 2011). Previous studies suggest that when mothers experience time-pressure, they reduce their personal leisure activities to ‘create’ extra time (Brandon, 2007; Smith et al., 2010). Our findings present a different perspective to the previous knowledge by suggesting that in managing family routines, mothers adjust time allocation by reducing their self-care activities first, rather than personal leisure time. Perhaps time spent on self-care is an easy task to alter because it only involves mothers themselves. Unlike personal leisure time that may involve considering other people’s schedules, time spent on self-care could be an immediate solution for mothers to adjust in everyday routines. Although the cost of reduced personal leisure time has been discussed in the context of both parents of children with and without disabilities (Ekert-Jaffé & Grossbard, 2015; Murphy et al., 2007), the cost of reduced time spent on self-care among parents has not been the focus of the previous studies. Mothers of children with ASD face more mental health issues, such as increased stress levels, than mothers of children without ASD (Zablotsky, Anderson, et al., 2013). Therefore, future studies should consider the impact of reduced time in self-care activities on mothers’ stress levels among these mothers. Further, the finding has an important policy implication to provide better support for these mothers. Since 2013, Australia has started rolling out a new funding scheme called The Australian National Disability Insurance Scheme (NDIS). Although NDIS asserts that there is potential funded support for families of children with disability (National Disability Insurance Agency, n.d.), the use of the funding can be more flexible to address the needs of carers, including mothers, as well as that of children with disability.

The study found that ‘me-time’ activities are not about the proportion of time spent on these activities, but about having the opportunity. This finding may shed some light on previous research that reported ‘me-time’ activities act as a coping strategy for mothers of children with disability to deal with the everyday demands, even though it is not easy for mothers to participate in these activities due to time constraints (Larson & Miller-Bishoff, 2014). The findings suggest that mothers may receive benefits from having ‘me-time’, regardless of the proportion of time spent on these activities. In other words, so long as there is an opportunity for mothers to engage in ‘me-time’ activities, it may assist mothers in coping with everyday demands. Therefore, in promoting health and wellbeing of mothers of children with ASD, health professionals are encouraged to explore family routines to identify an opportunity for these mothers to incorporate ‘me-time’ activities.

Similar to previous research, the participants felt a sense of guilt in making time to address their own needs (Bourke-Taylor & Jane, 2018). This may be due to the sociocultural context where mothers are naturally expected to attend children’s needs (Khanlou, Mustafa, Vazquez, Davidson, & Yoshida, 2017) and thus mothers of children with disability, in particular, can be under a significant pressure to be a ‘good’ mother (Knight, 2013). This study found that although mothers can be intrinsically motivated to participate in ‘me-time’ activities, because of their values and beliefs to support their children and family, mothers may require validation from external agents, such as health professionals, to spend time on themselves. The benefit of receiving external validation has been discussed in a previous study that found mothers of children with disability received a sense of validation with their own feelings and needs through sharing their experiences with others (Bourke-Taylor & Jane, 2018). The result has an important practice implication for health professionals working with these mothers where health professionals can act as an external agent to validate the needs for mothers to participate in ‘me-time’ activities. This external validation combined with intrinsic motivation could assist mothers to overcome a sense of guilt in promoting their health and wellbeing.

Limitation

There are several limitations in this study. Firstly, the participants were only recruited from Western Australia. Therefore, caution should be taken to generalise the results to other population. Secondly, the potential issues of household labour division noted in this study warrants the needs to include spouses in future studies. Finally, for participants from regional areas, this study only recruited mothers from inner regional areas. Inclusion of mothers from outer regional and remote areas may have demonstrated more nuanced differences between mothers of regional areas and their counterparts.

Conclusions and Implications for practice and future research

The current study that explored the complexity of family routines among mothers of children with ASD has important implications for clinical practice, policy and future research. Although providing childcare can be challenging, family routines allow mothers to obtain or maintain a sense of control in parenting. Health professionals who work with these mothers should consider using family routines as a parenting strategy instead of directly managing children's behaviour, and that may, in turn, lead to better maternal health and wellbeing. Further, future research should consider a way to provide appropriate support for these mothers in constructing family routines. Given the complexity of family routines, not only parental and child factors but also environmental factors should be investigated. All mothers who participated in this study were motivated to provide the optimal support for their children and family, despite the challenges they experienced. Mothers demonstrated autonomous motivation as a sign of their resiliency. The contribution mothers make to the outcome of their children should be recognised by health professionals, adopting a strength-based approach, when working with these mothers. Contrary to previous studies, self-care activities were the first activities to be sacrificed by mothers when they experienced time-pressure. Mothers from major city areas seemed to have experienced this impact more acutely than their counterparts. Potential underlying factors for this difference can be explored to support mothers from major city areas. However, regardless of region of residence, mothers of children with ASD are more prone to experience health issues than mothers of children without ASD. Policies should be flexible in supporting these mothers to address their own needs. Adding to previous research, the study argues that having an opportunity to participate in ‘me-time’ activities is important for mothers’ health and wellbeing. Health professionals should discuss family routines with mothers of children with ASD to assist them scheduling ‘me-time’ while validating their needs to participate in these activities.

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Conflict of Interest

The authors confirm that there is no conflict of interest.

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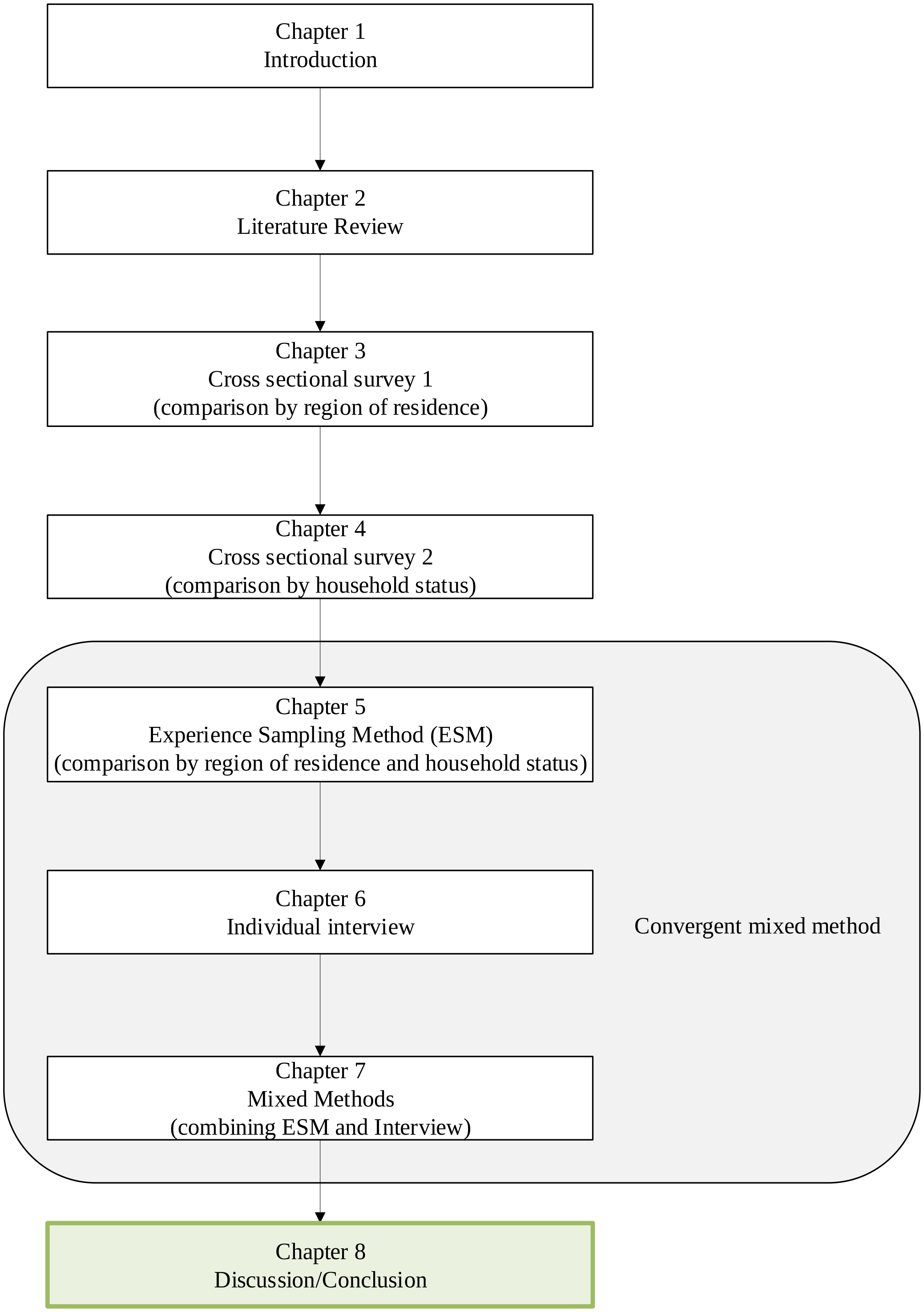
Chapter 8 Discussion/Conclusion



This chapter presents the findings of the thesis that are comprised of the five papers (Chapters 3 to 7). First, an overview of the thesis is presented, including the overall aim. Second, a brief summary of each paper is presented, and then the findings of the overall thesis are presented under three themes: 1) experiences of mothers of children with ASD regardless of household status and region of residence; 2) comparison between single and coupled mothers' experiences; and 3) comparison between mothers from regional areas and mothers from major city areas. Building on the findings, unique issues mothers of children with ASD experience in managing family routines are discussed and a theoretical framework is applied to depict these mothers' experiences. Lastly, implications for practice and research when working with mothers of children with ASD are presented.

Overview of the Thesis

The overall aim of the thesis was to examine the experiences of mothers of children with ASD in constructing family routines concerning aspects of their health and wellbeing, such as QoL, stress and coping strategies. The thesis investigated these mothers' experiences in relation to their health and wellbeing, such as quality of life (QoL), stress and coping strategies. The thesis endeavoured to fill the gap in the field of family routines that commonly focused on outcomes of children and the '*family as a whole*'. Most mothers assume responsibility to manage family routines more so than fathers (Hartley et al., 2014), therefore, their experiences should be of focus. The thesis also took a unique perspective by investigating the experiences of those often overlooked in research; single mothers and mothers from regional areas. The number of single mothers are expected to increase not only in Australia, but also globally due to change in family structure in modern society (Australian Bureau of Statistics, 2010; The Organisation for Economic Co-operation and Development [OECD], 2012). Despite this trend, limited research with this population has been conducted in the ASD context (Dyches et al., 2016). Similarly, mothers from regional areas have not been the focus in previous family routine research. Although major city areas hold two thirds of the population in Australia, accounting for 81% of the population growth between 2016 and 2017 (Australian Bureau of Statistics, 2018), the experiences of people from regional and remote areas should be considered as their experiences may be unique due to characteristics pertaining to a vast country like Australia, such as less accessible services (Baxter et al., 2011). Therefore, this thesis also attempted to compare the experiences of mothers of children with ASD by their household status (i.e., single versus coupled) and region of residence (i.e., regional and major city areas).

Summary of each study

Cross Sectional Survey 1 (Chapter 3)

To investigate the differences and similarities in everyday experiences between mothers from regional and remote areas (i.e., less densely populated areas) and those from major city areas (i.e., densely populated areas), a secondary analysis of existing population-based data was conducted to compare their family routines, service usage, and stress levels among families of children with ASD with a total of 476 participants from major city areas and 59 participants from regional areas. The findings revealed that compared with families living in more densely populated areas, families living in less densely populated areas: 1) had reduced employment hours, 2) travelled greater distance to access medical facilities, and 3) reported less severe stress levels than their counterparts. The results may have been attributed to a lack of flexible employment opportunities in less densely populated areas, which could limit those families' abilities in daily planning, and a scarcity of medical professionals employed in these areas, which could add extra strain to family routines to accommodate increased time in transit. The reason for the families living in these areas to have lower severe stress levels than their counterparts is unknown; however, the results suggested better accessibility to social supports may buffer stress levels in less densely populated areas. The study did not find any other significant differences between these two groups of families. However, the results were based on the analysis of custom survey that was originally designed to investigate the cost associated in raising a child with ASD (Horlin et al., 2014). Further, due to the design of the survey, the authors were unable to compare mothers' experiences based on their household status (i.e., single versus coupled mothers). Therefore, the results highlighted the importance of using different methods, such as using validated instruments to measure parental stress levels and including household status as a variable, to obtain a more detailed and accurate understanding of the experiences of mothers of children with ASD.

Cross-sectional Survey 2 (Chapter 4)

Using validated instruments, a cross sectional survey with 207 mothers of children with ASD was conducted and their experiences was compared by their household status (43 single mothers and 164 coupled mothers). Due to a lack of statistical power, comparing the experiences of these mothers by their region of residence was not possible (i.e., 11.1% outer regional [*n* = 23], 5.3% remote [*n* = 11], and 1.9 % very remote [*n* = 4] participants). Mothers' stress levels, QoL, coping styles and their time-use were compared using logistic regression analysis. The instruments used in this study included WHOQOL BREF (The WHOQOL Group, 1996), Brief COPE (Carver, 1997), APSI (Silva & Schalock, 2012), and a 24-hour time-use table. The study found the following results: 1) single mothers were more likely to experience lower environmental QoL than coupled mothers; 2) single mothers were more likely to use acceptance coping style before adjusting for total number of children, household income and employment status; and 3) there was no difference in time-use and stress levels by household status. The differences found between single and coupled mothers were somewhat limited; however, the findings indicated financial hardship and a lack of flexible employment opportunities that may be attributed to lower environmental QoL among single mothers. Albeit inconclusive, the findings implied that single mothers were carrying the same burden as coupled mothers by themselves. The findings highlighted the need to further compare the experiences of mothers of children with ASD by their household status, using different methods. The study employed a time-use table that may have allowed mothers to over or under estimate their time-use. The study identified the need to use a method that provides more comprehensive and accurate information of mothers' time-use, such as experience sampling method (ESM). ESM allows researchers to collect *in-the-moment* experiences of participants and may reduce recall bias (Hektner et al., 2007; Shiffman et al., 2008). ESM has not been used among mothers of children with ASD previously.

Experience Sampling Method (Chapter 5)

To obtain a more accurate understanding of mothers of children with ASD, ESM was employed to investigate in-the-moment experiences of mothers of children with ASD (i.e., time-use and related feelings). Mothers' experiences were compared by their household status (n = 20 single and 20 coupled mothers) and region of residence (n = 10 regional and 30 major city mothers). The results of Mann-Whitney U tests and multilevel analyses revealed: 1) regardless of household status or region of residence, all mothers spent most time in childcare and least time in self-care activities; 2) coupled mothers were more likely to feel supported overall; 3) coupled mothers were less likely to feel supported in domestic tasks; 4) mothers from major city areas were more likely to feel challenged in self-care activity, and 5) mothers from major city areas were more likely to feel supported in productivity. The results highlighted the importance of appropriate support that accommodates the needs of these mothers. Similar to the first study, the differences that were found between mothers from regional and major city areas may be attributed to flexible employment opportunities in major city area, as well as social support available in regional areas. Spouses are a valuable support for coupled mothers (Kuhaneck et al., 2010); however, the findings indicated a gap between mothers' expectations for their spouse in sharing household responsibilities and the levels or types of support they received. Building on the results of the first and second studies, the results of the ESM study indicated that regardless of household status and region of residence, the experiences of mothers of children with ASD were similar. There was no significant difference in time-use between these subgroups of mothers, and all mothers felt more challenged and stressed, and less in control and supported in childcare; however, mothers spent the most time in childcare, indicating their commitment to support their children. Although the study was unable to identify if direct or indirect childcare was consuming more time for mothers, previous research suggest that indirect childcare, such as dealing with service providers, can increase time-pressure among these mothers and reduce time available for themselves (Gevir et al., 2006; Green, 2007). Indeed, the study found that mothers spent the least amount of time in self-care activities. Mothers prioritised activities based on meanings attributed to each activity (Gevir et al., 2006). Therefore, the need to explore the meanings behind the experiences of mothers of children with ASD, using other approaches, such as the Interpretive Phenomenological Approach (IPA), was identified to supplement the findings of ESM and cross-sectional studies. IPA allows researchers to collect meaningful and important account of participants' experiences (Larkin et al., 2006; Smith et al., 2009). Therefore, IPA is helpful to explore the experiences of constructing family routines for mothers of children with ASD in a more in-depth manner.

Individual Interviews (Chapter 6)

A qualitative study with a purposive sample (*n* = 20) using IPA was used to explore meanings mothers of children with ASD find in constructing family routines. Mothers who completed the ESM study participated in the individual interviews and their experiences in managing family routines were explored in relation to their perceptions towards their health and wellbeing. Five themes emerged: 1) keeping on track keeping healthy; 2) my life is busy, because I do everything for everyone else; 3) keeping on track all the time is tiring or frustrating; 4) looking after my family by looking after myself; and 5) I am not perfect and it's OK. These five themes described the meaningful experiences of mothers when managing family routines in relation to their health and wellbeing. The study found many mothers assume the main responsibilities in managing family routines, which can be an onerous experience for mothers. However, mothers go above and beyond their capacities to provide the best care for their family and children. To cope with the daily demands, mothers adopted a perspective to allow themselves to be imperfect and accepted their own needs to have ‘me-time’ activities. The study depicted the paradox of these mothers’ experiences in balancing the demands to manage family routines and their needs to address own health and wellbeing. However, family routines are complex phenomena, involving multiple factors (Larson & Miller-Bishoff, 2014); therefore, the need to employ mixed methods to obtain more comprehensive pictures of the experiences of mothers in constructing family routines, still remained following the ESM and interview studies. A mixed method approach has not been widely used in the field of family routines (Crespo et al., 2013). This approach is particularly useful when investigating complex phenomena to enhance existing understanding and researchers interpretations (Collins et al., 2006; Teddlie & Tashakkori, 2003).

Mixed Method Study (Chapter 7)

To extend the results of the ESM (Chapter 5) and the interview studies (Chapter 6), a mixed method approach was applied. The mixed method study compared and contrasted the results of the two studies (i.e., Chapter 5 and 6) to form meta-inferences by enhancing the interpretations of the existing results (Collins et al., 2006; Teddlie & Tashakkori, 2009). Where possible, the differences and similarities between household status and region of residence were considered to interpret the two data sets. Five themes emerged through joint display. The first theme captured mother’s intrinsic motivation to participate in childcare activities, even though it was considered challenging. The first theme also described one function of family routines was to promote mothers’ sense of control in childcare. The second theme depicted two benefits mothers gained from work. First, mothers were able to obtain a sense of personal achievement, and second, work provided a respite from everyday responsibilities. The third theme only applied to coupled mothers, highlighting the dissonance between perceived and received support in domestic tasks. The fourth theme applied to mothers from major city areas more so than mothers from regional areas, describing the sacrifice mothers make in self-care activities when they experience time-pressures in constructing family routines. The last theme highlighted the importance of having ‘me-time’ activities for all mothers. The proportion of time spent on ‘me-time’ activities did not have to be long, instead just having the opportunity for ‘me-time’ activities were important for these mothers’ health and wellbeing. To overcome a sense of guilt in spending time on ‘me-time’ activities, external validation to support mothers’ participation in these activities was crucial.

Summary Findings of the Thesis

The thesis aimed to examine the experiences of mothers of children with ASD in constructing family routines concerning aspects of their health and wellbeing, such as QoL, stress levels and coping strategies. The thesis also endeavoured to explore the experiences of those overlooked in previous research (i.e., single mothers and mothers from regional areas).

Experiences of Mothers of Children with ASD Regardless of Household Status and Region of Residence

The findings demonstrate the arduous efforts mothers make to construct and manage family routines, which may be a sign of their resilience. The participants sacrificed their own needs, such as self-care, to address the needs of their children and family. However, many mothers in the thesis understood the significance of their role in managing family routines and they realised the need to take care of their health and wellbeing. Mothers addressed family members’ needs while incorporating their own needs, adding to the complexity in constructing family routines. Family routines are developed and maintained through reciprocal interactions between family members, while external factors, such as work, school, and health service provisions, are integrated (Boyce et al., 1983; Boyd et al., 2014; Fiese et al., 2002; Larson & Miller-Bishoff, 2014; Segal & Frank, 1998). The findings suggest that mothers navigate the complex transactions between themselves and children or other family members and between themselves and external factors in constructing family routines.

Although constructing family routines is an onerous task, mothers benefitted from the process, such as obtaining or maintaining a sense of control from a structured lifestyle that was established through family routines. Previous research suggests when mothers feel less in control, their perceived health status is likely to decline (Erlandsson & Eklund, 2004). The findings indicate that constructing family routines becomes the mechanism through which mothers obtain or maintain a sense of control, which, in turn, can be a coping strategy to manage their health and wellbeing, particularly when mothers experiences difficulties in balancing everyday demands (Erlandsson & Eklund, 2003).

Comparison between Single and Coupled Mothers' Experiences

The thesis did not find much difference between single and coupled mothers in constructing family routines. This finding was surprising, given spouses who can share everyday experiences are critical supports to cope with everyday demands among mothers of children with ASD (Higgins et al., 2005; Kuhaneck et al., 2010). The results of the thesis indicate that in investigating the experiences of mothers of children with ASD in managing family routines, their household status may not be crucial. The thesis found that both single and coupled mothers spent an equal amount of time in childcare and domestic tasks, supporting the previous finding that families of children with ASD commonly assume a traditional division of household tasks, that is, fathers to engage with paid employment, while mothers take household and childcare responsibilities (Hartley et al., 2014). It should be noted; however, the ESM data were collected between 7.30 am and 9 pm to minimise the disruption to the participants who were already experiencing time-pressure. The results may have been different if the ESM captured activities completed outside these hours.

The results of the thesis indicated that regardless of household status, the experiences of mothers are similar, unlike a previous study that suggested single mothers experience more challenges in managing daily routines (Larson & Miller-Bishoff, 2014). However, there are unique factors that pertain to single motherhood, including small informal support networks (Cairney et al., 2003) and financial hardship (Dyches et al., 2016; OECD2012). Therefore, the experiences of single mothers should be investigated further to develop the knowledge in the context of ASD.

Future research could consider using a new approach to the analysis of qualitative data to investigate the differences or similarities between single and coupled mothers. Advanced functions of computer assisted qualitative data analysis software, such as NVivo (QSR International Pty, 2015), allows researchers to use participants' characteristics in the analysis process, such as household status. This may be beneficial in analysing data with a specific view of comparing groups (Leech & Onwuegbuzie, 2011; Wiltshier, 2011). However, it should be noted that these functions have not been often used in qualitative analysis (Leech & Onwuegbuzie, 2011). An important focus of qualitative analysis is to obtain meanings people ascribed to their experiences using their perspectives against their context (Liamputtong, 2011). Use of advanced functions in a computer assisted qualitative data analysis software may result in loss of context, because researchers may become *'distant'* to the words of their participants (Serry & Liamputtong, 2011). Hence, caution should be taken before employing such a new analytical approach.

Comparison between Mothers from Regional and Major City Areas

The thesis did not find many significant differences between mothers from regional areas and mothers from major city areas in constructing family routines. The results may be attributed to similarity in service provisions. Travelling long distance to access appropriate therapy and medical services is one of the main issues that parents of children with disability who live in regional and remote areas experience (Carbone et al., 2010; Wacker et al., 2013). In this thesis, the region of residence was categorised using the Australian Statistical Geography Standards (ASGS) remote structure that are classified into five remoteness areas (RAs) (Australian Bureau of Statistics, 2013b). RAs are categorised based on the distance to the nearest service centres (Australian Bureau of Statistics, 2013b). Although simply comparing the results with previous studies is problematic due to the difference in definition of region of residence, the results may suggest that the disparity in service provisions between major city and regional areas have been reduced, at least in Western Australia

(WA). Indeed, the WA government has invested half billion dollar to improve access to health care services for regional residents since 2011 (WA Country Health Service, 2016).

The results may have been different if more participants from remote and very remote areas were recruited. Recruitment of participants of studies within the thesis were promoted through regional autism-related organisations to reach potential participants. However, not enough participants were recruited from remote and very remote areas to accurately understand their experiences. Of those who participated in the second cross-sectional survey (N = 207), 11.1% of the participants were from outer regional [n = 23], 5.3% were from remote [n = 11], and only 1.9 % were from very remote [n = 4] areas. Future studies, therefore, should consider employing more targeted recruitment strategies, such as hosting outreach events in the remote communities (Fahrenwald, Wey, Martin, & Specker, 2013), to increase the number of participants from those areas.

Some of the differences found may be attributed to lifestyle, where major cities operate at a faster pace that may increases stress levels, and regional and remote areas may possibly have more supportive communities than major city areas (Costello, 2007; Valentine, 1997). The thesis found that mothers from major city areas experienced more difficulty in engaging in self-care activities. The finding is similar to a previous study that found a lack of '*me-time'* among caregivers who are from major city areas (Bouldin et al., 2018). An earlier study found that regional and remote caregivers who have limited access to services appear to be more proactive in solving problems (O'Connell, Germaine, Burton, Stewart, & Morgan, 2013). Regional and remote mothers may be more proactive in seeking support in their communities when they encounter challenging situations. However, identifying the potential problem-solving mechanisms that worked for these mothers was beyond the scope of this thesis. Nonetheless, to increase the knowledge that inform policies and local service delivery in regional and remote areas, future study should recruit more participants from outside major city areas, with a particular focus on remote and very remote areas.

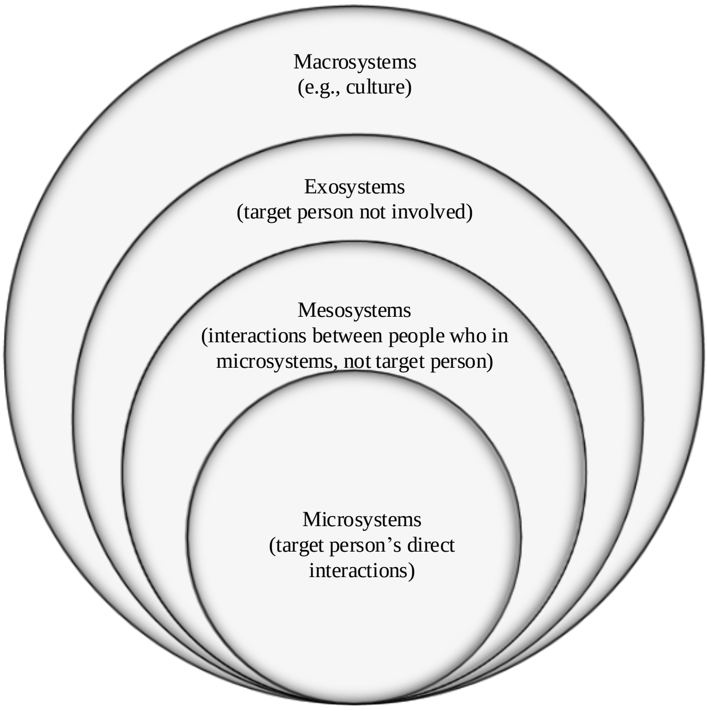
Contribution of the Thesis to the Field of Family Routines

Complexity in Family Routines and its Demands on Mothers

Regardless of household status and region of residence, this thesis found that mothers of children with ASD experience challenges in constructing family routines due to its complexity. The transactional model (Sameroff, 2009) is useful to depict the complexity involved in constructing family routines against children's development. Children and their social context, such as parents, influence each other through the transactions they engage in and both are active participants in family routines (Fogel, 2009; Sameroff, 2010; Sameroff & Fiese, 2000; Sameroff & Mackenzie, 2003). Likewise, family systems theory considers multidirectional relationships between family members or between family members and their environments (Cox & Paley, 1997; Fiese et al., 2000). Although both the transactional model and family systems theory consider contexts and their influence on children or family members and other environments (Fiese et al., 2000; Sameroff, 2009), neither of the theoretical frameworks systematically describes the intricacies of transactions that occur in multiple contexts. The thesis found that in constructing family routines, mothers navigate the complex transactions between themselves and children or family and between themselves and external contexts. Therefore, the ecological systems theory (EST) will be used to illustrate the cumulative impact that different contexts have on constructing family routines.

To depict the complexity mothers are required to navigate in constructing family routines more accurately, the thesis adapted the EST (Bronfenbrenner, 1979). Commonly, the EST is explained as a 'nested' structure of four systems to demonstrate the interactions between the target person and his or her environment: 1) microsystem, 2) mesosystem, 3) exosystem, and 4) macrosystem (Figure 8.1) (Bronfenbrenner, 1979).

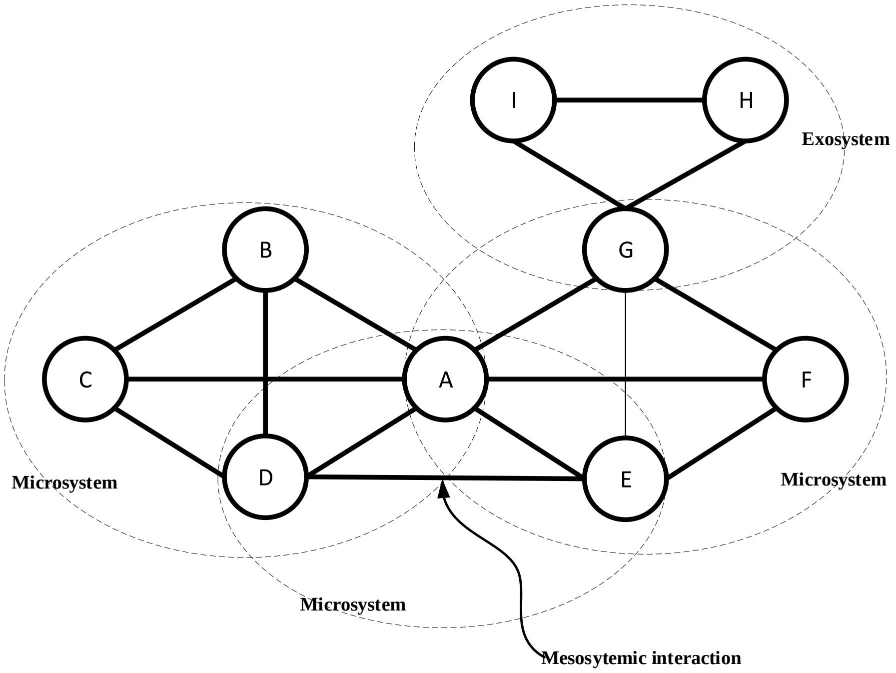
Figure 8.1: Bronfenbrenner's Ecological system theory. Adapted from *The Ecology of Human Development: Experiments by Nature and Design* by U. Bronfenbrenner, 1979, Cambridge: Harvard University Press. 1979 by U. Bronfenbrenner.



The micro system is where the target person interacts with other people directly, the target person holds roles, and is directly involved in interactions (Bronfenbrenner, 1979). Mesosystems are where two people from the microsystem, not the target person, interact (Bronfenbrenner, 1979, 1986). Exosystems include settings that the target person is not directly involved with, but the target person is affected if any changes in this system occurs. The macrosystems are comprised of broad contextual factors that are related to the target person, such as cultural, political and economic systems (Bronfenbrenner, 1979, 1986). Bronfenbrenner (1986) later, added a chronosystem that explains changes or continuity across the lifespan. This system was created to demonstrate the cumulative effects of changes to the target person's life (Bronfenbrenner, 1986).

Building on the work of Bronfenbrenner (1979), Neal and Neal (2013) proposed that the EST should be considered as a networked structure (Figure 8.2). The main difference between Bronfenbrenner (1979) and Neal and Neal (2013) is the definition of a 'setting' in which each system is considered to be embedded within or arise from the system.

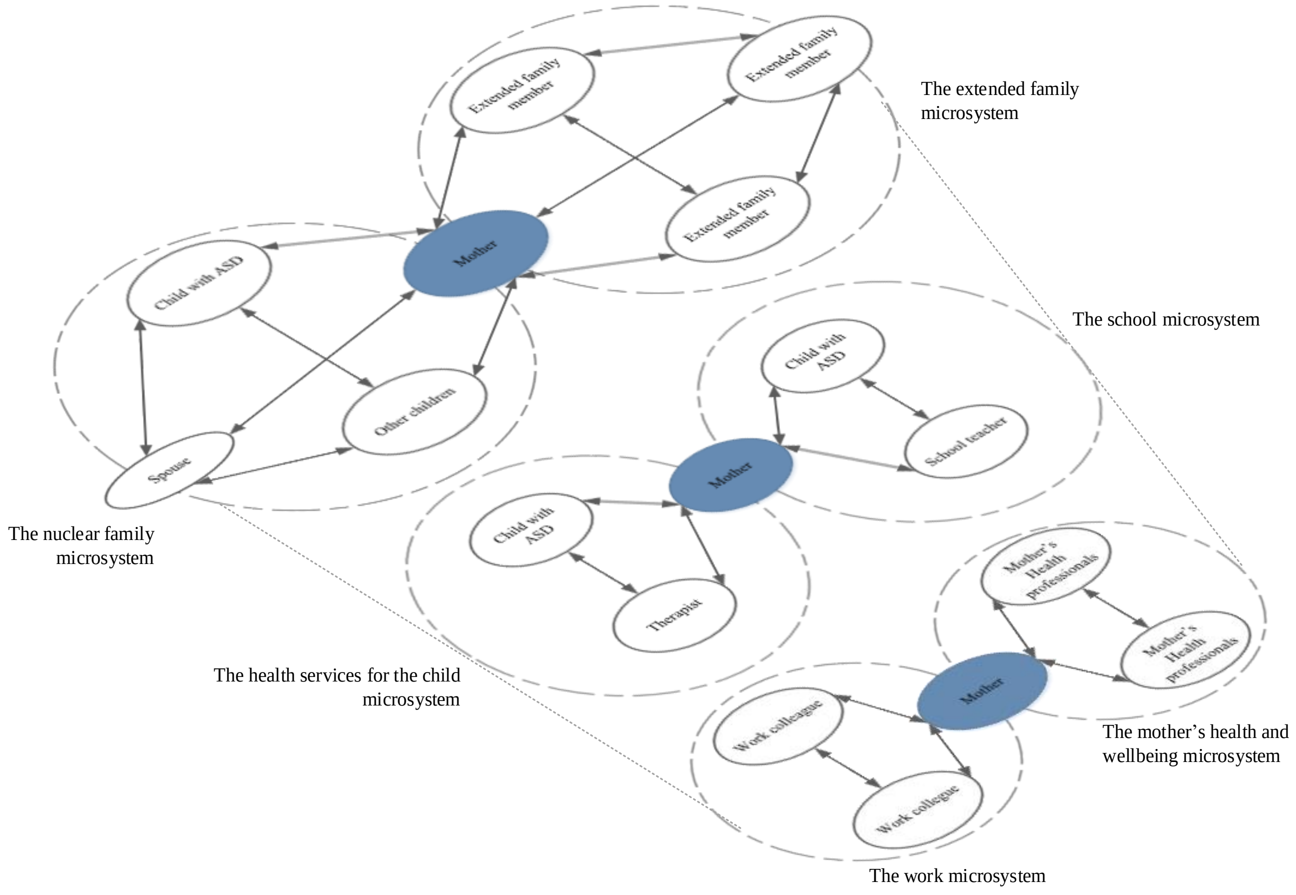
Figure 8.2: Networked model of ecological systems. Reprinted from "Nested or networked? Future directions for ecological systems theory", by J.W. Neal and Z.P. Neal, 2013, *Social Development, 22*, 728. 2013 by "J.W. Neal and Z.P. Neal".



Bronfenbrenner (1979) considered that a setting is where individuals interact with each other. However, Neal and Neal (2013) contended that a setting is "…a set of people engaged in social interaction, which necessarily occurs in, and is likely affected by the features of, a place" (p. 727). Through focusing on the interactions between people, Neal and Neal (2013) argued that the EST is a networked system because each system is connected directly or indirectly through social interactions of people involved in each system (Neal & Neal, 2013).

The thesis adapted the EST that is proposed by Neal and Neal (2013) as the findings suggest that mothers of children with ASD are required to deal with complex transactions of people and external factors to construct family routines. Figure 8.3 shows a complex transaction that represents the process of constructing family routines. A mother is in the middle of this transaction, which portrays her major role in constructing family routines. Each black line with arrows demonstrates interactions and dotted lines delineate each system.

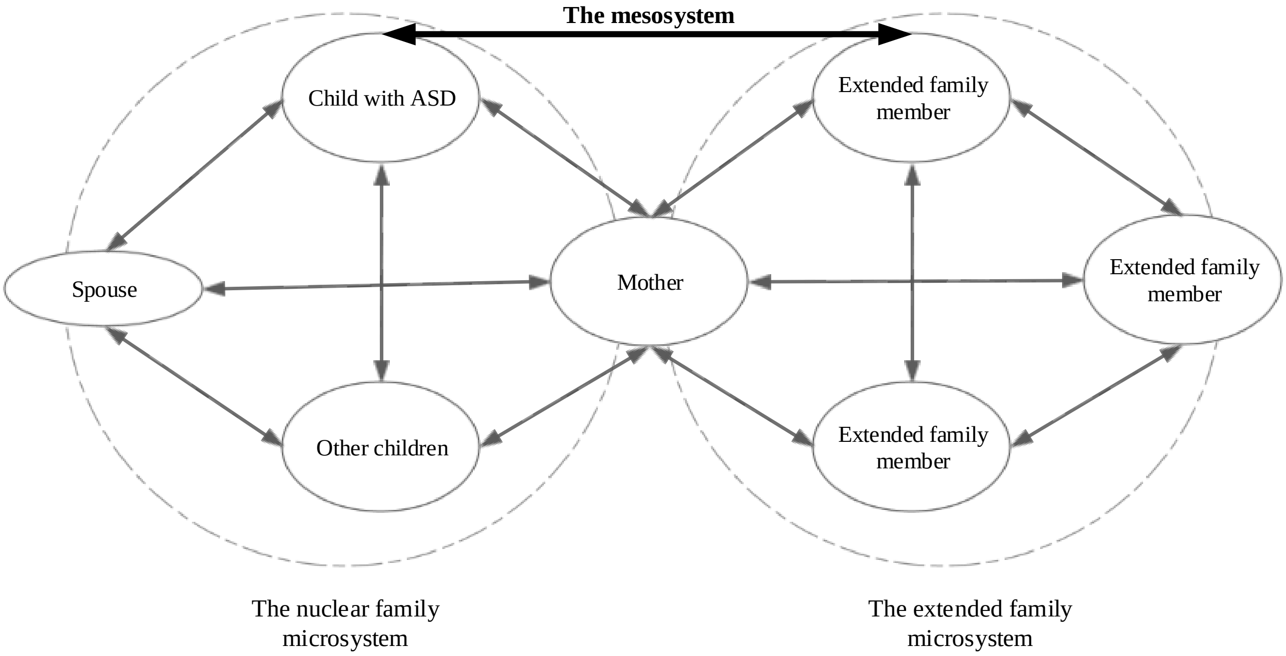
Figure 8.3: Complexity of family routines



The figure exemplifies 6 microsystems, in 3 layers due to the complexity of the transactions that mothers are involved in: 1) the nuclear family microsystem, 2) the extended family microsystem, 3) the school microsystem, 4) the health services for the child microsystem, 5) the work microsystem, and 6) the mother’s health and wellbeing microsystem.

Through transactions mothers have with others in each of these six microsystems, activities that are integrated into family routines emerge. For example, through transactions mothers have with their children, childcare activities emerge (i.e., the nuclear family microsystem), but childcare activities also arise through transactions mothers have with a child’s therapist (i.e., the health services for the child microsystem). Previous research indicated that factors, such as the nature of the disability of the child and parental stress levels, need to be considered when constructing family routines (Evans & Rodger, 2008; Larson & Miller-Bishoff, 2014). The thesis found maternal factors, such as mother's values and beliefs, personal characteristics (e.g., followed a structured lifestyle prior to having a child with ASD), and their coping styles, are important in constructing family routines. These identified factors may alter the way transactions occur in each system. For example, children with ASD commonly demonstrate challenging and/or restricted and repetitive behaviours (Harrop, McBee, & Boyd, 2016; Matson & Sipes, 2010) and mothers' coping styles are, in turn, influenced by challenging behaviour of children (Lai & Oei, 2014). However, to construct family routines, mothers need to deal with their children and their challenging behaviour for childcare activities to occur. A mesosystem is demonstrated through the transactions between the child with ASD and an extended family member (Figure 8.4).

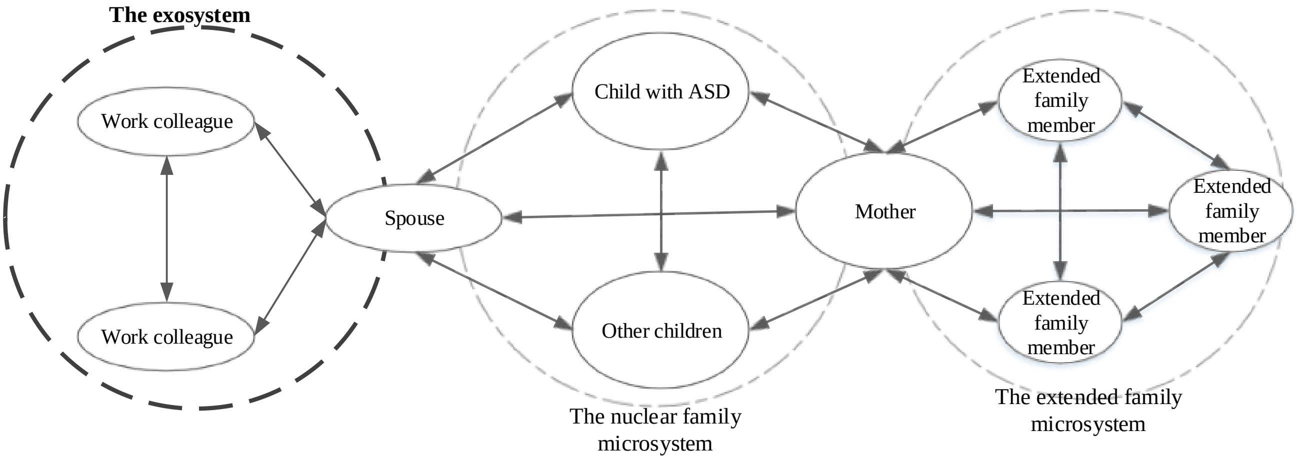
Figure 8.4: Complexity of family routines mesosystem



Support from extended family, such as grandparents, can contribute to reduce parental stress levels (Kahana et al., 2015). This mesosystem interaction may support mothers to integrate challenging activities that need to be included in the family routines, such as mother's personal self-care, by off-setting their childcare responsibilities. An exosystem demonstrated in Figure 8.5 comprises '*spouse* –

work colleague – work colleague' transactions. Increased demand for a spouse to work, through exsosystem transactions, can indirectly influence mothers by reducing the amount of support a spouse is able to offer with household responsibilities.

Figure 8.5: Complexity of family routines exosystem



Neal and Neal (2013) explained that while macrosystems and chronosystems do no arise in a setting, these two systems influence "…social interactions that define the setting" (p.729). In the thesis, household status and region of residence are the main macrosystems concerned. The results suggest that closer community networks that may exist in regional areas support mothers of children with ASD to address their own needs, such as engaging in self-care activities. This situation can be interpreted as an example of the influence that region of residence (i.e., macrosystem) has on mothers' social interactions in the microsystems (e.g., mothers in regional areas interact with community members more than their counterparts). Likewise, social expectations for females to assume childcare and domestic task responsibilities can influence the interactions mothers have with their spouses (i.e., influence of household status).

Previous research indicate that role of mothers and their daily time-use change as children grow older (Crowe & Michael, 2011; Francis-Connolly, 1998). These changes demonstrate how the chronosystem alter social interactions in each system. For example, mothers of adolescents with disabilities spend less time in childcare activities than mothers of young children with disability (Crowe & Florez, 2006; Crowe & Michael, 2011). Although each system (i.e., micro, meso, exso, macro, and chrono system) is shown separately in different figures, it should be noted that transactions involved in all systems occur repeatedly and continuously, which makes construction of family routines a complex process (Boyce et al., 1983; Sameroff & Fiese, 2000).

Mothers' role in constructing family routines may be analogous to the role of an air traffic controller. As a controller, mothers must communicate with every airplane (e.g., transactions with the child with ASD, spouse, therapists, and school teachers) to ensure the process of landing or taking off (i.e., activities) occur in a coordinated manner without any issues. Mothers' attempt to guide airplanes may be influenced by other factors, such as conditions of runways, weather, and visibility (i.e., exo, macro and chronosystem). The goal of the controller (i.e., mothers) is to ensure safe and efficient operations of the airport (i.e., functional family routines that support health and wellbeing of family). Although some families share the role of the controller between mothers and their spouse, generally, mothers are the ones who orchestrate activities and people in family life (Larson, 2000b).

The thesis found activities that support mothers' own needs, such as 'me-time' or self-care, are difficult to integrate into family routines. Mothers (i.e., air traffic controllers) must allow her own airplanes to take-off or land (i.e., activities) among all other planes (i.e., children or other family members). However, the results indicate that mothers sacrifice their own needs and prioritise the needs of others in constructing family routines. Perhaps it is an easier option for mothers to keep their own airplane from taking off (i.e., activities that address their own needs), while giving preference to other planes to take-off or land to ensure safe operations at the airport (i.e., family routines). Previous research found that family routines should be flexible in accommodating the needs of the child with ASD (Pruitt et al., 2016). The current thesis more specifically identified that mothers are the ones who need to be flexible in constructing family routines. Although constructing family routines can be burdensome for mothers (Larson & Miller-Bishoff, 2014), the thesis found that mothers demonstrated a sign of resilience by continuously managing family routines that are complex in nature.

Implications for Health Professionals

The findings that mothers play an important role in constructing family routines and the sacrifices they make in the process of construction pose a question about the role health professionals, such as occupational therapists, play in the complex transactions. As Figure 8.3 depicts, health professionals are part of the process in constructing family routines. For example, health professionals are part of the multiple transactions that mothers engage in for childcare activities (i.e., the nuclear family, the health services for the child and the school microsystem). Importantly, a transaction is about a whole relationship of people and their environment, rather than duality (Dewey & Bentley, 1949). This ‘wholeness’ means that childcare activities arise from joint actions of mothers and health professionals, rather than an input from one entity (e.g., mothers or health professionals) (Dickie, Cutchin, & Humphry, 2006). In other words, both mothers and health professionals are essential for effective childcare activities to occur.

Traditionally, in the area of family routines, ‘mealtime’ or ‘bedtime’ routines that occur within individual families have received much focus, suggesting family routines are more likely to occur within an individual family environment (Ausderau & Juarez, 2013; Bagatell, 2016; Evans & Rodger, 2008; Marquenie et al., 2011; Rodger & Umaibalan, 2011). Interventions that directly address family routines, such as the four R’s of routine interventions (i.e., remediation, redefinition, realignment, and re-education) (Fiese, 2007; Sameroff & Fiese, 2000), also consider changes with family members within an individual family context. Accordingly, external environments, such as health services, are seen as separate to family routines.

The separation between individual families and their environments may be attributed to the family systems theory that considers individual family exists in their own entity while acknowledging communication required with *outside* of its system (i.e., receive and send inputs to and from outside individual family) (Minuchin, 1988). The emphasis of the family systems theory is ‘wholeness’ in a family, and this wholeness only extends to individual family members, not external environments (Nichols & Schwarts, 2008). Therefore, when the family systems theory is applied, family routines are considered to occur only within a family system. The thesis, however, offers a new perspective that family routines occur in a transaction between individual families and their external environments as well as within individual families. External environments, such as health services, are not outside of family routines, but they form part of the process in constructing family routines. Health professionals should, therefore, more carefully consider possible influences they can have on the process of constructing family routines when working with mothers of children with ASD.

Services, such as occupational therapy, intend to support parents as well as children; however, rigid service structures do not accommodate the needs of families of children with ASD (Galpin et al., 2018; Hodgetts et al., 2014). Families of children with ASD use multiple services to assist their children to learn social skills, promote development, and reduce maladaptive behaviours (Carbone et al., 2010; McCann et al., 2012; Myers & Johnson, 2007). Working with multiple health and therapy services to ensure optimal support for their children means mothers are expected to create extra time to coordinate all services (Bourke-Taylor et al., 2010; Hodgetts et al., 2014; Hodgetts et al., 2013). In addition to the coordination, mothers are commonly expected to hold extra responsibility to conduct home therapy interventions to maximise the benefits for their children (Hodgetts et al., 2014). Although many service providers claim that they employ family-centred-practice, current modes of services delivery are often designed around the needs of children, rather than the needs of the entire family (Dunst, 2002; Hodgetts et al., 2014). Therefore, mothers are required to be flexible and sacrifice their own needs to adjust family life in accommodating service structures (Hodgetts et al., 2014). Family-centred approaches that address the needs of individual families and parents who interact with service providers should be adopted more widely (Galpin et al., 2018).

Engaging in dialogue with mothers who assume the main responsibility in constructing family routines will assist health professionals in developing interventions that suit the needs of individual families, which may, in turn, promote family-centred-practice (Dodd, Saggers, & Wildy, 2009). A family is a complex system that comprises unique structural features (e.g., composition), psychobiological characteristics (e.g., health), and historical and sociocultural elements (Broderick, 1993). Family complexity is not commonly considered by health professionals in designing children’s interventions (Dodd et al., 2009); however, due consideration of family routines that reflect values and goals of each family might be a way to address this complexity (Bernheimer & Weisner, 2007).

Parental health and wellbeing, in particular their mental health, should be addressed by health professionals, as parental mental health may affect the overall family system (Jellett, Wood, Giallo, & Seymour, 2015). The thesis found that many mothers consciously engaged in activities to address their own needs, such as ‘me-time’, for maintaining their health and wellbeing; however, these activities were found to be difficult for mothers to prioritise within family routines.

Mothers of children with ASD have been found to experience poorer physical and mental health and lower QoL than mothers of children with other developmental disabilities or typically developing children and the general population (Bourke-Taylor et al., 2012; Vasilopoulou & Nisbet, 2016; Zablotsky, Anderson, et al., 2013). Supporting parents and their mental health will assist in achieving therapy outcomes for children with disability (Hastings, 2002). This link between parental health and children’s outcomes may be explained by family systems theory that considers bidirectional effects between family members (Bowen, 1966; Fiese et al., 2000; Morgan, 1988). Individual family members influence one another through transactions that occur within a family

(Cox & Paley, 1997; Fiese et al., 2000). Therefore, therapists and service providers need to support mothers of children with ASD by understanding their unique needs (Kuhaneck et al., 2010).

Previously proposed practice guidelines to support health and wellbeing of carers of children with ASD discussed the importance for parents to have appropriate social support, coping strategies (e.g., problem solving), stress management, and accurate information about ASD (Catalano, Holloway, & Mpofu, 2018). Although previous research suggest that services should support mothers to engage in health promoting activities (Bourke-Taylor et al., 2012), addressing parental needs in current services models that solely focus on children can be challenging. However, the health and wellbeing of mothers who are key in constructing family routines should be addressed. The thesis proposes that by combining some of the microsystems (see Figure 3), the complexity mothers must navigate in constructing family routines may be reduced, which could, in turn, create an opportunity to address their health and wellbeing. For example, health professionals can work with mothers to address their health issues while attending children's health or therapy services (i.e., combining the childcare and self-care microsystems). Previous research found that successful therapy interventions for children and adolescents with disabilities, including ASD, that support family health and well-being need to be integrated with family routines (Bagatell, 2016; Bernheimer & Weisner, 2007). Similarly, to promote mothers' health and wellbeing, the fit between family routines and mothers' health promotion activities should be considered by health professionals concurrently when working with mothers of children with ASD.

Conclusion

The aim of the thesis was to examine the experiences of mothers of children with ASD in constructing family routines concerning aspects of their health and wellbeing, such as QoL, stress and coping strategies. The thesis compared and contrasted the experiences of these mothers by their household status and region of residence to fill a gap in the field of family routines. The thesis found that regardless of household status and region of residence, the experiences of mothers of children with ASD were challenging. In line with previous research (Bagatell, 2016; Larson, 2006), mothers were found to be crucial in constructing family routines. Mothers sacrificed their own needs, such as self-care, to address the needs of family members. Meeting the high demands of constructing family routines may influence the health and wellbeing of these mothers.

Although constructing family routines is arduous, the structure generated through family routines provided benefits for mothers of children with ASD, by allowing them to obtain or maintain a sense of internal control. Family routines may, therefore, act as a coping strategy among these mothers. Despite the daily challenges encountered, mothers were motivated to continuously construct family routines to support their children and family, demonstrating their resilience. Mothers' commitments to support their children and family underpinned their motivation to participate in '*me-time'* activities that promote their health and wellbeing. The health and wellbeing of mothers, who are key in constructing family routines, should be supported by health professionals. The findings indicated that having an opportunity to participate in these activities was important among mothers. Therefore health professionals should consider the fit between family routines and mothers' health promoting activities.

The differences found between single and coupled mothers, as well as mothers from regional areas and major city areas were somewhat limited. Unlike previous study (Larson & Miller-Bishoff, 2014), the results do not support the notion that single mothers experiences more challenges in managing family routines. Limited differences found between regional and major city mothers may be a reflection of similarity in service provisions in these two areas. Given access to services is one of the major issues for regional and remote areas, this finding is positive. It should be noted, however, that the results may have been different if more participants from remote and very remote areas were included in studies. Nonetheless, the thesis contributes to increase the current understanding of these mothers who have been overlooked in previous research.

The thesis depicted the complexities mothers must navigate in constructing family routines, using the five systems (i.e., micro, meso, exo, macro and chronosystems) from the EST (Bronfenbrenner, 1979; Neal & Neal, 2013). The thesis identified six microsystems (i.e., nuclear family, extended family, health services for the child, school, work and mother's health and wellbeing microsystems) that mothers are involved in. In each of these six microsystems, activities that comprise family routines occur through transactions that mothers have with family members as well as outside their families. Mothers are required to navigate those transactions in a coordinated manner to construct functional family routines, while exo, macro and chronosystems influence mothers' abilities to transact with family members as well as external environments.

The thesis offers a new perspective of family routines. Structures considered to be external environments to the family, such as health services, have been traditionally considered as factors outside of family routines. However, the findings indicate external environments are part of the complex transactions that occur in constructing family routines. For example, childcare activities that form part of family routines arise through various transactions, including between mothers and health professionals (i.e., an outside factor). Unless both sides participate in the transactions, the activity that comprises family routines may not be as functional or efficient. The thesis, therefore, argues that family routines entail external environments, in addition to individual families, which is in contrast to the previous research that often considered family routines within the context of individual families (Marquenie et al., 2011; Rodger & Umaibalan, 2011). External environments, including health professionals, are involved in the process of constructing family routines. Therefore, health professionals need to carefully consider the role they play in constructing family routines when working with mothers of children with ASD.

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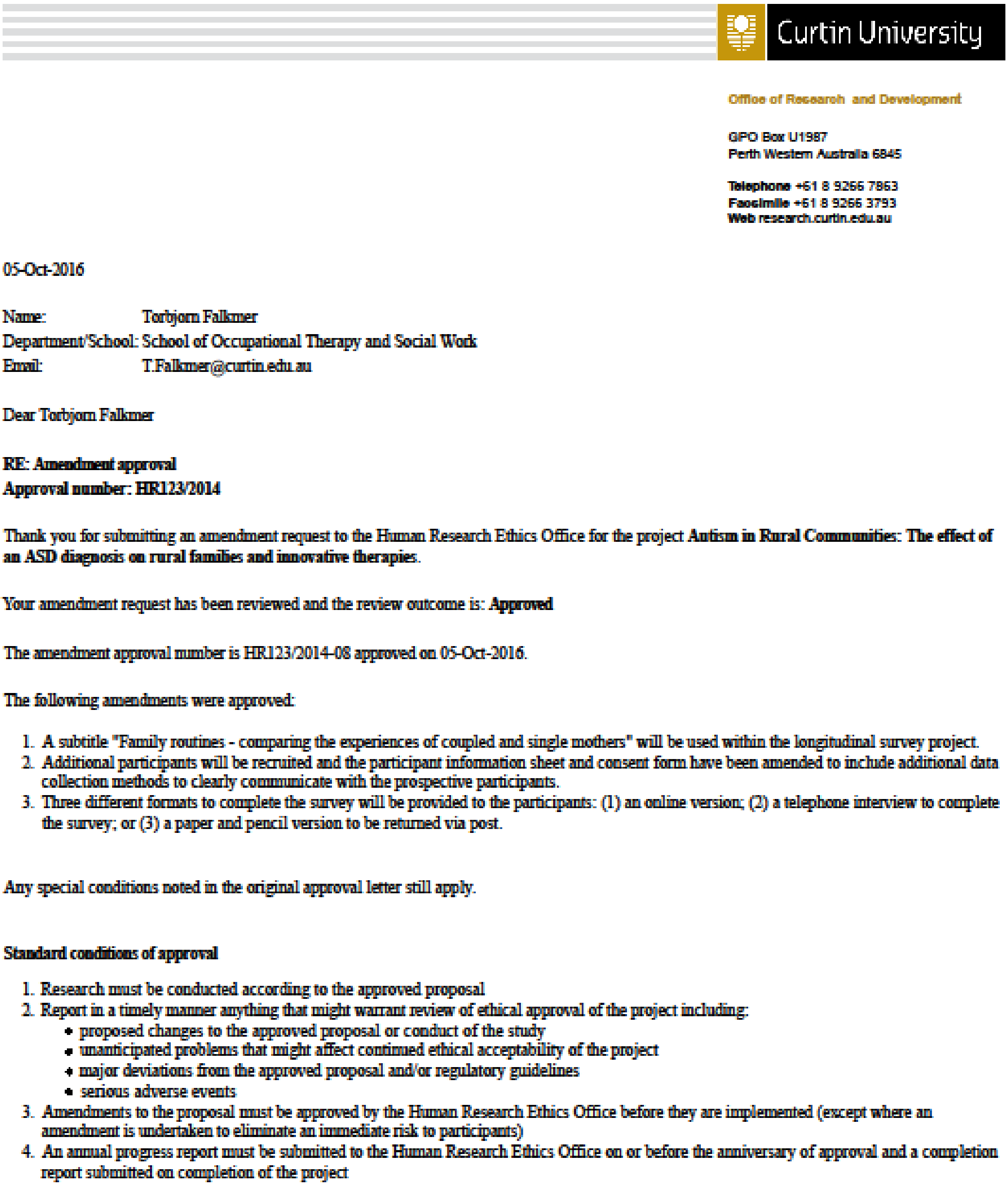
Copyright Statement

Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear form any copyright owner who has been omitted or incorrectly acknowledged.

Signature

Date: 25.01.2019

Appendix A: Human Research Ethics Committee approval



Curtin University

Office of Research and Development

GPO Box U1987
Perth Western Australia 6845

Telephone +61 8 9266 7863
Facsimile +61 8 9266 3793
Web research.curtin.edu.au

05-Oct-2016

Name: Torbjorn Falkmer
Department/School: School of Occupational Therapy and Social Work
Email: T.Falkmer@curtin.edu.au

Dear Torbjorn Falkmer

RE: Amendment approval
Approval number: HR123/2014

Thank you for submitting an amendment request to the Human Research Ethics Office for the project **Autism in Rural Communities: The effect of an ASD diagnosis on rural families and innovative therapies**.

Your amendment request has been reviewed and the review outcome is: **Approved**

The amendment approval number is HR123/2014-08 approved on 05-Oct-2016.

The following amendments were approved:

1. A subtitle "Family routines - comparing the experiences of coupled and single mothers" will be used within the longitudinal survey project.
2. Additional participants will be recruited and the participant information sheet and consent form have been amended to include additional data collection methods to clearly communicate with the prospective participants.
3. Three different formats to complete the survey will be provided to the participants: (1) an online version; (2) a telephone interview to complete the survey; or (3) a paper and pencil version to be returned via post.

Any special conditions noted in the original approval letter still apply.

Standard conditions of approval

1. Research must be conducted according to the approved proposal
2. Report in a timely manner anything that might warrant review of ethical approval of the project including:
    - proposed changes to the approved proposal or conduct of the study
    - unanticipated problems that might affect continued ethical acceptability of the project
    - major deviations from the approved proposal and/or regulatory guidelines
    - serious adverse events
3. Amendments to the proposal must be approved by the Human Research Ethics Office before they are implemented (except where an amendment is undertaken to eliminate an immediate risk to participants)
4. An annual progress report must be submitted to the Human Research Ethics Office on or before the anniversary of approval and a completion report submitted on completion of the project

Appendix B: Participant information and consent

B 1: Chapter 4

Autism in Western Australia:
Surveying the experience of families of children with Autism Spectrum Disorders (ASD)

PARTICIPANT INFORMATION SHEET (Participant copy)

Thank you for participating in this survey. Your participation is important in supporting our effort to improve diagnostic procedures and services for families with a child with ASD through research.

Why is this survey important?

The survey is particularly timely with the introduction of the new National Disability Insurance Scheme (NDIS). Information collected from this survey will inform future services and policy.

What is the study about?

The Curtin Autism Research Group (CARG), led by Professor Torbjorn Falkmer, in collaboration with the Disability Services Commission of WA are conducting a survey to learn about the experience of families with a 2-18 year old child/young person with ASD. This study is supported by the South West Autism Network (SWAN) and funded by the Val Lishman Health Research Foundation (VLHRF).

Who can participate in the study?

If you are a parent or a primary caregiver of a 2-18 year old child/young person diagnosed with ASD, and live in Western Australia, you are eligible to participate in the survey.

What will you be asked to do?

You will be asked to complete a survey on the processes families go through to obtain an ASD diagnosis and to access services, the additional costs associated with having a child with ASD, and the impacts of having a child/young person with ASD on the family's everyday life. The survey can be completed online, by telephone or paper and pencil. It takes approximately 60 minutes to complete the survey.

You will be given the choice to provide us with your personal details so that we can contact you in the future. You can also participate in the survey and choose NOT to provide us with your personal details.

You will be given the choice to give us permission to access your child's medical records and other Department of Health and Education registers. This will allow us to examine which treatments and investigations your child received and when they occurred.

Does my family have to participate in the study?

Participation in this survey is entirely voluntary, and you are free to withdraw at any time without providing a reason to do so.

How and where will the information be stored?

All information you provide will remain strictly confidential. Only the researchers will have access to your answers and your individual answers will not be reported. The information that you provide in this survey will be linked to the follow-up surveys to help us better understand your situation over time. All information collected will be stored securely and disposed of after 25 years according to the Western Australian University Sector Disposal Authority guidelines. At the time of disposal, all data will be deleted electronically or shredded.

Non-identifiable findings from the survey will be made available to families as part of the Curtin Autism Research Group's ongoing open evening sessions where researchers present their findings in lay-man language.

Does this study have ethical approval?

This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (HR 123/2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: hrec@curtin.edu.au, mail: c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845. Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

Who are the study investigators?

If you have any questions regarding the research project, please do not hesitate to contact the research team at Autismstudy@curtin.edu.au

Alternatively, you may directly contact the primary investigators listed below:

Chief Investigators

Dr. Sharmila Vaz, Postdoctoral Research Fellow

School of Occupational Therapy and Social Work

Phone: 08-9266-1849

Email: s.vaz@curtin.edu.au

Professor Torbjörn Falkmer, School of Occupational Therapy and Social Work

Phone: 08-9266-9051

Email: t.falkmer@curtin.edu.au

Associate Professor Reinie Cordier,

School of Occupational Therapy and Social Work

Phone: 08-9266-2583

Email: reinie.cordier@curtin.edu.au

B 2: Chapter 5 and 6

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	HR123/2014
Project Title:	Autism in Rural Communities: The effect of an Autism Spectrum Disorder (ASD) diagnosis on rural families and innovative therapies *Family routines: comparing the experiences of coupled and single mothers*
Principal Investigator:	Torbjörn Falkmer
Student researcher:	Tomomi McAuliffe
Version Number:	1
Version Date:	18.09.2016

What is the Project About?

Mothers organise the family's routines and use different strategies to do so. Mothers of children with ASD may have unique experiences in managing their family's daily routines due to the unique characteristics of their child. In this study, we want to understand how mothers perceive their experiences in managing family routines and the meaning of these experiences. The results of this study will provide a new perspective of routines in families of children with ASD through mothers' experiences.

Who is doing the Research?

The project is being conducted by Ms Tomomi McAuliffe (PhD Candidate), Associate Professor Reinie Cordier, Dr Sharmila Vaz, Professor Torbjorn Falkmer at Curtin University and Dr Yvonne Thomas at Worcester University in UK. The results of this research project will be used by Ms Tomomi McAuliffe to obtain a Doctor of Philosophy at Curtin University and is funded by the University.

What will I have to do?

We will visit you on two occasions at a time and location convenient to you. During the first visit we demonstrate to you how to use the ESM survey and how to complete the survey and will leave two questionnaires for you to complete over the next week. At our second visit, approximately one week later, we will collect the ESM survey and completed forms from you and conduct an interview. All these tasks are outlined in more detail below.

1. ESM Survey

   You will be asked to record your activities and related emotions and stress levels (ESM survey) by using an app called 'P.I.E.L' on an iDevice. In the survey, we will ask you questions, such as what main activity you were doing and if you felt happy or sad while doing the activity. An iDevice will be provided to you if you do not have one.

   The app will prompt you seven times a day for one week during waking hours to complete the survey. Each survey takes less than 2 minutes to complete. As we are interested in mothers' everyday experiences, we ask you to carry the device or keep it in close proximity for one week so we can capture your 'lived experience'. However, we do not expect you to complete the survey when it is not appropriate to do so (e.g. while you are driving or having a shower).

   Prior to the commencement of the study, we will provide you with a demonstration of the app until you feel comfortable to use it by yourself. This demonstration takes approximately 30 minutes and we can arrange a place and time, which are convenient to you. We will collect the iDevice from you after one week at a time and place convenient to you.

2. The survey

   If you have not previously completed the online survey, Autism in Western Australia, we ask you to complete this survey online, or by telephone or paper and pencil format. This survey is about the experiences of families with a child/young person (aged 2-18 years old) with Autism Spectrum Disorders (ASD). It takes approximately 60 minutes in total to complete the survey. When you complete this survey online, you can re-enter the survey at the last question you answered. This means that you can complete this survey 10 minutes at a time, rather than spending 60 minutes to complete the full survey.

3. Two assessments

   You will be asked to complete two assessments, called Family Routines Inventory (FRI) and Family Rituals Questionnaire (FRQ). The FRI asks you about the frequency and the importance of family routines and the FRQ asks you about how your family participate in family rituals. We will leave two assessments with you at our first visit and collect the forms when we collect the ESM surveys, so you will have one week to complete the forms.

4. Interview

   We are interested in your opinions. For this study, you are asked to be interviewed by a researcher regarding your perspectives in managing family routines. The interview may take somewhere between 60 and 90 minutes and the place and time of the interview will be arranged at your convenience. If over the phone interview is preferred, this can be arranged if you do not have enough time when we collect the ESM survey. We may ask you questions such as “Please describe an ordinary day with your family” “What does maintaining family routines mean to you as a mother?” and “What is your role in keeping family routines?” so we can understand your personal experiences. The interview will be audio recorded.

Are there any benefits’ to being in the research project?

There may be no direct benefit to you from participating in this study. However, we hope the results of this study will:

- Improve the current knowledge we have about the experiences of mothers of children with ASD in relation to family daily routines
- Guide health professionals who work with these mothers to employ a new approach while using family daily routines in their interventions

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

We do not expect that there will be any risks or inconveniences associated with taking part in this study. We have been careful to make sure that the questions in the interview do not cause you any distress. But, if you feel anxious about or uncomfortable with any of the questions you do not need to answer them. If the questions cause any concerns or upset you, we can refer you to a counsellor. There will be no costs to you and you will be provided with a $20 gift voucher for participating in this study.

Who will have access to my information?

The information collected in this study will be re-identifiable (coded). This means that we will remove identifying information on any data stored and replace it with a code. Only the research team and the Curtin University Ethics Committee have access to the code to match your name if it is necessary to do so. Any information we collect will be treated as confidential.

Electronic data will be password-protected. The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the study has ended and then it will be destroyed/kept indefinitely. You, as a participant, have the right to access, and request correction of, your information in accordance with relevant privacy laws.

We would like you to consider letting us share the information we collect during this research with other researchers working in this area in future. The data will be sharing will be non-identifiable and the same principles discussed above apply to any future research.

Will you tell me the results of the research?

We will write to you at the end of the research (in about 6 months) and let you know the results of the research. Results will not be individual but based on all the information we collect and review as part of the research. The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Do I have to take part in the research project?

Taking part in this study is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. Please let us know you want to stop so we can make sure you are aware of any thing that needs to be done so you can withdraw safely. If you chose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues. If you chose to leave the study, we will destroy any information we have collected from you.

What happens next and who can I contact about the research?

If you are interested in participating in this study, please contact Tomomi McAuliffe (email: tomomi.mcauliffe@curtin.edu.au) to obtain further information. If you decide to take part in this study, we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HR123/2014). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au

B 4: Example consent form

CONSENT FORM

HREC Project Number:	HR123/2014
Project Title:	Autism in Rural Communities: The effect of an Autism Spectrum Disorder (ASD) diagnosis on rural families and innovative therapies *Family routines: comparing the experiences of coupled and single mothers*
Principal Investigator:	Torbjörn Falkmer
Student researcher:	Tomomi McAuliffe
Version Number:	1
Version Date:	18.09.2016

- ☐ I have read the information statement version listed above and I understand its contents.
- ☐ I believe I understand the purpose, extent and possible risks of my involvement in this project.
- ☐ I voluntarily consent to take part in this research project.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- ☐ I understand that this project has been approved by Curtin University Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- ☐ I understand I will receive a copy of this Information Statement and Consent Form.

☐ I do ☐ I do not consent to being audio-recorded
☐ I do ☐ I do not consent for the data collected to be used in future research

Participant Name	
Participant Signature	
Date	

Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Researcher Name	
Researcher Signature	
Date	

Autism in Western Australia:

Surveying the experience of families of children with Autism Spectrum Disorders (ASD)

Consent to Participate

(Participant copy)

<u>Prior to beginning the survey, we need to assess your eligibility.</u>

Are you a *<u>parent/caregiver of a child aged 2 – 18</u>* with any of the following diagnoses?

Autistic Disorder (Autism), High-functioning Autism, Asperger's Syndrome, Pervasive Developmental Disorder – not otherwise specified (PDD-NOS), Rett's Syndrome or Childhood Disintegrative Disorder?

○ Yes
○ No

Do you live in Western Australia?

○ Yes
○ No

What is your postcode? __________

Do you consent to participate in the current study?

○ Yes
○ No

Are you interested in participating in follow-up versions of this study?

○ Yes
○ No

Do you give the researchers permission to access your child's hospital records and other Department of Health and Education registers?

○ Yes
○ No

Would you like to be provided with information/be invited to participate in research projects in the future?

- ○ Yes
- ○ No

This survey is the first part of a longitudinal study. To enable us to call you to complete the survey and follow up with you in the future, please provide us with your personal details. Your contact details will be removed from your responses and stored in a secure server that is only accessible to the researchers:

Please provide us with your contact details:

Name (first and surname) ____

Address ____

City ____

State ____

Post Code ____

Email address ____

Phone number ____

Your date of birth [dd/mm/yy]____

Appendix C: Chapter 4 survey

Autism in Western Australia:

Surveying the experience of families of children with Autism Spectrum Disorders

This survey is divided into 4 major sections, which can be completed in more than one sitting:

Section 1: General questions about yourself

Section 2: Your child with ASD:
- a) The process of diagnosis
- b) Services your child accesses

Section 3: Your family:
- a) General information and services you access
- b) Your stress, coping, quality of life, and daily routine

Section 4: More about your child with ASD:
- a) Sleep habits
- b) Behaviours
- c) ASD related symptoms

Should you experience any difficulties, please do not hesitate to contact the research team at

Autismstudy@curtin.edu.au

Or at:

Curtin Autism Research Group

Curtin University

Reply Paid 1987

Perth WA 6845

SECTION 1: *General questions about yourself*

1. Please indicate today's date [dd/mm/yyyy]: ______________________

2. What is your gender?

○ Female
○ Male
○ Other

3. What is your relationship to the child with ASD?

○ Biological mother
○ Biological father
○ Foster mother
○ Foster father
○ Step parent - mother
○ Step parent - father
○ Grandmother
○ Grandfather
○ Other (please specify): ________________________________

4. How many of your children have a diagnosis of ASD?

○ 1
○ 2
○ 3
○ 4 or more

Please complete the questions that follow regarding your experiences with your **eldest child with ASD, aged 18 or under.** If you require subsequent surveys for your other children with a diagnosis of ASD please contact the researchers at Autismstudy@curtin.edu.au

Or at:

Curtin Autism Research Group

Curtin University

Reply Paid 1987

Perth WA 6845

SECTION TWO: *Your child with ASD, and the process of receiving an ASD diagnosis*

1. What is the date of birth of your child with ASD? [dd/mm/yyyy]

____

2. What is your child's gender?

○ Female
○ Male
○ Other

3. What is your child's official ASD diagnosis?

○ Autistic Disorder
○ High-functioning Autism
○ Asperger's Syndrome
○ Pervasive Developmental Disorder – no otherwise specified (PDD-NOS)
○ Rett's Syndrome
○ Other
○ Don't know

4. Has your child ever had epilepsy, seizures or fits?

○ Yes
○ No, please skip to Question 5.

4A. How old was your child when the seizures or fits first started?

Years: ________________
Months: ________________

4B. How often were the seizures or fits?

○ Daily
○ Weekly
○ Monthly
○ None in the last year

5. Does your child with ASD also have a diagnosis of <u>cognitive impairment/intellectual disability</u> or similar?

○ No
○ Yes (please specify): ________________________________

6. Does your child with ASD also have a diagnosis of a psychological/mental health condition or similar?

○ No

○ Yes (please specify): ________________________________

7. Does your child with ASD also have a diagnosis of a physical/medical condition or similar?

○ No

○ Yes (please specify): ________________________________

8. Was your child ever admitted to hospital during the first two years of life?

○ Yes

○ No

9. How old was your child when you or someone else first noticed something was different or not quite right?

○ Less than 3 years old

○ Between 3 -4 years old

○ Between 4 -5 years old

○ Between 5 -6 years old

○ Between 6 -7 years old

○ Between 7 -10 years old

○ 10 years old or older

10. Please specify what that behaviour of concern was:

____

____

____

11. How old was your child when you first sought advice about your concerns?

○ Less than 3 years old

○ Between 3 -4 years old

○ Between 4 -5 years old

○ Between 5 -6 years old

○ Between 6 -7 years old

○ Between 7 -10 years old

○ 10 years old or older

12. How old was your child when he/she was formally diagnosed with ASD?

○ Less than 3 years old

○ Between 3 -4 years old
○ Between 4 -5 years old
○ Between 5 -6 years old
○ Between 6 -7 years old
○ Between 7 -10 years old
○ 10 years old or older

13. How old was your child when he/she first began <u>accessing therapeutic services</u>?

○ Less than 3 years old
○ Between 3 -4 years old
○ Between 4 -5 years old
○ Between 5 -6 years old
○ Between 6 -7 years old
○ Between 7 -10 years old
○ 10 years old or older

14. Who diagnosed your child?

○ Medical doctor / Paediatrician
○ Psychiatrist
○ State/territory government assessment service / multidisciplinary team
○ A private multidisciplinary team service
○ Other (please specify): ________________________________

15. At the time of diagnosis, what type of insurance did you have?
(please select all that apply)

○ Medicare
○ Private health insurance - hospital
○ Private health insurance – extras/ancillary cover
○ None
○ Don’t know
○ Other (please specify): ________________________________

16. Please indicate which of the following services collaborated with the paediatrician/psychiatrist to determine the ASD diagnosis of your child
(please select all that apply)

○ Not applicable
○ Occupational therapist
○ Physiotherapist
○ Speech pathologist

- ○ Psychologist
- ○ Audiologist
- ○ Optometrist/Ophthalmologist/Orthoptist
- ○ Other (please specify): ________________________________

***17.* For each of the services that assisted in the diagnosis of your child, how were the costs of these services covered?** *(please select all that apply)*

NB: Out of pocket or 'gap' expenses refers to payments you make either meet the full cost of a service, or a cost shared with Medicare, private health insurance or other funding bodies.

	Not applicable	Medicare	Private health insurance	FACHSIA funding (Better Start)	Out of pocket	If out of pocket how much per visit on average?
General practitioner (GP)	○	○	○	○	○	
Specialist (e.g. paediatrician, neurologist)	○	○	○	○	○	
Occupational therapist	○	○	○	○	○	
Physiotherapist	○	○	○	○	○	
Speech pathologist	○	○	○	○	○	
Psychologist	○	○	○	○	○	
Audiologist	○	○	○	○	○	
Optometrist/ Ophthalmologist/ Orthoptist	○	○	○	○	○	
Other: (please specify)	○	○	○	○	○	

18. On average, how long was your round trip (travel there and back) for the initial autism diagnosis?

________________________________ (Hours and minutes)

SECTION 2 continued: *Health services accessed by your child with ASD*

19. Currently, what type of insurance coverage does your child with ASD have?
(please select all that apply)

- ○ Medicare
- ○ Private health insurance - hospital cover only
- ○ Private health insurance - extras/ancillary cover

○ None
○ Don’t know
○ Other (please specify): ________________________________

20. Does your child have a Health Care Card OR are they covered by your Health Care Card?

○ Yes
○ No

21. Do you receive any additional funding support for medical or therapy services for your child? (e.g., Centrelink, *FaHCSIA* funding)

○ No
○ Yes (please list all funding supports): ________________________________

22. How many ASD-related visits/appointments does your child have <u>on average over six months?</u>

NB: ASD-related medical visits are those visits only related to aspects of your child’s ASD diagnosis i.e. medications

	Number of ASD-related visits/appointments your child has on average over six months									If more than 8, please specify:
	0	1	2	3	4	5	6	7	8	
General practitioner (GP)										
Specialist (e.g. paediatrician, neurologist)										
Occupational therapist										
Physiotherapist										
Speech pathologist										
Psychologist										
Audiologist										
Optometrist/Ophthalmologist/Orthoptist										
Dietician/Nutritionist										
Dentist										
Pharmacist										
Hospital										
Complementary/Alternative/Natural therapies										

23. On average, how long is your roundtrip to access the listed services, and what is the usual mode of transport for getting there?

	N/A	Time taken (roundtrip)

		Hours	Minutes	Usual mode of transport
General practitioner (GP)	○			
Specialist (e.g. paediatrician, neurologist)	○			
Occupational therapist	○			
Physiotherapist	○			
Speech pathologist	○			
Psychologist	○			
Audiologist	○			
Optometrist/Ophthalmologist/Orthoptist	○			
Dietician/Nutritionist	○			
Dentist	○			
Pharmacist	○			
Hospital	○			
Complementary/Alternative/Natural therapies	○			

24. For each of the listed services, do you have out-of-pocket expenses?

NB: Out of pocket or 'gap' expenses refers to payments you make either meet the full cost of a service, or a cost shared with Medicare, private health insurance or other funding bodies.

	N/A	Yes	No	If yes, how much do you pay per visit on average?
General practitioner (GP)	○	○	○	
Specialist (e.g. paediatrician, neurologist)	○	○	○	
Occupational therapist	○	○	○	
Physiotherapist	○	○	○	
Speech pathologist	○	○	○	
Psychologist	○	○	○	

Audiologist	○	○	○
Optometrist/Ophthalmologist/Orthoptist	○	○	○
Dietician/Nutritionist	○	○	○
Dentist	○	○	○
Pharmacist	○	○	○
Hospital	○	○	○
Complementary/Alternative/Natural therapies	○	○	○

25. Which of the following <u>Complementary/Alternative/Natural services</u> do you access to aid the treatment of your child's ASD?
(please select all that apply)

○ Alternative Medical Systems (Homeopathic remedies; Acupuncture; Naturopathic remedies)
○ Diets (Casein-free; Low glycaemic diet; No additives and preservatives; Sugar free; Yeast free; Caffeine free; Digestive enzymes; Essential fatty acids
○ Mineral and/or Vitamin Supplements (Magnesium; Selenium; Calcium; Vitamin B6/12; Vitamin C; Vitamin D; Echinacea; Garlic oil; Strawberry oil; Nutritional supplements; Omega 3 oil)
○ Melatonin
○ Manipulative and Body-based Therapist (Body-based relaxation therapies; Chiropractic; Massage; Sensory integration; Therapeutic horse riding)
○ Mind-Body and Psychologist Therapist (Music therapist; Counselling; Spiritual healing; Play therapy)
○ Irlen Lenses
○ Other (please specify): ________________________________

SECTION TWO continued: *Health services accessed by your child with ASD*

26. How would you rate the following statement:

"It is easy for my child to access the following services/professionals…"

	N/A	Strongly disagree	Disagree	Agree	Strongly agree
General practitioner (GP)	○	○	○	○	○
Specialist (e.g. paediatrician, neurologist)	○	○	○	○	○
Occupational therapist	○	○	○	○	○
Physiotherapist	○	○	○	○	○
Speech pathologist	○	○	○	○	○
Psychologist	○	○	○	○	○
Audiologist	○	○	○	○	○
Optometrist/Ophthalmologist/Orthoptist	○	○	○	○	○
Dietician/Nutritionist	○	○	○	○	○
Dentist	○	○	○	○	○
Pharmacist	○	○	○	○	○
Hospital	○	○	○	○	○
Complementary/Alternative/Natural therapies	○	○	○	○	○

27. What limitations do you face accessing the listed services for your child with ASD?

(For each service, please select all that apply)

	N/A	None	Transport	Scheduling Issues	Long wait-list period	Unsuitable waiting areas	Unsuitable wait times to see professional	Child's behaviour problems	Cost	Shortage/ No service providers in the area	Other	If other, please specify
General practitioner (GP)	○	○	○	○	○	○	○	○	○	○	○	
Specialist (e.g. paediatrician, neurologist)	○	○	○	○	○	○	○	○	○	○	○	
Occupational therapist	○	○	○	○	○	○	○	○	○	○	○	
Physiotherapist	○	○	○	○	○	○	○	○	○	○	○	
Speech pathologist	○	○	○	○	○	○	○	○	○	○	○	
Psychologist	○	○	○	○	○	○	○	○	○	○	○	
Audiologist	○	○	○	○	○	○	○	○	○	○	○	
Optometrist/ Ophthalmologist/ Orthoptist	○	○	○	○	○	○	○	○	○	○	○	
Dietician/ Nutritionist	○	○	○	○	○	○	○	○	○	○	○	
Dentist	○	○	○	○	○	○	○	○	○	○	○	
Pharmacist	○	○	○	○	○	○	○	○	○	○	○	

Hospital	○	○	○	○	○	○	○	○	○	○	○
Complementary/ Alternative/ Natural therapies	○	○	○	○	○	○	○	○	○	○	○

28. How would rate the quality of services delivered by the following professionals/services?

	N/A	Poor	Below average	Above average	Excellent
General practitioner (GP)	○	○	○	○	○
Specialist (e.g. paediatrician, neurologist)	○	○	○	○	○
Occupational therapist	○	○	○	○	○
Physiotherapist	○	○	○	○	○
Speech pathologist	○	○	○	○	○
Psychologist	○	○	○	○	○
Audiologist	○	○	○	○	○
Optometrist/ Ophthalmologist/ Orthoptist	○	○	○	○	○
Dietician/ Nutritionist	○	○	○	○	○
Dentist	○	○	○	○	○
Pharmacist	○	○	○	○	○
Hospital	○	○	○	○	○
Complementary/ Alternative/ Natural therapies	○	○	○	○	○

29. If your child accesses or accessed *Early Intervention therapy* as part of ASD treatment prior to the age of 7, how many hours of therapy <u>in an average week</u> does he/she complete?

○ Hours per week:

____

○ Not applicable, please skip to Question 30

29A. For how long has/did your child received Early Intervention therapy?

________________________________ (Years and months)

30. If your child is aged *7 years or older,* how many hours of intervention/therapy does he/she access in an <u>average week</u> as part of their ASD treatment?

○ Hours per week:

____

○ Not applicable

31. Has ASD-related intervention/therapy improved your child's quality of life?

○ Yes, definitely
○ Yes, somewhat
○ Disagree
○ Strongly disagree
○ Not applicable

SECTION TWO continued: *Educational and care services for your child and other children*

32. Does/did your child with ASD attend?

○ Mainstream private school
○ Mainstream public school
○ Autism specific program in a mainstream school
○ Education support centre/school
○ Home schooling
○ No school
○ Other (please specify): ________________________________

33. If your child diagnosed with ASD attends a school or education support centre, approximately how many hours per week does your child receive aide/education support in the classroom?

○ No in-class support
○ 5 hours or less
○ Between 6 – 10 hours
○ Between 11 – 15 hours
○ More than 16 hours
○ Not applicable

34. How many hours per week does your child with ASD spend playing with friends (outside of school or other organised group activities)?

○ None
○ 1 – 2 hours
○ 3 – 5 hours
○ 6 – 8 hours
○ 9 – 12 hours
○ More than 12 hours

35. Do you access any of the following childcare services for your child with ASD?

	How often?	How many hours per month?	How much does it cost ($/hour)?
After-school care			
Day care			
Baby-sitter			
Children's residential respite services			
In-home respite services			

36. How difficult is it for you to access these services for your child with ASD? *(For each service, please select all that apply)*

	Not applicable	Not difficult at all	Somewhat difficult	Very difficult
After-school care	○	○	○	○
Day care	○	○	○	○
Baby-sitter	○	○	○	○
Children's residential respite services	○	○	○	○
In-home respite services	○	○	○	○

37. What limitations do you face accessing the listed services for your child with ASD?

(For each service, please select all that apply)

	N/A	None	Transport	Scheduling Issues	Long wait-list period	Child’s behaviour problems	Cost	Shortage/ No service providers in the area	Other	If other, please specify
After-school care	○	○	○	○	○	○	○	○	○	
Day care	○	○	○	○	○	○	○	○	○	
Baby-sitter	○	○	○	○	○	○	○	○	○	
Children’s residential respite services	○	○	○	○	○	○	○	○	○	
In-home respite services	○	○	○	○	○	○	○	○	○	

38. Do you access any of the following childcare services for your other children <u>due to the needs of your child with ASD</u>?

	How often?	How many hours per month?	How much does it cost ($/hour)?
After-school care			
Day care			
Baby-sitter			
Children’s residential respite services			

In-home respite services

Group counselling/support groups

Individual counselling/therapy

SECTION THREE: *Your family – general information*

1. What is your household composition?

○ Two-parent
○ Single parent
○ Extended family (grandparents, etc.)
○ Two-parent plus extended family
○ Single parent plus extended family
○ Foster situation
○ Other (please specify): ________________________________

2. How many children do you have?

○ 1
○ 2
○ 3
○ 4
○ 5
○ 6 or more

3. What is the mother's / female caregiver's highest level of completed education?

○ Year 9 or below (including Certificates I/II)
○ Year 10
○ Year 11
○ Year 12
○ Certificate III/IV
○ Advanced Diploma/Diploma
○ University undergraduate degree
○ University postgraduate degree
○ Not applicable

4. What is the father's / male caregiver's highest level of completed education?

○ Year 9 or below (including Certificates I/II)
○ Year 10
○ Year 11
○ Year 12
○ Certificate III/IV
○ Advanced Diploma/Diploma
○ University undergraduate degree
○ University postgraduate degree

○ Not applicable

5. What is your total household income (before tax) per year?
This includes income from investments, rent assistance, maintenance, family supplement, etc.

○ No income
○ $1 - 10,399
○ $10,400 - $15,599
○ $15,600 - $20,799
○ $20,800 - $31,199
○ $31,200 - $41,599
○ $41,600 - $51,999
○ $52,000 - $64,999
○ $65,000 -$77,999
○ $78,000 - $103,999
○ $104,000 - $129,000
○ $130,000 - $155,999
○ $160,000 - $207,999
○ $208,000 - $259,999
○ $260,000 or more

6. Please indicate the major sources of your household income:
(Please select all that apply)

○ Wage/salary from employment
○ Government benefits/pensions/allowances
○ Other (please specify: ________________________________

7. How many people does this income support?
(Please write the number of people)

Adults: __________________________

Children less than 18 of age: __________________________

Children over 18 years of age: __________________________

8. What is the employment status of the residents of your household/s?
(NB: 'Parent' refers to primary caregivers whether they are biological, step, foster or adoptive)

○ Both parents employed full time
○ Both parents employed part time
○ No parent employed
○ One parent employed full time, one parent employed part time
○ One parent employed full time
○ One parent employed part time
○ Single parent employed full time
○ Single parent employed part time
○ Single parent not employed
○ Other (please specify): ________________________________

9. How much has your child's ASD diagnosis affected the employment status of your household?

○ Both parents must work less hours
○ One parent (of a two-parent household) must work less hours
○ Single parent must work less hours
○ Both parents cannot work at this time
○ One parent (of a two-parent household) cannot work at this time
○ Single parent cannot work at this time
○ Both parents must work increased hours at this time
○ Single parent must work increased hours at this time
○ Unaffected
○ Other (please specify): ________________________________

10. If your household's employment status has changed because of your child's ASD diagnosis, please indicate by how much your combined household work hours per week have reduced or increased:

	N/A	0.5 day	1 day	1.5 days	2 days	2.5 days	3 days	3.5 days	4 days	4.5 days	5 days or more
Reduced work	○	○	○	○	○	○	○	○	○	○	○
Increased work	○	○	○	○	○	○	○	○	○	○	○

SECTION THREE Continued: *Your family, and supports you access*

11. What services do you currently access, or have you accessed in the past for yourself?

	How often?	**How many hours per month?**	**How much does it cost ($/hour)?**
Group counselling / support group			
Individual therapy / counselling			
Other (please specify):			
Other (please specify):			
Other (please specify):			

12. Who do YOU receive social/emotional support from?
(Please mark all that apply)

○ No one
○ My spouse
○ My/our parents and/or siblings
○ Extended family members
○ Friends
○ Other families with children diagnosed with ASD
○ Support groups (either online or in person)
○ Other (please specify): ________________________________

13. How would you rate your level of social/emotional support?

○ Lots of social support
○ Some social support
○ A little social support
○ No social support

SECTION THREE continued: *How your child with ASD impacts yourself and your family*

14. In the past ONE month, as a result of your child's health how much of a problem has your family had with:

Daily activities

	Never	Almost never	Sometimes	Often	Almost Always
1. Family activities taking more time and effort	○	○	○	○	○
2. Difficulty finding time to finish household tasks	○	○	○	○	○
3. Feeling too tired to finish household tasks	○	○	○	○	○

15. In the past ONE month, as a result of your child's health how much of a problem has your family had with:

	Never	Almost never	Sometimes	Often	Almost Always
1. Lack of communication between family members	○	○	○	○	○
2. Conflict between family members	○	○	○	○	○
3. Difficulty making decisions together as a family	○	○	○	○	○
4. Difficulty solving family problems together	○	○	○	○	○
5. Stress or tension or tension between family members	○	○	○	○	○

SECTION THREE continued: *Stress*

16. **Please rate the following aspects of <u>your child's health according to how much stress it causes you and/or your family</u>, by selecting the option that best describes your situation.**

How stressful is:

	Not stressful	Sometimes create stress	Often creates stress	Very stressful on a daily basis	So stressful sometimes we feel we can't cope
Your child's social development	○	○	○	○	○
Your child's ability to communicate	○	○	○	○	○
Tantrums/meltdowns	○	○	○	○	○
Aggressive behaviour (siblings, peers)	○	○	○	○	○
Self-injurious behaviour	○	○	○	○	○
Difficulty making transitions from one activity to another	○	○	○	○	○
Sleep problems	○	○	○	○	○
Your child's diet	○	○	○	○	○
Bowel problems (diarrhoea, constipation)	○	○	○	○	○
Potty training	○	○	○	○	○
Not feeling close to your child	○	○	○	○	○
Concern for the future of your child being accepted by others	○	○	○	○	○
Concern for the future of your child living independently	○	○	○	○	○

SECTION THREE continued: *Ways you have been coping with stress in your life, since your child was diagnosed with ASD*

17. **There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Different people deal with things in different ways.**

Each item says something about a particular way of coping. Each statement asks to what <u>extent you've been doing what the item says</u>, in terms of how much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things	○	○	○	○
I've been concentrating my efforts on doing something about the situation I'm in	○	○	○	○
I've been saying to myself "this isn't real"	○	○	○	○
I've been using alcohol or other drugs to make myself feel better	○	○	○	○
I've been getting emotional support from others	○	○	○	○
I've been giving up trying to deal with it	○	○	○	○
I've been taking action to try to make the situation better	○	○	○	○
I've been refusing to believe that it has happened	○	○	○	○
I've been saying things to let my unpleasant feelings escape	○	○	○	○
I've been getting help and advice from other people	○	○	○	○
I've been using alcohol or other drugs to help me get through it	○	○	○	○
I've been trying to see it in a different light, to make it seem more positive	○	○	○	○
I've been criticising myself	○	○	○	○

I’ve been trying to come up with a strategy about what to do	○	○	○	○
I’ve been getting comfort and understanding from someone	○	○	○	○
I‘ve been giving up the attempt to cope	○	○	○	○

	I haven’t been doing this at all	I’ve been doing this a little bit	I’ve been doing this a medium amount	I’ve been doing this a lot
I’ve been looking for something good in what is happening	○	○	○	○
I’ve been making jokes about it	○	○	○	○
I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	○	○	○	○
I’ve been accepting the reality of the fact that it has happened	○	○	○	○
I’ve been expressing my negative feelings	○	○	○	○
I’ve been trying to find comfort in my religion or spiritual beliefs	○	○	○	○
I’ve been trying to get advice or help from other people about what to do	○	○	○	○
I’ve been learning to live with it	○	○	○	○
I’ve been thinking hard about what steps to take	○	○	○	○
I’ve been blaming myself for things that happened	○	○	○	○
I’ve been praying or meditating	○	○	○	○
I’ve been making fun of the situation	○	○	○	○

SECTION THREE continued: *Your quality of life, health, or other areas of your life.*

18. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. Please answer based on your life <u>in the last two weeks.</u>

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	○	○	○	○	○

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	○	○	○	○	○

The following questions ask how about <u>how much</u> you have experienced certain things in the <u>last two weeks.</u>

	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	○	○	○	○	○
How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
How much do you enjoy life?	○	○	○	○	○
To what extent do you feel your life to be meaningful?	○	○	○	○	○
How well are you able to concentrate?	○	○	○	○	○

How safe do you feel in your daily life?	○	○	○	○	○
How healthy is your physical environment?	○	○	○	○	○

The following questions ask about <u>how completely</u> you experience or were able to do certain things in the <u>last two weeks.</u>

	Not at all	A little	Moderately	Mostly	Completel y
Do you have enough energy for everyday life?	○	○	○	○	○
Are you able to accept your bodily appearance?	○	○	○	○	○
Have you enough money to meet your needs?	○	○	○	○	○
How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
To what extent do you have the opportunity for leisure activities?	○	○	○	○	○

	Very poor	Poor	Neither poor nor good	Good	Very good
How well are you able to get around?	○	○	○	○	○

The following questions ask you to say how <u>good or satisfied</u> you have felt about various aspects of your life over the <u>last two weeks.</u>

	Not at all	A little	Moderately	Mostly	Completely
How satisfied are you with your sleep?	○	○	○	○	○
How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
How satisfied are you with your capacity for work?	○	○	○	○	○
How satisfied are you with yourself?	○	○	○	○	○
How satisfied are you with your personal relationships?	○	○	○	○	○
How satisfied are you with yourself?	○	○	○	○	○
How satisfied are you with your sex life?	○	○	○	○	○
How satisfied are you with the support you get from your friends?	○	○	○	○	○
How satisfied are you with the conditions of your living place?	○	○	○	○	○
How satisfied are you with your access to health services?	○	○	○	○	○
How satisfied are you with your transport?	○	○	○	○	○

The following question refers to <u>how often</u> you have felt or experienced certain things in the <u>last two weeks.</u>

	Never	Seldom	Quite often	Very often	Always

How often do you have negative feelings such as blue mood, despair, anxiety, depression?	○	○	○	○	○

SECTION THREE continued: *your daily routine as a parent/caregiver*

19. Please list the time spent engaging in the following activities for an average day during the week and average day during the weekend. Duration should be listed in terms of hours, with the total time adding up to 24 hours. You may have engaged in more than one activity at once, for example looking after a child while cooking. Please choose the main activity and list the time spent on that activity. If you are a part-time worker, please use the day you work.

	Average day during the WEEK (in hours)	Average day during the weekend (in hours)
Sleep		
Grooming and personal hygiene (e.g. having a shower, putting on make-up)		
Meal preparations and clean up		
Having a meal		
Taking care of child (e.g. assisting in their grooming, playing with child, taking child to medical appointments, etc		
Travel time to and from school/work		
Time spent at work		
Personal leisure time (e.g. playing sports, hobby, etc)		
House duties (e.g. cleaning, laundry, banking, etc)		
Shopping		
Having quiet time or down time		
Visiting family/friends		
Studying		

Voluntary work

Other (please specify):

Other (please specify):

Other (please specify):

Total

SECTION FOUR: *Your child's sleep habits and possible difficulties with sleep*

1. **Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken), choose the most recent typical week.**

   Answer *USUALLY* if something occurs 5 or more times in a week
   Answer *SOMETIMES* if it occurs 2 to 4 times in a week
   Answer *RARELY* if something occurs never or 1 time during a week

   Please indicate whether or not the sleep habit is a problem by indicating Yes, No or Not applicable (N/A).

Bedtime

What is the child's bedtime? (E.g. 5.00pm): _________________

Child:

	Frequency			Is it a problem?		
	Usually	Sometimes	Rarely	Yes	No	N/A
Goes to bed at the same time at night	○	○	○	○	○	○
Falls asleep within 20 minutes after going to bed	○	○	○	○	○	○
Falls asleep in own bed	○	○	○	○	○	○
Falls asleep in parent's or sibling's bed	○	○	○	○	○	○
Falls asleep with rocking or rhythmic movements	○	○	○	○	○	○

Needs special object to fall asleep (doll, special blanket, etc)	○	○	○	○	○	○
Needs parent in room to fall asleep	○	○	○	○	○	○
Is ready to go to bed at bedtime	○	○	○	○	○	○
Resists going to bed at bedtime	○	○	○	○	○	○
Struggles at bedtime (cries, refuses to stay in bed, etc)	○	○	○	○	○	○
Is afraid of sleeping in the dark	○	○	○	○	○	○
Is afraid of sleeping alone	○	○	○	○	○	○

Sleep Behaviour

Please indicate the child's usual amount of sleep each day, in hours and minutes:

____

Child:

	Frequency			Is it a problem?		
	Usually	Sometimes	Rarely	Yes	No	N/A
Sleeps to little	○	○	○	○	○	○
Sleep too much	○	○	○	○	○	○
Sleeps the right amount	○	○	○	○	○	○
Sleeps about the same amount each day	○	○	○	○	○	○
Wets the bed at night	○	○	○	○	○	○
Talks during sleep	○	○	○	○	○	○
Is restless and moves a lot during sleep	○	○	○	○	○	○
Sleepwalks during the night	○	○	○	○	○	○
Moves to someone else's bed during the night (parent, brother, sister, etc.)	○	○	○	○	○	○
Reports body pains during sleep	○	○	○	○	○	○
If so where?						
Grinds teeth during sleep (your dentist may have told you this)	○	○	○	○	○	○
Snores loudly	○	○	○	○	○	○
Seems to stop breathing during sleep	○	○	○	○	○	○
Snorts and/or gasps during sleep	○	○	○	○	○	○

Has trouble sleeping away from home (visiting relatives, vacation, etc)	○	○	○	○	○	○
Complains about sleep problems	○	○	○	○	○	○
Awakens during night screaming, sweating and inconsiderable	○	○	○	○	○	○
Awakens alarmed by a frightening dream	○	○	○	○	○	○

SECTION FOUR. *Your child's sleep habits and possible difficulties with sleep*

Waking During the night

	Frequency			Is it a problem?		
	Usually	Sometimes	Rarely	Yes	No	N/A
Child wakes up during the night	○	○	○	○	○	○
Child awakes more than once during the night	○	○	○	○	○	○
Child returns to sleep without help after waking	○	○	○	○	○	○

Number of minutes a night waking usually lasts: ___________________

Morning Waking

Time of day child usually wakes in the morning (e.g. 6:00am): __________________

Child:

	Frequency			Is it a problem?		
	Usually	Sometimes	Rarely	Yes	No	N/A
Wakes up by him/herself	○	○	○	○	○	○
Wakes up with alarm clock	○	○	○	○	○	○
Wakes up in negative mood	○	○	○	○	○	○
Adults or siblings wake up child	○	○	○	○	○	○

Has difficulty getting out of bed in the morning	○	○	○	○	○	○
Takes a long time to become alert in the morning	○	○	○	○	○	○
Wakes up very early in the morning	○	○	○	○	○	○
Has a good appetite in the morning	○	○	○	○	○	○

Daytime Sleepiness

	Frequency			Is it a problem?		
	Usually	Sometimes	Rarely	Yes	No	N/A
Child naps during the day	○	○	○	○	○	○
Child suddenly falls asleep in the middle of active behaviour	○	○	○	○	○	○
Child seems tired	○	○	○	○	○	○

During the past week, your child has appeared very sleepy or fallen asleep during the following: *(please check all that apply)*

	Not sleepy	Very sleepy	Falls asleep
Play alone	○	○	○
Watching TV	○	○	○
Riding in car	○	○	○
Eating meals	○	○	○

SECTION FOUR continued: *Symptoms related to your child's diagnosis of ASD*

Please select the statements that apply to your child. If a statement does not apply to your child, please leave it blank.

1. **Social interaction:**
   - ○ Impairment in the use of multiple nonverbal behaviours, such as eye-to-eye gaze (e.g., eye contact), body posture, or gestures.
   - ○ Failure to develop peer relationships appropriate to developmental level (e.g., little to no interest in forming friendships or lack of understanding of how to interact socially with others).
   - ○ Does not spontaneously seek to share enjoyment, interest or achievements with others (e.g., now showing, bringing, or pointing out objects he/she finds interesting).
   - ○ Lack of social or emotional reciprocity (e.g., not actively participating in social play or games, preferring solitary activities.)
   - ○ Rarely seeking or using others for comfort in times of stress or rarely offering comfort or affection to others in stress

2. **Communication:**
   - ○ Delay in development or lack of spoken language (i.e., not accompanied by an attempt to communicate by alternate means, such as gestures or mime).

- ○ Impairment in initiating or sustaining conversations with others (for those with adequate speech).
- ○ Stereotyped and repetitive use of language or idiosyncratic/peculiar language (e.g., using words in a peculiar or odd way).
- ○ Lack of varied, spontaneous make-believe play (e.g., pretend/imaginary play) or socially imitative play (e.g., imitating adults) appropriate to developmental level.
- ○ Lack of emotional response to other's verbal or non-verbal communication.
- ○ Lack of variation in the rhythm or emphasis of speech (e.g., speech is monotone or flat; without change)
- ○ Impaired use of gestures non-verbal behaviour to aid spoken communication.

3. **Restricted, repetitive and stereotyped patterns of behaviour, interest or activities:**
   - ○ Preoccupation with one or more stereotyped and restricted patterns of interest with abnormal intensity or focus (e.g., few interests).
   - ○ Inflexible attachment to specific, non-functional/essential routines or rituals.
   - ○ Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping/twisting, or other complex whole-body movements such as rocking, dipping or swaying).
   - ○ Persistent preoccupation with parts of objects (e.g., with buttons or parts of the body).
   - ○ Specific attachments to unusual objects (e.g., string)
   - ○ Distress over changes in small, non-functional/essential details of the environment.
   - ○ Either overly-sensitive or under-sensitive to sensory input (e.g., sight, sound, touch, smell, taste, balance or body awareness.
4. **Developmental History:**
   - ○ Delays or abnormal functioning in at least one of the previous areas (questions 1 to 3) was present prior to the age of 3.

SECTION FOUR continued: *At times, all children and teenagers behave in challenging ways.*

2. **The following statements relate to your <u>child's behaviour at home</u>. Please read each statement and select the most appropriate category representing your level of agreement.**

	Strongly Agree	Agree	Disagree	Strongly Disagree
My child <u>never</u> has tantrums	○	○	○	○
My child aggravates others	○	○	○	○
My child is <u>never</u> aggressive and violent towards others	○	○	○	○
My child does not mind when I leave them at home with another adult while I go out	○	○	○	○
My child can be stubborn and uncooperative	○	○	○	○

I am able to manage the most challenging and difficult behaviours effectively on my own home	○	○	○	○
My child is happy and content at home most of the time	○	○	○	○
My child follows the family routine easily	○	○	○	○

Your involvement in research studies such as this is invaluable, in improving our understanding of the experiences of families such as yours.

You are welcome to contact the research team at Autismstudy@curtin.edu.au regarding any queries or comments relating to this study. We will be sending out emails in the future with updates about our research and the findings of this study.

Are there any additional comments that you would like to make regarding your experiences?

____

____

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END OF SURVEY – Thank you for your time

Please return the completed survey to:

Curtin Autism Research Group

Curtin University

Reply Paid 1987

Perth WA 6845

Appendix D: Chapter 3 published paper

DEVELOPMENTAL NEUROREHABILITATION
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ORIGINAL ARTICLE

A comparison of families of children with autism spectrum disorders in family daily routines, service usage, and stress levels by regionality

Tomomi McAuliffe[a], Sharmila Vaz[a], Torbjörn Falkmer[a,b,c,d], and Reinie Cordier[a]

[a]School of Occupational Therapy and Social Work, Faculty of Health Sciences, Curtin University, Perth, Australia; [b]School of Occupational Therapy, La Trobe University, Melbourne, VIC, Australia; [c]Rehabilitation Medicine, Department of Medicine and Health Sciences (IMH), Faculty of Health Sciences, Linköping University & Pain and Rehabilitation Centre, UHL, County Council, Linköping, Sweden; [d]Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), Long Pocket, Brisbane, Australia

ABSTRACT

Purpose: To explore whether family routines, service usage, and stress levels in families of children with autism spectrum disorder differ as a function of regionality. *Methods*: Secondary analysis of data was undertaken from 535 surveys. Univariate and multivariate analyses were performed to investigate differences between families living in densely populated (DP) areas and less densely populated (LDP) areas. *Results*: Families living in LDP areas were found to: (1) have reduced employment hours (a two-parent household: Exp (B) = 3.48, $p < .001$, a single-parent household: Exp (B) = 3.32, $p = .011$); (2) travel greater distance to access medical facilities (Exp (B) = 1.27, $p = .006$); and (3) report less severe stress levels (Exp (B) = 0.22, $p = .014$). *Conclusions*: There were no differences in family routines; however, flexible employment opportunities and travel distance to medical services need to be considered in families living in LDP areas.

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ASD; employment status; regional and remote; travel distance

Introduction

It is estimated that 0.5% of all Australians had autism in 2012; equating to a 79% increase from the 2009 Australian national survey.[1] Individuals with Autism Spectrum Disorder (ASD) have difficulties in (1) communication, (2) establishing reciprocal relationships with others, and (3) displaying rigid and repetitive interests and activities,[2] which are related to the triad of ASD symptoms. These symptoms and other common issues, such as challenging behavior and anxiety, cause stress within the family;[3–5] which, in turn, may impact on activity participation, everyday family functioning, and quality of life (QoL).[6–11]

The experiences and needs of families of children with ASD living in regional and remote areas are often overlooked as previous research in the area of family routines, family stress, and QoL has predominantly collected data from highly populated areas.[3,4,12–16] This has resulted in gaining a limited understanding of specific experiences of those families living in regional and remote areas. Regionality in this study is defined in terms of difference in population density; with the terms densely populated (DP) areas and less densely populated (LDP) areas used to contrast the difference between highly populated areas and regional and remote areas. On average, families of children with ASD use between four and eight different treatments for their child;[17–20] some families use as many as seven treatments concurrently.[18] Parents of children with ASD regularly schedule therapeutic services for their children to maximize their functional independence, promote social and play skills, enhance development and learning, and reduce maladaptive behaviors.[21–23] Families of children with ASD spend more time attending therapeutic appointments to manage their children's symptoms, compared with families of typically developing children.[23,24] The extra visits to health services and the increased length of time for appointments places extra burden on the child care demands for those parents.[23] This increased demand on child care is associated with higher levels of parental stress, decreased QoL, and a higher prevalence of depression and anxiety among parents of children with ASD.[6–11,25,26] While meeting the increased demands in caring for the child with ASD, parents make remarkable efforts to sustain family daily routines by using different strategies, such as changing environments and detailed planning.[27–29]

Effective family routines assist in organizing, sustaining, and propagating a family's everyday life and provide stability and continuity to the household.[30–32] The daily routines in families of children with ASD often center on the idiosyncratic demands of the child with ASD rather than the family as a unit.[3,13,31,33] For example, families of children with ASD often report difficulties in engaging in mealtime activities as a family unit, due to the sensory needs of the child with ASD,[27] or experiencing increased stress due to the need to accommodate the unique demands of the child with ASD.[4,27,28]

The evidence to date on the nature and degree of the impact of ASD on family daily routine is largely inconclusive.[32] For example, findings from some studies have found no significant differences in the mean number of routines that families with and without a child with ASD engage in.[12,13] Conversely, others report adjustments in daily routines in families of children with ASD in order to accommodate the idiosyncratic demands of the child with

CONTACT Reinie Cordier ✉ reinie.cordier@curtin.edu.au School of Occupational Therapy and Social Work, Faculty of Health Sciences, Curtin University, GPO Box U1987, Perth, 6845, Australia.

ASD,[3,4,31] which are associated with the triad of ASD.[34] What is largely unexplored is whether there exists differences in family routines, stress and QoL between families living in DP areas compared with LDP areas.

The construct of regionality takes on precedence within the Australian context given the geography of the continent. In Australia, nearly 90% of the population live in DP areas.[35] This uneven spread of population density has resulted in increased service availability in those areas. Families living in LDP areas reported limited access to ASD specific therapy services.[36] Similar findings of reduced access to ASD specific therapeutic service have been reported by families of children with ASD living in rural Canada[37] and rural USA.[38] This reduced accessibility to service may influence the ability of families of children with ASD to form and maintain their family daily routines.

As such there is a need to compare those families living in LDP areas to those who live in DP areas to obtain a better understanding of the geographical constraint encountered, in order to inform appropriate services development and delivery. Thus, the aim of the current study was to explore differences due to regionality in: (1) family daily routines (for example, hours of parental employment, parental ability to socialize, parental participation in leisure activities, and engagement in play activities outside of school), (2) service usage (for example, travel distance to medical facility and average weekly hours of attending therapeutic services) and (3) perceived stress levels.

Methods

Development of the questionnaire

The questionnaire was originally developed for a study which investigated the cost associated with raising a child with ASD.[39] Although the questionnaire was developed for a specific purpose, it contained a broader range of questions, including socio-demographic status of family; children's official ASD diagnosis, presence of intellectual disability and other medical conditions; travel distance to the medical and therapeutic services; frequency in visiting the medical and therapeutic services; hours partaking in Early Intervention Therapy; the types of school the children with ASD attend; the types and use of childcare services; parental employment status; the levels of social support received; the impact of ASD diagnosis on parental ability to socialize; and the parental perception of family's stress levels due to having a child with ASD. The full questionnaire is available from Horlin et al.[39] The development of the questionnaire was informed by anecdotal reports from clinicians, families of children with ASD, current literature and insurance reports on expenses related to having a child with ASD. It was refined following the comments from clinicians and service providers and pilot testing was conducted with three families of children with ASD. The questionnaire was further adjusted following the pilot testing and 73 items were included in the full version of the questionnaire. Most of the questions had a Likert scale with an average of seven options to choose from. Researchers experienced in the field of ASD, the second and fourth authors, selected 35 questions which were relevant to the aim of the current study from these questionnaire items. The last page of the questionnaire included a diagnostic checklist of DSM-IV-TR/ICD10 symptoms of ASD[40] to verify that child meet diagnostic criteria at the time of completing the survey. This checklist contains three main domains of ASD symptoms, including: impairment in social interaction; communication impairment; and restricted, repetitive, stereo typed patterns of behavior. The respondents were asked to indicate if any of the symptoms listed in each domain were currently present or were previously present for their children with ASD.

Participants and procedures

In 2013, the questionnaire was distributed to 3,723 families of children with ASD who were under the age of 18 years and registered with the Disability Service Commission (DSC) of Western Australia. The DSC recommended to include only families of children with ASD under the age of 18 years to increase the chance of obtaining correct/valid information from the register. Those families with more than one child with ASD received one questionnaire per child with ASD. A total of 3,965 questionnaires were distributed and 192 were returned as "address unknown". A total of 545 questionnaires were returned, resulting in a response rate of 14%. Of those, 535 contained relevant data to the current study.

Data analyses

Analysis of non-respondents

Six months after the initial mail out, 405 families were randomly selected and contacted telephonically from the DSC register for the purpose of a drop-out analysis. If the families reported that they did not complete the original questionnaire, they were asked to complete the abbreviated version of the original questionnaire, which contained twenty questions, including the socio-demographic status of the family; children's official ASD diagnosis, presence of cognitive/intellectual disability and other medical conditions; cost of medical/therapeutic treatment; parental employment status; and the parental perception of family's stress levels. A comparison of demographic variables between non-respondents and those families who completed the original questionnaire was made using *t*- and *chi*-square tests of independence. One hundred and thirty-eight out of 405 families could not be reached largely due to incorrect phone numbers recorded on the DSC register. Sixty-four families completed the original questionnaire, therefore were excluded and 55 families declined to participate. One hundred and forty-eight families agreed to complete the short-form questionnaire; of those, two families did not have children with ASD therefore were excluded. No significant difference was found in children's age, children's official ASD diagnosis, and household composition. However, the timing of receiving formal diagnosis of ASD was earlier among the respondents. Further, the child with ASD in the respondents' families was slightly more likely to be male and the respondents had noticed developmental abnormality of their children earlier than non-respondents. Nevertheless, the non-respondent analysis largely confirmed that the limited sample of 535 families in the current study represented the much larger target group.

Statistical analysis

Data were analyzed by using the Statistical Package for the Social Sciences (SPSS) version 22.[41] Descriptive statistics were analyzed to provide demographic information of the study participants.

The Australian Statistical Geography Standards (ASGS) remoteness structure was used to classify postcodes. The ASGS remoteness structure is classified into five remoteness areas (RAs).[42] RAs are based on road distances to the nearest service centers and average scores are calculated using the Accessibility/Remoteness Index of Australia (ARIA +) grid, which is a one square kilometer grid covering all of Australia.[43] The RAs include the following five remoteness categories: (1) major cities (average scores between 0 to 0.2); (2) inner regional (average scores greater than 0.2 and less than or equal to 2.4); (3) outer regional (average scores greater than 2.4 and less than or equal to 5.92); (4) remote (average scores greater than 5.92 and less than or equal to 10.53); and (6) very remote (average scores greater than 10.53).[43] Participants' postcodes in the current study were recoded based on this classification. The RAs were further collapsed into a dichotomous variable for the purpose of undertaking logistic regression. In doing so, DP category was formed by collapsing the major city and inner regional city post codes and LDP category was formed by merging the outer regional, remote and very remote postcodes.

The selected 35 questions were structured into demographic, family daily routines and accessibility to services categories and used as independent variables (IVs). Chi-square and t-tests were conducted to identify IVs which significantly associated with the regionality, which was the dependent variable (DV). Binary logistic regression analyses were then run with the identified IVs to identify key factors associated with LDP areas in family daily routines, the service usage and their stress levels.

Ethical approval

The study conformed to the principles of the Declaration of Helsinki.[44] Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR138/2012) and the internal ethical review board in Western Australia. When respondents completed and returned the questionnaire, it was considered that they provided consents to participate in the study.

Results

Descriptive profile of the study participants

Figure 1 provides an overview of the spread of the respondents by regionality. A total of 476 participants (89%) resided in DP areas and 59 participants (11%) resided in LDP areas in WA. The sample's demographic profile was comparable; there were no significant group differences due to regionality. For example, over 80% of the respondents' children with ASD were boys regardless of regionality.

Chi-square and t-tests analyses

Chi-square test for independence and t-test were conducted to identify IVs significantly associated with the regionality (DV). Associations at the nominated significance level ($p < 0.1$) were found between regionality (DV) and the following IVs: (1) types of school attended by the child with ASD (p = .014); (2) access to in-home respite services (p = .009); (3) effect of a child's ASD symptoms on primary care-givers' employment hours (p = .002); (4) number of employment hours reduced due to having a child with ASD (p = .047); (5) impact of having a child with ASD on primary care-givers' ability to socialize (p = .042); (6) travel distance to medical facility (p = .005); (7) average weekly hours which a child with ASD attend Early Intervention Therapy (p = .016); (8) frequencies of respite care utilization (p = .003); (9) levels of social support primary care-givers receive (p = .032); (10) parental perception of levels of family stress due to the impact of having a child with ASD (p = .003); (11) hours arranged for their other children, if any, without ASD to attend day care (p = .063); (12) average weekly hours the child with ASD spend with friends (p = .073); and (13) average monthly visits to non-medical services other than intervention or behavioral therapy (p = .071). These significant IVs were entered into the univariate analysis. The non-significant IVs include: (1) hours arranged for a child with ASD to attend day care centers and after school care; (2) evening and weekend babysitter hours arranged for a child with ASD; (3) hours arranged for their other children, if any, without ASD to attend after school care; (4) evening and weekend baby sitter hours arranged for their other children without ASD; (5) primary care-givers' weekly leisure hours; (6) average monthly number of ASD related medical visits; (7) average monthly number of non-ASD related medical visits; (8) distance to therapeutic services; (9) weekly average therapy interventions hours attended by a child with ASD who is older than 7 years; (10) average weekly education support hours which a child with ASD receive; (11) difficulty finding babysitters for a child with ASD; (12) if the family moved since their child was diagnosed with ASD; (13) types of people whom the primary care-givers receive support from; (14) presence of dual diagnosis of ASD and intellectual disability; (15) presence of dual diagnosis of ASD and mental health diagnosis; (16) presence of dual diagnosis of ASD and

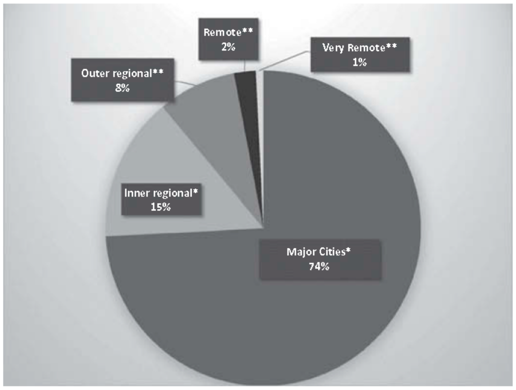

Figure 1. Percentage of responses in each response category for the residential postcode question. *Densley populated areas (DP), **Less densely populated areas (LDP).

chronic illness; and (17) impact of interventions on children's QoL. These non-significant IVs were excluded from further analysis.

Univariate analysis

All significant IVs at the nominated level were tested in univariate analysis to select IVs which would be included in multivariate logistic regression analysis. The following IVs were found to be significant and therefore included in the multivariate logistic regression analysis: (1) types of school attended by the child with ASD (p = .032); (2) effect of a child's ASD symptoms on primary care-givers' employment hours (p = .026); (3) travel distance to medical facility (p = .012); (4) parental perception of levels of family stress due to the impact of having a child with ASD behavioral therapy (p = .031); and (5) average monthly visits to non-medical services other than intervention or behavioral therapy (p = .019). The following non-significant IVs were excluded in the multivariate logistic regression analyses: (1) access to in-home respite services; (2) number of employment hours reduced due to having a child with ASD; (3) impact of having a child with ASD on primary care-givers' ability to socialize; (4) average weekly hours which a child with ASD attend Early Intervention Therapy; (5) frequencies of respite care utilization; (6) levels of social support primary care-givers receive; (7) hours arranged for their other children, if any, without ASD to attend day care; and (8) average weekly hours the child with ASD spend with friends.

Multivariate logistic regression analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant (X^2 = 33.9, DF = 4, p < 0.001). Four significant factors included explained 14% of the variability of the outcomes (Nagelkerke R^2 = 0.14). The overall accuracy of the model was 89.6%. The Wald statistic was used to identify statistically significant factors associated with families of children with ASD living in LDP areas and Exp (B) was used to predict the direction of prediction (Table 2).

For the two IVs (overall family stress and overall employment hours) which were ordinal in nature, dummy variables were created to analyze the difference within each category of the variable. The analysis revealed three factors, including two categories in one of the IVs (overall employment hours), which significantly contributed towards living in LDP areas. These included:

1. Employment hours (two-parent household) due to having a child with ASD (p < .001)
   Participants living in LDP areas were 3.48 times more likely to reduce employment hours.
2. Employment hours (single-parent household) due to having a child with ASD (p = .011). Participants living in LDP areas were 3.32 times more likely to reduce employment hours.
3. Travel distance to medical facility (p = .006). Participants living in LDP areas were 1.26 times more likely to travel greater distance to access medical facility.
4. Parental perception of *very* severe stress levels resulting from having a child with ASD (p = .014). Participants living in LDP areas were 0.22 times less likely to report *very* severe stress levels.

The following factors did not significantly contribute to the multivariate model: (1) types of school the child with ASD attended; and (2) average monthly visits to non-medical services other than intervention or behavioral therapy. Although overall ratings were significant for the two IVs (overall family stress levels and overall employment hours), following the analysis using dummy variables, the subsequent categories within each variable were found to be statistically non-significant. These categories included: (1) ratings of mild stress levels resulting from having a child with ASD; (2) ratings of moderate stress levels resulting from having a child ASD; (3) ratings of severe stress levels resulting from having a child with ASD; (4) ratings of employment hours reduced due to having a child with ASD for both parents; (5) ratings of one parent unable to work due to having a child with ASD in a two-parent household; and (6) ratings of both parents unable to work due to having a child with ASD in a two-parent household.

Discussion

Family daily routines

The current study found that the parents in LDP areas, regardless of household composition, were more likely to report reduced employment hours due to having a child with ASD than their DP counterparts. This may be related to a lack of opportunities in obtaining flexible employment in those areas in Australia, where the major sources of employment are in agriculture, forestry, fishing and mining industries.[45] The recent legislative change and the introduction of a variety of leave entitlements in Australia, such as a paternity leave, has resulted in more flexible and family friendly employment conditions.[46,47] However, there continues to exist notable difference between industries in providing flexible employment opportunities. For example, nearly half of the agriculture, forestry and fishing workers are required to be on call,[48] which limits workers' flexibility in daily planning. This contrasts with the employment conditions in the professional, scientific and technical service industries, where 70% of the workers are offered the flexibility of choosing their start and finish times; more than twice that of the mining industry workers.[47] Given the variability in employment opportunities due to industry type, it is plausible to argue that a limited range of employment options and less flexible employment conditions in LDP areas adversely affect the ability of parents to participate in workforce while accommodating the needs of their child with ASD.[49]

This study did not find much difference in families' engagement in daily routine between DP and LDP areas, apart from the finding in parental reduced employment hours. The results indicate that routines in families of children

Table 1. Characteristics of the families of children with ASD for the total sample, the sample of participants living in DP areas of Australia and the sample of participants living in LDP areas of WA.

	Total sample		DP areas of WA sample		LDP areas sample	
Characteristics	$N = 535$	%	$N = 476$	%	$N = 59$	%
Children's Age (month) Mean (standard deviation)	119.51 (50.5)	119.52 (50.8)	118.91 (48.8)			
					$t = 0.86$, $p = 0.56$	
Children's Gender						
Male	442	82.9	397	83.8	45	76.3
Female	91	17.1	77	16.2	14	23.7
					$X^2 = 2.07$, $DF = 1$, $p = 0.15$	
Official ASD diagnosis						
Autism	289	55.7	253	54.3	36	63.2
HFA	113	21.8	107	23.2	6	10.5
AS	37	7.1	30	6.5	7	12.3
PDD-NOS	80	15.4	72	15.6	8	14
					$X^2 = 8.24$, $DF = 6$, $p = 0.22$	
Presence of cognitive impairments/intellectual disability						
Yes	147	27.8	133	28.2	14	24.1
No	382	72.2	338	71.8	44	75.9
					$X^2 = 0.43$, $DF = 1$, $p = 0.51$	
Presence of other diagnosed psychological/mental health						
Yes	114	21.5	101	21.4	13	22
No	416	78.5	370	78.6	46	78
					$X^2 = 0.01$, $DF = 1$, $p = 0.91$	
Presence of other medical diagnosis						
Yes	173	33	157	33.6	16	27.6
No	352	67	310	66.4	42	72.4
					$X^2 = 0.85$, $DF = 1$, $p = 0.35$	
Respondents' relationship to child						
Biological mother	430	80.7	379	80	51	86.4
Biological father	94	17.6	88	18.6	6	10.2
Grandparent	4	0.8	2	0.4	2	3.4
Foster parent	3	0.6	3	0.6	0	0
Step parent	1	0.2	1	0.2	0	0
Other	1	0.2	1	0.2	0	0
					$X^2 = 9.1$, $DF = 5$, $p = 0.1$	
Timing of when noticed 1st sign of something not right						
Less than 12 months	129	24.2	114	24.1	15	25.4
12 to 18 months	154	28.9	140	29.5	14	23.7
19-24 months	106	19.9	95	20	11	18.6
2 to 6 years	131	24.6	114	24.1	17	28.8
6 to 12 years	11	2.1	9	1.9	2	3.4
13 to 18 years	2	0.4	2	0.4	0	0
					$X^2 = 2.0$, $DF = 5$, $p = 0.84$	
Care-givers' employment status						
Both fulltime	39	10.7	37	11.4	2	5.3
None employed	8	2.2	8	2.5	0	0
One fulltime and one part time	121	33.3	105	32.3	16	42.1
Only one fulltime	122	33.6	112	34.5	10	33.6
Both part time	14	3.9	13	4.0	1	2.6
Single parent full time	13	3.6	10	3.1	3	7.9
Single parent not employed	29	8	27	8.3	2	5.3
Single parent part time	17	4.7	13	4.0	4	10.5
					$X^2 = 9.6$, $DF = 8$, $p = 0.28$	
Household composition						
Two parent	406	77.6	359	77.4	47	79.7
Single parent	76	14.5	66	14.2	10	16.9
Extended family	4	0.8	3	0.6	1	1.7
Two parent and extended family	24	4.6	23	5	1	1.7
Single parent and extended family	10	1.9	10	2.2	0	0
Foster	3	0.6	3		0	0.6
					$X^2 = 3.9$, $DF = 5$, $p = 0.56$	

with ASD do not differ by regionality. However, IVs used in the current study did not include commonly examined family routine activities, such as mealtime and bedtime,[4,16,50–52] morning routine[53,54] and family leisure activity.[55] While previous research suggest that the unique characteristics of ASD impact on family routine engagement,[4,33] investigations into the experiences of families of children with ASD in LDP areas are limited. Hence, future study should include those commonly examined family routine activities to obtain a better picture of the unique experiences among families in LDP areas in engaging in daily routine.

Service usage

We found that families of children with ASD living in LDP areas travelled significantly greater distance to access medical services, which may be a reflection of an uneven distribution

Table 2. Variables associated with families of children with ASD living in LDP areas.

LDP areas

Independent Variables	B	SE	Wald	p	Exp (B)	95 % CI for Exp (B)	
						Lower	Upper
Reduced employment hours due to having a child with ASD (a two-parent household)	1.24	0.33	14.08	<.001	3.48	1.81	6.69
Reduced employment hours due to having a child with ASD (a single-parent household)	1.20	0.47	6.49	.011	3.32	1.31	8.39
Travel distance to medical facility	.23	0.86	7.51	.006	1.27	1.07	1.50
Family's very severe stress levels due to having a child with ASD based on parental perception	−1.51	0.61	6.09	.014	0.22	0.06	0.73

of medical services between DP and LDP areas in Australia. In 2011, the per capita ratio of GPs and specialists working in LDP areas was found to be lower than those in DP areas.[56] The geographical limitation unique to countries like Australia may be contributing to the fact that people with disability, including ASD, who reside in LDP areas access medical services less frequently than their DP counterparts.[57] However, children with ASD often require on-going medical and therapy support[21] and parents are committed to meeting the needs of their children with ASD.[14,58,59] Having to travel long distances to medical services increases the time spent in transit. This could potentially add extra strain and cost to the life of families in LDP areas.

The current study did not find much difference in service usage between the two areas, apart from travel distance to medical facility. This finding may indicate a lack of services which caters for children with ASD in general, considering the low response rate (total of 125 out of 535 respondents) for this question. No significant difference between families living in DP and LDP areas were found in difficulty finding baby sitters for their child with ASD and many of the respondents reported "very to somewhat" difficulty in finding baby sitters. Mothers of children with ASD have reported their unmet needs in receiving support in child care.[60] It is imperative to provide child care support services to those families, given the higher levels of stress among this population.[25,26]

Perceived stress levels

Families in LDP areas were less likely to report *very* severe levels of stress in this study. Although increased parental role strain and related stress due to lack of services can be a common issue in LDP areas,[58] the advantage of living in these areas may be that families receive better support from within the community. Having adequate social support moderates the adverse effects of stress on health.[10,11] However, given the small odds ratio, we need to consider the possibility that service provision in DP areas may already include strategies which increase community connections in supporting parents of children with ASD.

Taking a community approach to support the families of children with ASD in LDP areas may foster positive parental perceptions of community acceptance of their child with ASD and their family.[59] These increased positive parental perceptions would be expected to encourage those families to socialize within their community, resulting in establishing further personal connections with others. Factors, such as the difficulty finding a family friendly environment which caters to the needs of the child with ASD; people's prejudicial attitudes towards children with ASD due to lack of knowledge; and the substantial parental efforts to educate others repeatedly by explaining their children's behavior,[14],[15] can lead the families of children with ASD to feel stressed in public spaces. However, people living in small communities in LDP areas may become familiar with the child with ASD more intimately. The increased awareness of the unique needs of the child with ASD could allow people to provide better support to the child and their families.[59] The opportunity to form closer community relationships in LDP areas may act as a protective factor for the families of children with ASD from experiencing higher stress levels.

Limitations

There are some limitations in the current study. First, this study was a secondary analysis of the previously collected data.[39] Although we used a specific question to measure families' stress due to having a child with ASD, validated measures for stress or family daily routines were not used. Caution therefore ought to be exercised while generalizing the results. Second, the representation of the participants from LDP areas was low (11%). More targeted recruitment strategies to increase a better representation of LDP family participants is recommended. Third, the response rate observed was low (14%).[39] This may be because the contact details of families registered with the DSC are maintained sporadically and as a consequence, a number of records contained incomplete or inaccurate entries. Additionally, due to the manner in which the DSC database is set up, the questionnaire was only addressed to the father of the registered clients. This would mean that mothers of separated couples did not receive the questionnaire. Given the children's mothers were the primary respondents (80%) in this study, overlooking this sample group would be expected to reduce the response rate. However, it should be noted that the non-respondent analysis suggested the sample was representative.

Conclusion

Overall, this current study did not find much difference in the nature of family routines and service usage due to families' residential location, except the three factors discussed. The results indicate: (1) underlying inequality of employment opportunities in LDP areas; (2) the scarcity of medical professionals in LDP areas; and (3) lower parental perception of family stress levels in

LDP areas. A further exploration of the factors and associated issues with the geographical expansion in LDP areas, targeting employment and medical service provision, is required. The reason for lower stress levels in LDP areas should be further examined to benefit parents in DP areas. Detailed investigation into family routines by breaking down activities and by using a method which captures "lived experience" of family, such as experience sampling method, may be useful to elicit the experiences of families of children with ASD. Future studies should also consider using valid family routine and stress measures, combined with qualitative methods, in order to guide the direction of research and practice in this area.

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Declaration of interest

The research was conducted in collaboration with the Disabilities Services Commission Western Australia (DSC). All aspects of the current study, including design, implementation, data collection, analysis and interpretation, were conducted independently from the DSS. The authors collaborated with the DSC and received assistance in data collection phase. Approval to submit this study for publication was sought from Autism CRC, DSS and DSC; however, the authors took sole responsibility to write and submit this current study. All researchers are independent from both DSS and DSC and take full responsibility for the integrity of the work.

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Appendix E: Chapter 4 published paper

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ORIGINAL PAPER

Quality of Life, Coping Styles, Stress Levels, and Time Use in Mothers of Children with Autism Spectrum Disorders: Comparing Single Versus Coupled Households

Tomomi McAuliffe[1] · **Reinie Cordier**[1] · **Sharmila Vaz**[1] · **Yvonne Thomas**[2] · **Torbjorn Falkmer**[1,3,4,5]

Abstract This study aimed to examine the influence of differences in household status on the parental stress, coping, time use and quality of life (QoL) among mothers of children with autism spectrum disorders. Forty-three single and 164 coupled mothers completed the survey. Data were analysed using multivariate logistic regression. We found that single mothers were 1.05 times more likely to report lower levels of environmental QoL. Whilst they were 1.73 times more likely to use acceptance coping style, this association did not persist after adjusting for total number of children, household income and employment status. There was no difference in time use and stress between these mothers. Possible environmental issues for single mothers and implications for future research are discussed.

Keywords ASD · Single and coupled mothers · Time use · Quality of life · Stress · Coping

Introduction

Parenting a child with autism spectrum disorders (ASD) can be a challenging task (Nicholas et al. 2016). It is well documented that parents of children with ASD experience higher levels of stress than parents of children without ASD (Griffith et al. 2010; Montes and Halterman 2007; Zablotsky et al. 2013). Limited social skills, challenging behaviour of the child with ASD (Bromley et al. 2004; Griffith et al. 2010) and low levels of family support (Bromley et al. 2004) are some of the factors associated with the increased parental stress levels.

Previous studies with families of children with ASD have developed knowledge on the parental experiences, such as parental stress levels (Griffith et al. 2010), coping styles (Marshall and Long 2010), time use (Sawyer et al. 2010), and quality of life (QoL) (Dardas and Ahmad 2014a). In the study of the parental experiences, the experiences of mothers of children with ASD are commonly examined (Ekas et al. 2010; Ekas and Whitman 2010; Kuhaneck et al. 2010;

✉ Tomomi McAuliffe
tomomi.mcauliffe@curtin.edu.au

Reinie Cordier
reinie.cordier@curtin.edu.au

Sharmila Vaz
s.vaz@curtin.edu.au

Yvonne Thomas
y.thomas@worc.ac.uk

Torbjorn Falkmer
t.falkmer@curtin.edu.au

[1] School of Occupational Therapy and Social Work, Faculty of Health Sciences, Curtin University, GPO Box U1987, Perth, WA 6845, Australia

[2] Allied Health and Social Sciences, Institute of Health & Society, University of Worcester, Henwick Grove, Worcester WR2 6AJ, UK

[3] School of Occupational Therapy, La Trobe University, Melbourne, VIC, Australia

[4] Rehabilitation Medicine, Department of Medicine and Health Sciences (IMH), Faculty of Health Sciences, Linköping University & Pain and Rehabilitation Centre, UHL, County Council, Linköping, Sweden

[5] Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), Long Pocket, Brisbane, QLD, Australia

Marshall and Long 2010; Seymour et al. 2013). Mothers face an increased risk of ill health (Allik et al. 2006), and are required to assume multiple roles to cater for the unique demands of the child with ASD (Safe et al. 2012). Studies that specifically examined the experiences of fathers are somewhat limited (Burrell et al. 2017; Cheuk and Lashewicz 2016); however, some studies have compared the experiences between mothers and fathers of children with ASD (Allik et al. 2006; McStay et al. 2014; Mugno et al. 2007). For example, there is emerging evidence to suggest mothers of children with ASD experience lower levels of QoL than fathers (McStay et al. 2014).

Previous studies have used various parental characteristics in investigating the experiences of parents of children with ASD. These characteristics include age (Gray 2006; Pruitt et al. 2016), gender (Allik et al. 2006; Lee 2009; McStay et al. 2014; Mugno et al. 2007), employment status (Dardas and Ahmad 2014a), and household income (Dardas and Ahmad 2014a). In fact, a recent review on coping styles among parents of children with ASD reported that age and gender of parents are the most commonly discussed factors (Lai and Oei 2014). Spousal relationship factors, such as spousal support (Dunn et al. 2001), marital satisfaction (Higgins et al. 2005), and marital quality (Harper et al. 2013), are other parental characteristics used to investigate the experiences of parents of children with ASD. Parents of children with ASD were found to experience spousal relationship issues when they used maladaptive coping strategies, such as escape-avoidance (Dunn et al. 2001).

Few studies have compared the experiences of parents of children with ASD using a parental characteristic of single versus coupled household status. Household status is common demographic information to be collected in the study of parents of children with ASD; however, it is not always used as the primary variable of interest (Mugno et al. 2007). One study reported insufficient statistical power to compare parental coping strategies based on the single versus coupled household status (Twoy et al. 2007). Some studies have used the household status in their statistical analyses (Benjak 2011; Bromley et al. 2004; Reed et al. 2016). For example, one study that compared subjective QoL between parents of children with ASD and parents of children without a disability in Croatia conducted a logistic regression analysis with an independent variable of single versus coupled household status (Benjak 2011). However, the focus of the previous studies that used the variable of the household status was not to investigate the parental experiences due to single versus coupled household status. This current study, therefore, intends to fill the gap in the study of parents of children with ASD through analysing various parental experiences, such as stress levels, coping styles, time use, and QoL that relate to single versus coupled household status.

Mothers' Experiences When There is a Child with ASD in Their Families

To date, parental experiences, such as stress levels, coping styles, time use and QoL have been examined among mothers of children with ASD (Benson 2010, 2014; Dardas and Ahmad 2014a, b, 2015; Mugno et al. 2007; Sawyer et al. 2010). Families of children with ASD tend to assume traditional family roles where mothers commonly hold the primary caregiver's role (Nealy et al. 2012; Pepperell et al. 2016). As primary caregivers, mothers are more likely to experience parenting related difficulties. One study that examined child related stressors, availability of resources, and coping strategies among parents of children with ASD found that mothers experienced higher levels of stress than fathers (McStay et al. 2014). Although parents of children with ASD use various coping styles, such as acceptance, humour, and gaining hope from child's improvement (Marshall and Long 2010), some coping styles used may be counterproductive or maladaptive (Hall and Graff 2011; Sivberg 2002). A recent longitudinal study, which was conducted over a 7-year period, on maternal coping styles and adjustment among mothers of children with ASD found that increased use of maladaptive coping styles was related to increased stress proliferation and distress, and decreased parental efficacy (Benson 2014). It is therefore important to examine the parental coping styles, in particular those of mothers, given that mothers are commonly the primary organisers of the family schedules (Larson 2000).

The role of being a mother is time intensive, especially when children have a disability (Olson and Esdaile 2000). Compared with parents of typically developing children, parents of children with special needs spend longer time in childcare activities (Crowe and Florez 2006; McCann et al. 2012). One study found that mothers of children with a disability engaged in childcare activities on average 13.1 h more per week than mothers of children without a disability (Crowe and Florez 2006). Parents of children with ASD were found to spend on average 43 h per week in caring for their children (Järbrink et al. 2003). A consequence of increased childcare hours is a reduction of time available for other daily activities among parents, including personal leisure, work, and personal care (Brandon 2007). Mothers feel physically and mentally exhausted by meeting this increased care needs, while not spending much time in personal care, such as sleeping (McGuire et al. 2004).

A recent systematic review found that the QoL of parents of children with ASD is lower than that of parents of typically developing children or the general population (Vasilopoulou and Nisbet 2016). Various factors are associated with parents of children with ASD reporting lower QoL. These factors include increased challenging behaviours of the child with ASD (Dardas and Ahmad 2014a;

McStay et al. 2014; Tung et al. 2014), severity of ASD (Pozo et al. 2014), lower household income (Dardas and Ahmad 2014a), decreased levels of social support (Pozo et al. 2014), parental distress (Dardas and Ahmad 2014a), and parental coping style (Dardas and Ahmad 2014a; Pozo et al. 2014). The complex interplay between these factors should, therefore, be considered when describing the QoL among parents of children with ASD. Parents of children with ASD are often required to adjust many aspects in their life, including their family interactions, family lifestyles, marital relationships, work arrangement, coping styles, and their perspective of life (Ooi et al. 2016). QoL is useful in capturing the complexity of the lives of these parents and should be considered in understanding the impact of having a child with ASD on parents (Dardas and Ahmad 2014a).

Parental Experiences Among Single Mothers

The family structure has changed over the years in Western society due to the decreased marriage rates, the increased divorce rates, and the increased number of cohabiting couples (The Organisation for Economic Co-operation and Development [OECD] 2012). One of the notable family structural changes is an increase of single parent families. In Australia, by 2031 the rate of the single-parent families is projected to increase by between 40 and 77% (Australian Bureau of Statistics 2010). Other OECD countries, such as UK and Norway, have projected similar trends of an increase of single parent families (OECD, 2012). In 2015, there were 617,800 single parent families with dependants living with them in Australia and of those, 84% were led by single mothers (Australian Bureau of Statistics 2016). This over-representation of single parent families that are led by mothers is predicted to remain unchanged over the next 15 years (Australian Bureau of Statistics 2010).

Single motherhood, in general, presents some unique challenges, for example, additional time pressure in managing daily family responsibilities (Compas and Williams 1990; Sachs et al. 1995) and financial pressures (Cooper et al. 2008; Sachs et al. 1995). One study that compared the experiences of single and coupled first-time mothers of typically developing infants found that single mothers experienced higher levels of stress than their counterpart (Copeland and Harbaugh 2010). Both global (Witvliet et al. 2014) and Australian (Crosier et al. 2007) studies indicate that single mothers experience poorer physical and mental health outcomes compared to coupled mothers.

Single motherhood has been previously explored particularly within the area of social welfare and employment research (Cook 2012b, c; Herbst and Tekin 2014; Wu et al. 2014); however, there is a paucity of research on single mothers of children with chronic health conditions, including children with a disability (Brown et al. 2008). Even fewer studies have been conducted with single mothers of children with ASD (Dyches et al. 2016). Given the challenges that single mothers face, combined with the unique factors identified among mothers of children with ASD, such as increased stress levels and lower QoL, there is a need to investigate the experiences of single mothers of children with ASD.

The Aim of the Study

The aim of the current study was to examine the influence of differences in household status (single versus coupled) on the stress levels, coping styles, time use and QoL among mothers of children with ASD. For the purpose of this study, we employed the definition of lone parent provided by the Australian Bureau of Statistics (2015) to define single mothers. Single mothers in this study are those who have “no spouse or partner usually resident in the household but who forms a parent–child relationship with at least one child usually resident in the household” (Australian Bureau of Statistics 2015, para. 21).

Methods

Study Design

The present study was part of a larger cross-sectional study that investigated the experiences of families of children with ASD in Western Australia. Researchers at Curtin University conducted this study in collaboration with the Disability Services Commission of Western Australia (DSC) and South-West Autism Network (SWAN). The larger study examined a number of topics related to the experiences of families of children with ASD, with a cross-sectional survey that consisted of the following four sections: (1) demographic information of the family, (2) the process of ASD diagnosis and access to health services, (3) the impact of having a child with ASD on family life, and (4) possible behavioural difficulties related to the characteristics of ASD. The survey was pilot tested with a convenient sample for clarify of questions, the flow of content, and estimating completion timeframe. The survey was refined following the pilot testing.

Participants

A parent or a primary caregiver of a 2–18 year old child or young person diagnosed with ASD living in Western Australia was eligible to participate in this study. The participants were recruited through the existing internal lists of families of children with ASD who agreed to participate in future research held at Curtin University and the Telethon Kids Institute; service providers, such as DSC and SWAN; ASD related events held at Curtin University; health professionals working with families of children with ASD; and media release on radio.

Instruments

Four measures were used in this current study: (1) The World Health Organisation Quality of Life BREF (The WHOQOL Group 1998), (2) Autism Parental Stress Index (Silva and Schalock 2012), (3) The Brief COPE (Carver 1997), and (4) time use estimate table. All four measures were included in section three of the survey (i.e., the impact of having a child with ASD on family life).

The World Health Organisation Quality of Life Brief (WHOQOL BREF)

The WHOQOL BREF that is a short form of the WHOQOL-100 is a convenient and concise tool to use for studies in which QoL is of interest (The WHOQOL Group 1998). It is possible to calculate four domain scores: physical, psychological, social relationships, and environment. Social relationships and environmental domains are often not included in other short version of QoL assessments (The WHOQOL Group 1998). There are 26 items in total. Some examples of the items in the physical domain include pain and discomfort, energy and fatigue, mobility, and work capacity. In the psychological domain, items, such as positive and negative feelings, self-esteem, bodily image, and spirituality, are included. The social relationships domain includes personal relationships, social support, and sexual activity. In the environment domain, items, such as physical safety and security, home environment, financial resources, accessibility to services and its quality, and opportunities for leisure activity, are included (The WHOQOL Group 1998). Two items are independent from these four domains: respondents' overall perception of QoL and their overall perception of health (The WHOQOL Group 1996). A five-point Likert scale is used in WHOQOL BREF, and the respondents are asked to answer each item reflecting their experiences in the last 2 weeks (Skevington et al. 2004). Four domain scores are calculated using the mean score of each item within each domain, and in order to make the domain scores comparable with the WHOQOL-100, the mean scores are then multiplied by four (The WHOQOL Group 1996). Each domain is reported to have acceptable internal consistency. The alpha levels reported for each domain are as follows: for the physical domain 0.82, for the psychological domain 0.81, for the social relationships domain 0.68, and for the environmental domain 0.80 (Skevington et al. 2004). Likewise, acceptable test–retest reliability of 0.66 for the physical domain, 0.72 for the psychological domain, 0.76 for the social relationships domain, and 0.87 for the environment domain over a 2–4 week period was reported (The WHOQOL Group 1998).

Autism Parental Stress Index (APSI)

The APSI has an overall parental stress scale and three subscales that measure stress levels of parents of a child with ASD, specifically identifying the areas with which parents require further support (Silva and Schalock 2012). These three subscales include (1) the core autism symptoms, (2) comorbid behaviours, and (3) comorbid physical issues. The results of the APSI validation suggests good internal consistency for the overall scale (Cronbach's alpha = 0.83). The acceptable internal consistency of 0.79 for the core autism symptoms; 0.76 for the co-morbid behaviours; and 0.67 for the co-morbid physical issue was reported. A good test–retest reliability of 0.88 was reported for the overall scale over a 4-month period (Silva and Schalock 2012).

Brief COPE

The 28-item Brief COPE was developed as a shorter version of the full COPE, and it measures 14 different coping styles (Carver 1997). The 14 theoretically derived subscales that consist of two items per subscale represent different coping styles: (1) active coping, (2) planning, (3) positive reframing, (4) acceptance, (5) humour, (6) religion, (7) emotional support, (8) instrumental support, (9) self-distraction, (10) denial, (11) venting, (12) substance use, (13) behavioural disengagement, and (14) self-blame. The Brief COPE is a useful tool for researchers to assess a range of coping styles, whilst reducing participant response burden. Respondents are asked to rate each statement that describes a coping style on a 4-point scale that ranges from 'I haven't been doing this at all' to 'I've been doing this a lot'. On average, adequate internal reliabilities (α ranged from 0.50 to 0.90) have been reported (Carver 1997).

Time Use Estimate Table

This constituted a 24-h format table that participants completed to describe their average weekday and weekend day by providing estimated hours on each of the 14 activities presented. We chose these 14 activities from previous publications on time use of mothers of children with a disability (Gevir et al. 2006; McCann et al. 2012). The fourteen activities listed in this study were (1) sleep, (2) grooming and personal hygiene, (3) meal preparations and clean up, (4) having a meal, (5) taking care of child, (6) travel time to and from school or work, (7) time spent at work, (8) personal leisure time, (9) house duties, (10) shopping, (11) having quiet time or down time, (12) visiting family/friends, (13) studying, and (14) voluntary work.

Procedures

The survey was made available in three different formats for completion: (1) an online version, (2) a telephone interview to complete the survey, or (3) a paper and pencil version to be returned via post. The online survey was available from January 2015 to December 2015. The paper and pencil version of the survey was distributed to prospective participants at several events, which were organised by the Curtin Autism Research Group (CARG) in 2015. Participants who completed the online survey ($n = 150$) provided consent to participate in this study by completing the survey. For those participants who completed the survey ($n = 2$) by telephone, a researcher read the scripted consent prior to starting the survey, and the participants' response was recorded in the electronic data entry form. The participants who completed the paper and pencil survey ($n = 55$) were asked to return the signed consent form to the research team. We have conducted a sensitivity analysis with all variables that went into the univariate analysis between those participants who completed the online survey and those who completed the paper and pencil version. There were no meaningful differences between the two forms of data collection on any of the variables. Due to the procedure used to collect data, it was impossible to calculate how many potential participants who received the survey, opted not to participate.

All data were entered directly by participants online or the researchers entered data from the telephone and the paper and pencil versions online. These data were stored on Curtin University's Qualtrics Web Server, which was password protected. A total of 248 surveys were completed. We removed those double or triple entries made by the same participants ($n = 22$) and only kept their latest entry in this current study. We also removed the entries made by fathers ($n = 16$) and by grandparents ($n = 3$) as the targeted population of the current study was mothers. In total, 207 were completed by mothers, including biological, step and foster, and thus were deemed relevant to the current study. For the purpose of this study, those 207 participants were categorised into coupled mothers and single mothers.

Data Analyses

The Statistical Package for the Social Sciences (SPSS) version 22 (IBM Corp. 2013) was used to analyse data. The question on participant's household status was used to create a dichotomous variable, a coupled mother or a single mother. The participants chose their household status from the following seven options: (1) two-parent, (2) single parent, (3) extended family (grandparents), (4) two-parent plus extended family, (5) single parent plus extended family, (6) foster situation, and (7) other. The household status category of the coupled mother was formed by collapsing the two parent ($n = 156$) or the two-parent plus extended family options ($n = 3$). The household status category of the single mother was formed by combining the single parent ($n = 39$) and the single parent plus extended family options ($n = 4$). Those participants who chose the other option were included if further information to identify their household status (i.e. two-parent or single parent) was provided ($n = 5$). Those participants who chose the extended family option were not included in this current study. The newly created household dichotomous variable, a coupled mother or a single mother, was used as a dependent variable.

Although the structure of the coping styles with Brief COPE among parents of children with ASD has been previously explored (Benson 2010; Hastings et al. 2005), both studies yielded different factor structures and had smaller sample size (N = 113; N = 135 respectively) than the current study (N = 207). Therefore, factor analysis was conducted to explore the structure of the coping styles that best fit to the current study participants. A principal component analysis of the 28 items using oblimn rotation was undertaken. The scree-test was used to determine the number of factors with the eigenvalue greater than 1.0 (Field 2005; Osborne and Costello 2009) and factor loading greater than 0.40. Eigenvalues greater than one indicated that the first five factors, which are listed in Table 1, explained 18, 15, 9, 8, and 6% of the variance respectively. The sixth and the seventh factors had eigenvalues of just over 1%, and they explained 5 and 4% of the variance respectively. Following the initial examination of the correlation matrix, the two items that form a subscale of substance use and another two items that form a subscale of use of religion were excluded, as their correlations were high ($r > 0.8$). The Kaiser-Meyer-Olkein measure indicated good sampling adequacy (KMO = 0.75) (Field 2005). Bartlett's test of sphericity [χ^2 (276) = 1724.67, $p = 0.001$] indicated that the correlation between each item was sufficient (Field 2005). As a result, the five-factor solution explaining 56% of the total variance was used in the current study. Cronbach's alpha for each of the five-factor is reported in Table 1.

Unlike the previous two studies (Benson 2010; Hastings et al. 2005) that reported four factors, our analysis yielded five factors with one item dropped. The dropped items was 'I have been turning to work or other activities to take mind off things', which is an item for the self-distraction subscale. The result of the factor analysis is presented in Table 1. Our factors somewhat resembled the result of Hastings et al. (2005) and hence their labels suited the current extracted factors. Factor one (problem focused)

Table 1 Factor loadings for analysis of brief COPE items

Factor	Problem focused	Active avoidance	Positive coping	Limited use of relationship support	Acceptance
% Variance	18.44	15.34	9.02	7.74	5.74
Cronbach's alpha	0.77	0.78	0.74	0.75	0.70
Coping taking action to try to make the situation better	**0.722**	−0.052	0.028	−0.001	0.172
Coping concentrating my efforts on doing something about the situation I am in	**0.700**	0.081	0.033	−0.068	−0.087
Coping trying to come up with a strategy about what to do	**0.652**	0.208	0.041	−0.046	0.244
Coping thinking hard about what steps to take	**0.578**	0.117	−0.036	−0.028	**0.450**
Coping blaming myself for things that happened	0.147	**0.738**	−0.009	0.028	−0.035
Coping giving up the attempt to cope	−0.205	**0.735**	−0.184	0.048	0.186
Coping criticizing myself	0.151	**0.721**	−0.002	0.119	−0.102
Coping saying to myself this isnt real	0.096	**0.646**	0.131	0.120	−0.340
Coping refusing to believe that it has happened	0.231	**0.615**	−0.011	0.040	**−0.414**
Coping giving up trying to deal with it	**−0.470**	**0.543**	−0.017	0.109	0.335
Coping saying things to let my unpleasant feelings escape	−0.076	**0.523**	−0.122	−0.370	−0.123
Coping doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	−0.260	**0.409**	0.233	−0.245	0.188
Coping turning to work or other activities to take my mind off things	0.010	0.349	0.090	−0.023	0.172
Coping making jokes about it	−0.080	0.009	**0.894**	0.042	−0.039
Coping making fun of the situation	−0.161	0.009	**0.861**	0.001	−0.134
Coping trying to see it in a different light, to make it seem more positive	0.325	0.069	**0.594**	−0.050	0.127
Coping looking for something good in what is happening	0.211	−0.150	**0.536**	−0.083	0.195
Coping getting emotional support from others	−0.075	−0.058	−0.047	**−0.836**	0.015
Coping getting comfort and understanding from someone	−0.043	−0.231	0.139	**−0.726**	−0.029
Coping getting help and advice from other people	0.366	−0.199	0.100	**−0.611**	−0.064
Coping expressing my negative feelings	−0.055	**0.409**	0.144	**−0.570**	0.002
Coping trying to get advice or help from other people about what to do	0.359	0.084	−0.081	**−0.566**	0.040
Coping learning to live with it	0.137	−0.062	0.097	0.104	**0.715**
Coping accepting the reality of the fact that it has happened	0.234	−0.099	0.007	−0.081	**0.655**

Significant loadings are highlighted in bold

included all items of the planning and active coping subscales. This factor describes mothers' proactive coping styles to deal with stressors. Factor two (active avoidance) included all items of the self-blame, behavioural disengagement, denial and venting and one item from self-distraction subscales. This factor describes mothers' coping style to avoid stressors physically or emotionally. Factor three (positive coping) included all items of the humour and positive reframing subscales. This factor describes mothers' coping style to perceive stressors through their constructive lens. Factor four (lack of relational support) included all items of the emotional support and instrumental support and one item from venting subscales. This factor describes mothers' limited use of external support in dealing with stressors. Factor five (acceptance) included both items of the subscale of acceptance, and one item of the subscale of planning. This factor describes mothers' coping style to deal with stressors while adopting the situation.

A *chi*-square test was conducted to compare the relationship between single versus coupled household status and demographic variables. A univariate analysis was conducted to identify significant associations between single versus coupled household status and the scores for the WHOQOL BREF and the APSI, the extracted factors of the Brief COPE, and the number of hours reported in the time use estimate table. Binary logistic regression analyses were then performed with the significant variables to identify key factors associated with single mothers' stress levels, coping styles, time use, QoL, and demographic variables. A backward elimination method was used to develop the final model. In this method, all variables that were found significant in the univariate analysis were entered in the regression model initially and the least significant variable was removed one at a time until it reached the final model.

Results

Demographic Information of Participants

Table 2 provides an overall descriptive profile of the participants by single versus coupled household status. There were 43 single mothers (20.8%) and 164 coupled mothers (79.2%). Significant differences were found between single and coupled mothers on the following five demographic variables: (1) respondents' self-reported presence of cognitive impairment or intellectual disability with the child with ASD was higher among single mothers ($p = 0.009$), (2) total number of children was higher among coupled mothers ($p = 0.011$), (3) more single mothers were unemployed ($p < 0.001$), (4) household income was lower among single mothers ($p < 0.001$), and (5) single mothers had lower education levels ($p = 0.027$). No significant differences were found on any other demographic variables.

Univariate Analysis

Univariate analysis was conducted to identify independent variables significantly associated with single versus coupled household status. The following independent variables were found to be significant: (1) WHOQOL BREF physical domain ($p = 0.003$), (2) WHOQOL BREF psychological domain ($p = 0.028$), (3) WHOQOL BREF social relationships domain ($p = 0.012$), (4) WHOQOL BREF environment domain ($p < 0.001$), (5) WHOQOL BREF overall QoL ($p = 0.001$), (6) WHOQOL BREF health satisfaction ($p = 0.39$), (7) factor two (active avoidance) coping style ($p = 0.001$), (8) factor five (acceptance) coping style ($p = 0.008$), (9) estimated hours completing house duties during the week ($p = 0.04$), (10) estimated hours visiting family or friends during the weekend ($p = 0.049$), (11) APSI core autism symptoms ($p = 0.013$), (12) APSI comorbid behaviour ($p = 0.027$), (13) APSI comorbid physical ($p = 0.014$), and (14) APSI overall scores for parental stress levels ($p = 0.002$). These significant independent variables were entered into the multivariate logistic regression analysis. Apart from the two variables, estimated hours completing house duties during the week and visiting family or friends during the weekend, there were no significant difference between single and coupled mothers in their estimated time use. No significant difference was found with the variables of coping style factor three (positive coping) and factor four (lack of relational support). These non-significant independent variables were excluded in the multivariate logistic regression analysis.

Multivariate Logistic Regression Analysis

The model was tested for goodness of fit against a constant only model and was found to be statistically significant ($\chi^2 = 29.29$, $DF = 4$, $p < 0.001$). The included factors explained 21% of the variance (Nagelkerke $R^2 = 0.21$). The overall prediction success rate of the model was 80.3%. The Wald criterion was used to identify factors that were significantly associated with single mothers, and Exp (B) was used to predict the direction of the outcomes. Table 3 shows the results of the multivariate logistic regression analysis.

The multivariate logistic regression analysis revealed two factors that significantly contributed towards being single mothers: (1) WHOQOL BREF environment domain ($p < 0.001$); and (2) factor five, acceptance as a coping style ($p = 0.006$). The current results showed that single mothers were 1.05 times more likely to report lower levels of QoL in the environmental domain (OR 1.05; 95% CI 1.04, 1.09). Although factor five (acceptance) was found significant ($p < 0.05$) in the multivariate logistic regression analysis (OR 1.73; 95% CI 1.17, 2.25), which indicates single mothers were 1.73 times more likely to use acceptance as a coping style, this result did not persist after adjusted for total number of children, household income and employment status in the analysis. The WHOQOL BREF environmental domain remained significant ($p = 0.004$) following this adjustment.

The following factors did not significantly contribute to the multivariate model: (1) WHOQOL BREF Physical health domain, (2) WHOQOL BREF Psychological health domain, (3) WHOQOL BREF Social relationships domain, (4) estimated hours completing house duties during the week, (5) estimated hours visiting family or friends during the weekend, (6) overall scores for parental stress levels, and (7) factor two (active avoidance) coping style.

Discussion

The aim of this current study was to examine the influence of differences in single versus coupled household status on

Table 2 Characteristics of the mothers and their children for the total sample, the sample of single mothers and the sample of coupled mothers

Characteristics	Total sample		Single mothers		Coupled mothers	
	$N=207$	%	$N=43$	%	$N=164$	%
Children's age (month) mean (standard deviation)			10.23 (4.7)		9.95 (4.9) $t=0.73, p=0.78$	
Children's gender						
Male	173	83.6	37	86	136	82.9
Female	34	16.4	6	14	28	17.1
				$\chi^2=0.24, DF=1, p=0.62$		
Official ASD diagnosis						
Autistic disorder (autism)	111	55.8	23	57.5	88	55.3
HFA, AS, PDD-NOS	88	44.2	17	42.5	71	44.7
				$\chi^2=0.06, DF=1, p=0.81$		
Presence of cognitive impairments/intellectual disability						
Yes	55	27	18	42.9	37	22.8
No	149	73	24	57.1	125	77.2
				$\chi^2=6.79, DF=1, p=0.009^*$		
Children's age when noticed 1st sign of something not right						
<3 years old	166	80.2	35	81.4	131	79.9
3 years old and older	41	19.8	8	18.6	33	20.1
				$\chi^2=0.49, DF=1, p=0.82$		
Children's age when formally diagnosed						
<4 years old	84	41	16	37.2	68	42
4 years old or older	121	59	27	62.8	94	58
				$\chi^2=0.32, DF=1, p=0.57$		
Number of children with ASD						
One child	189	91.3	40	93	149	90.9
More than one	18	8.7	3	7	15	9.1
				$\chi^2=0.20, DF=1, p=0.65$		
Total number of children						
One child	32	15.5	12	27.9	20	12.2
Two or more children	175	84.5	31	72.1	144	87.8
				$\chi^2=6.44, DF=1, p=0.011^*$		
Employment status						
Employed	170	88.5	19	52.8	151	96.8
Unemployed	22	11.5	17	47.2	5	3.2
				$\chi^2=55.86, DF=1, p<0.001^{**}$		
Household income[a]						
Up to $51,999	46	22.9	31	73.8	15	9.4
$52,000 and over	155	77.1	11	26.2	144	90.6
				$\chi^2=78.01, DF=1, p<0.001^{**}$		
Mothers' education levels						
Did not complete school	25	12.1	5	11.6	20	12.2
Year 12	25	12.1	5	11.6	20	12.2
Post TAFE or certificate	73	35.3	23	53.5	50	30.5
University	84	40.6	10	23.3	74	45.1
				$\chi^2=9.14, DF=3, p=0.027^*$		

$^*p < 0.05$; $^{**}p < 0.001$

[a] The cut-off point was set based on the median household income in Western Australia at the time of the study

Table 3 (a) Variables associated with single mothers of children with ASD, and (b) variables associated with single mothers of children with ASD with demographic variables

Single mothers							
Independent variables	*B*	SE	Wald	*p*	Exp (B)	95% CI for Exp (B)	
						Lower	Upper
(a)							
WHOQOL environmental domain	−0.57	0.013	18.88	<0.001	0.945	0.92	0.97
Brief COPE factor five (acceptance)	0.55	0.199	7.60	0.006	1.73	1.17	2.55
(b)							
WHOQOL environmental domain	−0.57	0.013	18.88	<0.001	0.945	0.92	0.97
Brief COPE factor five (acceptance)	0.236	0.286	0.845	0.358	1.30	0.743	2.28
Total number of children	−1.30	0.642	4.11	0.043	0.272	0.77	0.958
Household income	−2.22	0.618	11.82	0.001	0.119	0.35	0.399
Employment status	2.21	0.787	7.85	0.005	9.08	1.94	42.50

the stress levels, coping styles, time use and QoL among mothers of children with ASD. The finding revealed that single mothers experience lower QoL in the environmental domain, whilst they use an adaptive coping style (acceptance) more to deal with everyday stressors.

Maternal Quality of Life

In this current study, single mothers reported lower levels of QoL in the environmental domain than coupled mothers. Financial hardship is a common issue among single mothers (Crosier et al. 2007; Dyches et al. 2016; Sachs et al. 1995; OECD 2012), in particular if they are from working class background (Rowlingson and McKay 2005). One of the reasons for single mothers to experience financial hardship may be due to a lack of suitable jobs, including those with flexible employment opportunity, which prevents those single mothers from obtaining full time employment. A study that examined the work force participation of single parents across 30 European countries found that single mothers were less likely to be employed full time than their counterpart, particularly while their children were young (Riggeri and Bird 2014). Other factors, such as a lack of suitable childcare services, may also prohibit single mothers' abilities to obtain full time employment (Broussard et al. 2012). In a meta-synthesis of single mothers' experiences of transitioning from welfare to work, the issues of the affordability, accessibility, and practicability of childcare services were found to exacerbate the already difficult transition process among these mothers in USA and Canada (Cook 2012a). Having access to suitable childcare support can be a challenging issue among mothers of children with ASD (Bromley et al. 2004). It is, therefore, speculated that this issue maybe even more pronounced among single mothers of children with ASD.

Mothers are generally able to increase working hours as children mature and start attending school, and the difference in full time employment rates between single and coupled mothers narrows (Riggeri and Bird 2014). However, mothers of children with complex needs, such as ASD, may need to seek part-time employment as the demand to cater for their children's unique needs (McCann et al. 2012; Sawyer et al. 2010) may continue through to young adulthood (Smith et al. 2010). In fact, parents of children with ASD report that reduced working hours and the associated loss in income are the single largest contributing factor to the cost of having a child with ASD (Horlin et al. 2014).

In Australia, social security payments were the largest source of income for 61% of single parent families in 2003–2004 (Australian Bureau of Statistics 2007). A legislative change in Australia, which shifted some single parents to lower social security payments, resulted in these single parent families facing increased risk of poverty (The Australian Council of Social Service 2012). In the current study, the single mothers reported lower household income than coupled mothers ($p < 0.001$), and more single mothers were unemployed ($p < 0.001$). Financial insecurity derived from a lack of flexible employment opportunity and insufficient social security payment among single mothers may have contributed to their lowered perceptions of QoL in the environmental domain.

This current study did not find differences between single and coupled mothers in the physical, psychological, and social relationships domains of QoL. This result may indicate that the status of being a single versus coupled household with a child with ASD does not have much impact on their QoL. It is also possible that both groups of mothers experience lower QoL compared to the general population, but there was no marked difference between the two groups. Indeed, one study has found that parents of children with ASD had lower QoL in every domain compared with the general population (Tung et al. 2014). Given that the current study did not have a control group, future research should consider comparing the QoL of these mothers with that of a control group to thoroughly understand the relative influence of being a single versus coupled household with a child with ASD.

Acceptance Coping Style

Single mothers were found to use the acceptance coping style more than coupled mothers. This finding is similar to a study by Compas and Williams (1990) where single mothers of typically developing young adolescents were found to use the acceptance and positive reappraisal coping style. Single mothers often need to cope with daily stressors without the support of an intimate partner, unlike coupled parents who have an option to share parental burden while supporting each other (Gray 2006). In fact, coupled mothers consider spousal support critical in coping with stressors (Kuhaneck et al. 2010). Coupled parents can access a dyadic coping strategy, where they combine individual skills and capacities to deal with daily stressors or to support their partner in managing stressors (Bodenmann 1995). In positive dyadic coping, couples can express and share stressful situations, receive both practical and emotional support from their partner, request for help in managing the stressors, and use a collaborative approach to cope with the stressors (Falconier et al. 2015). However, single mothers simply do not have access to spousal support. Instead, family and other social supports play a crucial role in managing stressors and sharing parental responsibilities for single mothers of children with a disability (Levine 2009; Muir et al. 2008). Some of these mothers consciously build and maintain their social support networks, in preparation for the future needs of their children (Levine 2009). However, finding reliable social support can be challenging due to multiple factors, for example, having to travel large geographical distances to access the support networks and having to train and empower people who lack knowledge and skills in caring for the child with complex needs (Muir et al. 2008). It may be plausible that given the complexity to establish and maintain reliable social networks, for single mothers of children with ASD, dealing situations by using the acceptance coping style maybe an easier option. While a lack of spousal and social support may be forcing these mothers to adapt the acceptance coping style, other factors may also be able to explain the current result.

The use of acceptance coping style did not remain significant after adjusting for total number of children, household income, and employment status. Our results suggest that those three demographic variables are critical in influencing the coping styles that single mothers adopt. Complex interactions between parental characteristics should be considered as coping is a process and is influenced by personal and situational factors (Folkman and Moskowitz 2004). Another possible explanation of this result is that both single and coupled mothers of children with ASD are resilient. There is emerging evidence to show that families of children with ASD are resilient (Bayat 2007; Bekhet et al. 2012; Tunali and Power 2002). Despite the unique daily challenges, such as lack of public or family understanding towards ASD (Higgins et al. 2005; Nealy et al. 2012) and challenging behaviour of the child (Bromley et al. 2004), mothers of children with ASD show extreme commitments in caring for their children (van Tongerloo et al. 2015). One study that explored the experiences of mothers of preschool children with ASD found that mothers developed hope and positive optimism over the years and their positive perspectives contributed towards their resilience (Bultas and Pohlman 2014). In a study that compared the psychological functioning and coping styles of the mothers of children with ASD ($n = 364$) and the mothers of children without ASD ($n = 61{,}408$), it was found that mothers of children with ASD were 1.8 times more likely to report that they were coping better with daily parenting issues (Montes and Halterman 2007). Parents of children with ASD develop more adaptable coping styles, such as acceptance over the years (Ooi et al. 2016), and the coping style of acceptance has been found to be a mediating factor between stress and QoL among parents of children with ASD (Dardas and Ahmad 2015). Parents are able to deal with stressors in a practical manner by accepting situations (Marshall and Long 2010). Acceptance is an indicator of resilience (Bekhet et al. 2012) that helps to unite families, which further strengthen their family relationships (Bayat 2007).

Time Use

This study did not find much difference in time use between single and coupled mothers. The current result may indicate that single versus coupled household status does not contribute to the difference in time use among mothers of children with ASD. A study conducted in Australia, found no statistically significant difference between single and coupled mothers in everyday time use (Craig and Mullan 2012; Le and Miller 2013). However, an earlier study that compared family life experiences between single and coupled mothers of children with a disability found that single mothers of children with a disability experienced more time pressures than coupled mothers (Schilling et al. 1986). In the current study, participants estimated hours for listed activities. Although time estimation method has previously been used with mothers of children with a disability (Padeliadu 1998), it may not have fully captured the experiences of mothers or account for day-to-day variations. Future study should use more comprehensive data collection methods, such as an experience sampling method, to obtain more accurate information of mothers' time use (Chen et al. 2015; Cordier et al. 2016).

Maternal Stress Levels

This study did not find difference in parental stress levels between single and coupled mothers, which was similar to a previous research finding for mothers of children with a disability (Schilling et al. 1986). The instrument used in this study, the APSI (Silva and Schalock 2012), measures parental stress levels that are specifically related to the characteristics of ASD and do not measure other parental stress factors, such as lowered income. Therefore, the results of the current study indicate that parents of children with ASD, regardless of single versus coupled household status, experience similar levels of parenting stress related to managing the characteristics of ASD. The demographic characteristics of the single mothers in this current study were reflective of common parental stress factors among single mothers in general (Cooper et al. 2009). Our single mother participants had on average lower household incomes, higher unemployment rates and lower educational levels compared with coupled mothers. Future research comparing single and coupled mothers of a child with ASD should consider using other instruments that measure broader stressors, such as financial pressures and lack of employment opportunities, as single mothers may be more prone to these stressors than their counterpart (Cook 2012a; Sachs et al. 1995).

Limitation

The current study has several limitations. The data collected were only from mothers who resided in Western Australia. Several recruitment strategies were employed in this study and the researchers did not have access to the actual number of surveys that were distributed or the pool of participants that were approached. Although we incorporated drop out analyses in the online version of the survey, none of the participants provided data. Hence, we were unable to determine whether the profile of the non-respondents differed from the participants and this limits our ability to calculate the true response rate. Therefore, caution should be taken when generalising the findings. The current study did not have a control group. The use of a control group would be useful to understand the impact of the single versus and coupled household status on parental experiences. The focus of the current study was to compare the broader parental experiences between single versus coupled mothers, rather than the impact of the unique characteristics inherent to ASD. However, factors, such as communication difficulties and limited social skills, have been found to be associated with parental QoL (Baghdadli et al. 2014). Future studies examining parental experiences should consider these aspects. Lastly, the method used to collect time use data may have allowed participants to over or underestimate their time, which may have resulted in an inaccurate reflection of their time allocation. For example, in a previous study, time spent on childcare was overestimated when time estimate format was used to collect data (Järbrink et al. 2003). However, due to the design of this current study, we were unable to use other methods, such as daily diary entry, to collect data.

Conclusion

This current study discussed possible environmental issues surrounding single mothers of children with ASD, including a lack of flexible employment opportunity, insufficient social security payment and the resultant financial disadvantage. The environmental factors that are associated with single mother's QoL should be further explored with a focus on the economic aspect. Prior to adjusting for demographic variables, our results demonstrated that single mothers use acceptance coping style more in managing stressors. These differences should be further investigated, in particular the reason for the use of this adaptive coping style among single mothers in order to understand the underlying factors that may assist coupled mothers in turn. We did not find much difference in time use and maternal stress levels between these two mothers. However, time pressure is a common issue in single motherhood and previous studies have identified unique parental stressors among single mothers. The use of different methods, such as experience sampling method and the use of other stress measures, maybe beneficial in comparing single and coupled mothers whilst highlighting the vital differences.

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Author Contributions TM assisted the data collection, performed the statistical analysis and interpreted the data, and drafted the final manuscript. RC obtained grant to conduct the larger study, participated in the design and coordination of the study and assisted the statistical analysis, interpretation of the data and drafting the manuscript. SV obtained grant to conduct the larger study, participated in the design and coordination of the study and assisted interpretation of the data and drafting the manuscript. TF obtained grant to conduct the larger study, assisted interpretation of the data and drafting the manuscript. YT assisted interpretation of the data and drafting the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors declare that there is no conflict of interest. The authors conducted this research project, independent of the Lishman Health Foundation and those view expressed are not necessarily those of the founder's. All researchers take full responsibility for the integrity of the work.

Ethical Approval The study was approved by the Curtin University Human Research Ethics Committee (HR123/2014) and all procedures performed in this study were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in this study.

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Appendix F: Chapter 6 published paper

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Feature Article

The experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing

Tomomi McAuliffe,[1,2] Yvonne Thomas,[3] Sharmila Vaz,[1] Torbjorn Falkmer[1,4] and Reinie Cordier[1]

[1]*School of Occupational Therapy, Social Work and Speech Pathology, Faculty of Health Sciences, Curtin University, Perth, Western Australia,* [2]*School of Health and Rehabilitation Sciences, The University of Queensland, St Lucia, Queensland, Brisbane, Australia,* [3]*Allied Health and Social Sciences, Institute of Health & Society, University of Worcester, Worcester, UK, and* [4]*Pain and Rehabilitation Centre, Department of Medical Sciences, Linkoping, Sweden*

Background/aim: *Families of children with autism spectrum disorder (ASD) use family routines to provide predictability and structure to support occupational engagement of their family members. Mothers assume the major role to orchestrate occupations in constructing family routines, which may impact their health and wellbeing. However, the experiences of mothers in managing family routines and their health and wellbeing have not been the main focus in previous research. Thus, this study explored the experiences of mothers of children with ASD in managing family routines and their perceptions of the impact of family routines on their health and wellbeing.*

Methods: *An interpretive phenomenological approach was used. Twenty mothers of children with ASD, aged between 28 and 56 years, participated in semi-structured interviews. Data were transcribed verbatim and each transcript was analysed.*

Results: *Five themes that summarise mothers' perceptions towards health and wellbeing when managing family routines emerged: (i) Keeping on track keeping healthy; (ii) My life is busy, because I do everything for everyone else; (iii) Keeping on track all the time is tiring or frustrating; (iv) Looking after my family by looking after myself; and (v) I am not perfect and it is OK.*

Conclusion: *This study highlighted the substantial efforts required in constructing family routines that may be at the cost of mothers' health and wellbeing. However, mothers may be able to cope with everyday demands in managing family routines by changing their perspectives. By integrating 'me-time' activities in family routines, mothers may be able to support their own health and wellbeing. Mothers' values and needs are reflected in family routines; hence, thorough understanding of family routines may be a key to support mothers' occupational engagement.*

KEY WORDS *child developmental disorders pervasive, mothers, parents of disabled children, routines and qualitative studies.*

Introduction

The parents of children with autism spectrum disorder (ASD) use family routines to provide expectations and predictabilities in everyday life (Larson, 2006). Family routines allow parents to integrate the needs of the child into family life (Larson, 2006) by accommodating the unique ASD characteristics, such as rigid and repetitive interests and activities (American Psychiatric Association, 2013) and sensory preferences, that commonly interfere with the occupational participation of the child (Schaaf, Toth-Cohen, Johnson, Outten & Benevides, 2011). As such, family routines serve to promote healthier coping mechanism among families of children with ASD (Kapp & Brown, 2011). However, appropriately

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Tomomi McAuliffe BOccThy (Hons I); PhD Candidate. **Yvonne Thomas** PhD JCU; Principle Lecturer, Academic Lead for Allied Health Professionals. **Sharmila Vaz** PhD Curt; Senior Research Fellow. **Torbjorn Falkmer** PhD; Dean Research and Graduate School. **Reinie Cordier** PhD Syd; Associate Professor.

Correspondence: Tomomi McAuliffe, School of Health and Rehabilitation Sciences, Faculty of Health and Behavioural Sciences, The University of Queensland, St. Lucia, Qld 4072, Australia. Email: t.mcauliffe@uq.edu.au

Conflicts of interest
The authors declare that there is no conflict of interest. The authors conducted this research project, independent of the founder and those view expressed are not necessarily those of the founder's. All researchers take full responsibility for the integrity of the work.

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designing family routines to suit the unique support requirements of the child with ASD is often challenging (Boyd, Harkins McCarty & Sethi, 2014).

In studies of family routine, the two related terms (i.e., family routines and rituals) are commonly discussed. The term 'routines' refer to patterned and continually repeated activities that have instrumental functions, whereas the term 'rituals' represent meaning arising from the patterned engagement (Fiese *et al.*, 2002; Marquenie, Rodger, Mangohig & Cronin, 2011). However, confusion exists in literature as these terms are used interchangeably, due to overlaps between the two terminologies (Denham, 2003). For example, mealtime provides instrumental functions, as well as meanings to family (Evans & Rodger, 2008). While the differences presented in previous literature (Fiese *et al.*) should be acknowledged, this study uses the term 'family routines' to encompass the elements of rituals (i.e., meaning derived from routines). Our decision to use this terminology is similar to a previous literature review on family routines among families of children with ASD that used 'routines' as the overarching term due to the conceptual relatedness between the two terminologies (Boyd *et al.*, 2014).

Routines provide a foundation for family life and allow members to engage in meaningful occupations, such as mealtime (Bagatell, Cram, Alvarez & Loehle, 2014). Mothers play a major role in orchestrating occupations to construct family routines (Bagatell, 2016; Larson & Miller-Bishoff, 2014) that develop connection between members and establish identity as a family unit (Evans & Rodger, 2008). While family routines provide stability (Schaaf *et al.*, 2011), structure, and order in the family environment (Fiese, 2007), the management of family routines is a complex process that requires considerable maternal efforts (Larson & Miller-Bishoff).

Empirical studies that explored mothers' own experiences in orchestrating family routines among families of children with disability are limited (Kellegrew, 2000; Larson, 2000b), while the entire family experiences (Bagatell, 2016; Schaaf *et al.*, 2011) and the impact of the disability characteristics on family routines have been examined commonly through mothers' perspectives (Bagatell *et al.*, 2014). Family routines and its management impact the health and wellbeing of family (Fiese, 2007). For example, families of children with ASD commonly experience increased stress levels during dinnertime routine (Marquenie *et al.*, 2011). However, maternal health and wellbeing in relation to management of family routines among mothers of children with disability, including ASD, has not been widely investigated (Larson & Miller-Bishoff, 2014). This lack of research can be an issue given mothers of children with ASD commonly assume the major role of managing family routines (Larson, 2006), and previous research suggest that managing family routines can be stressful for mothers of children with disability (Larson & Miller-Bishoff). Therefore, family routines and the health and wellbeing of mothers of children with ASD should be the focus of research for health professionals, including occupational therapists. This study, therefore, aimed to explore the experiences of mothers of children with ASD in managing family routines in relation to their perceptions towards their health and wellbeing.

Method

Research approach

A phenomenological approach that allows researchers to explore the experiences of participants was employed (Creswell & Poth, 2017). While there are various types in phenomenological approaches, this study used interpretative phenomenological analysis (IPA) to understand individual participants' experiences in their context. Some criticise IPA for lacking connection to the theoretical foundation of phenomenology (Giorgi, 2010). However, others argue that IPA is well founded in theories and thus an appropriate approach to investigate lived experiences of individuals (Smith, Flowers & Larkin, 2009).

IPA is widely used in the fields of health science research (Finlay, 2011). IPA allows researchers to explore the perspectives and experiences of participants, and not only describe them but also develop meanings in a thematic form (Larkin, Watts & Clifton, 2006). In the process of exploration, it is acknowledged that the interpretation includes both participants' and researchers' views (Finlay, 2011). This is because IPA uses a 'double hermeneutic' process: while participants make sense of their own experiences, researchers attempt to make sense of participants' sense-making experiences (Smith *et al.*, 2009). Therefore, in IPA, researchers take dynamic roles in the process of interpreting participants' perspectives (Smith *et al.*, 2009).

Participants

Purposive sampling methods were employed to recruit 20 mothers who have children with ASD, between the ages of 2 and 19 years, and lived in Western Australia (WA). Following the ethical approval from the Curtin University Human Research Ethics Committee (HR123/2014-01), the first author contacted prospective participants by email and phone. The flyers of the study were also disseminated to community organisations. Prospective participants were given opportunities to ask questions prior to confirming their intentions to participate in the study. The information sheets were provided, and informed consents were obtained from all participants prior to the interview. The demographic information of the participants is presented in Table 1.

Data collection

Consistent with the principles of IPA (Smith & Osborne, 2008), a semi-structured interview was used

TABLE 1: *Participants' demographics*

Participant number	Age of mothers	Household status	Mother's education	Age of the child with ASD	Gender of the child with ASD	Presence of cognitive impairment of the child[†]
1	41	Single	Post TAFE or Certificate	18	Male	Yes
2	47	Couple	Post TAFE or Certificate	9	Male	Yes
3	38	Single	Year 12	11	Male	No
4	ND[‡]	Couple	Post TAFE or Certificate	15	Female	Yes
5	56	Couple	Year 10	20	Female	No
6	43	Couple	Year 12	7	Male	No
7	51	Couple	University	13	Male	No
8	45	Couple	University	10	Female	Yes
9	47	Single	Post TAFE or Certificate	7	Male	Yes
10	55	Single	University	16	Female	No
11	43	Single	Year 12	9	Male	No
12	42	Single	University	14	Male	No
13	34	Single	Post TAFE or Certificate	12	Male	No
14	40	Couple	University	14	Male	No
15	ND[‡]	Couple	Year 12	11	Male	No
16	38	Couple	Year 12	11	Male	No
17	40	Single	Post TAFE or Certificate	12	Male	No
18	39	Couple	University	5	Male	No
19	28	Single	Year 10	8	Male	No
20	ND[‡]	Single	Year 12	10	Male	No

[†] Based on mothers' reports. [‡] Not disclosed.

as it allows researchers to collect meaningful and important accounts of individual participants (Larkin *et al.*, 2006). The interviews were conducted face-to-face at participants' homes or telephonically, depending on the participants' preferences and availabilities. The first author who is an occupational therapist conducted all the interviews. As discussed, the term 'family routines', rather than 'rituals', was used throughout the interview. Given a similarity between the study aim of Larson and Miller-Bishoff (2014) and that of this study, we adopted their explanation of family routines: "Routines are organised, sequenced activity patterns that occur at specific time and in specific space. This tight and intricate sequencing allows the family to organise the individual and shared activities necessary to sustain health, wellbeing and connectedness among family members" (Larson & Miller-Bishoff, p. 1). The semi-structured interview schedule that was developed by the first two authors and reviewed by the last author was used to guide the interview. Five main open-ended questions were developed to explore participants' perspectives and experiences as mothers in managing family routines and their views on a relationship between routine management and their health and wellbeing, and creating meaning of their experiences (Table 2). At the end of each interview, participants were provided with an opportunity to add any points that they felt important in relation to the topic but were not explored during the interview. The interview duration ranged between 60 and 90 minutes. Each interview was audio recorded digitally and transcribed verbatim.

Analysis

NVivo 11 (QSR International Pty, 2015) was used to manage and process data in this current study. A computer software, such as NVivo, aids researchers in managing large data sets (Leech & Onwuegbuzie, 2011), and improves efficiency and transparency in the process of analysis (Hoover & Koerber, 2011). However, it is important to note that researchers are the ones who conduct the analysis in qualitative research, not the software (Leech & Onwuegbuzie, 2011).

There are variations and flexibilities in the IPA analysis process (Finlay, 2011). This study adapted previously recommended IPA steps (Smith & Osborne, 2008) as a guide. The first and second authors separately read and re-read one interview transcript first, while making notes of points that were related to the research aim, and these points were discussed between the two authors. This process was repeated until the first two authors agreed with the analysis process. Following the agreement, the first author analysed other transcripts and initial notes were transformed into themes. The first author used codebooks in NVivo to record descriptions of emerged themes, and these codebooks were shared with the second author. Themes were reviewed until the first two authors reached consensus. The dialogue engaged by the first two authors in interpreting participants' perspectives and experiences was a lengthy process, due to the large volume of data.

The first author analysed all the data and engaged in reflexivity throughout the process by describing her own thoughts, values and experiences using the memo and annotation functions of NVivo, while referring to the field notes that were recorded after each interview. It should be noted that our intention to engage in reflexivity was not to reduce our own perceptions that were formed prior to the analysis process, like bracketing (Creswell & Poth, 2017), but rather for the researchers to be grounded in the interview transcripts while acknowledging own interpretations (Morse, 1991). The second author guided the first author who was not familiar with the IPA analysis throughout the process, exploring nuances in interpreting the data. This guidance acted as a practice of rigour in IPA (Smith *et al.*, 2009). The participants were not asked to validate the findings because: (i) IPA involves 'double hermeneutics' (Smith *et al.*), and (ii) the validation process may have caused undue burden for the participants who were time-poor.

TABLE 2: *Semi-structured interview guide used in this study*

	Main questions	Follow up questions
1	Please tell me about an ordinary week day or weekend day with your family	
2	What does maintaining family routines mean to you as a mother?	Are there any specific routines more meaningful to you or your family than others?
3	What is your role in keeping family routines?	What skills do you believe you need to have in managing family routines? How does the characteristics of autism impact on your ability to manage family routines?
4	What helps you managing family routines?	What do you do to look after yourself so that you can manage family routines? Do you think maintaining family routines is important for your wellbeing?
5	What restricts or limits you from being able to manage family routines	What support would you like to receive in managing family routines?
6	Is there anything you would like to add?	

Results

Five themes that demonstrate mothers' experiences and perceptions in managing family routines in relation to their perceived health and wellbeing emerged from the analysis: (i) Keeping on track keeping healthy; (ii) My life is busy, because I do everything for everyone else; (iii) Keeping on track all the time is tiring or frustrating; (iv) Looking after my family by looking after myself and (v) I am not perfect and it's OK. Pseudonyms were used in each participant's quote.

Theme 1: 'Keeping on track keeping healthy'

Mothers discussed the benefits of family routines for themselves, the child with ASD, and their entire family. Family routines acted as a framework for their family to put in a structure and provide predictability in everyday life.

> I like knowing what's happening and I like planning what's happening … I find it comforting as well, following those routines. I think we (my family) all probably do now. (Participant 8)

Most mothers agreed that because of family routines, their children with ASD felt secure. The sense of security offered to the child with ASD through structured lifestyle had a cascade effect on other family members. Participant 17 said, "…without those routines … there would be more meltdowns and more conflict in the family … So for his well-being and … the well-being of the rest of the family it is extremely important."

Family routines also provided practical benefits to mothers, such as completing tasks on time. Some mothers discussed that their actions to manage family routines had become "second nature" to them. No family routines meant chaotic life for mothers. "I'd be constantly chasing my kids to … be 'ready' in the morning…, and I would be rushing to work … I need to do a multitude of things before the kids go to bed" (Participant 7).

Some mothers discussed the benefits of family routines in nurturing their spirituality. As the mothers were the ones who designed and managed family routines, they could reflect their values, identities and needs on their family routines.

> To maintain those routines and I see … that was what being a 'good mother' is … being able to

> cook for my family and make sure … they have good relationships with each other … That's why I can find it extraordinarily stressful when some of those things 'fall apart'. Because I think it really does go to the core of who 'I' am. (Participant 8)

Theme 2: My life is busy, because I do everything for everyone else

This theme is about the participants' experiences of carrying large responsibilities to manage family routines. Mothers' lives were busy, and they had to juggle multiple roles. Participant 3 said, "You have to prioritise what you can and can't do. Because you don't always have time for everything." In managing family routines, mothers were "everything". Without them, there were no family routines. Mothers provided various titles in describing their role in managing family routines, for example, "project manager", "president" and "a captain of the ship". These titles demonstrate mother's insights that they were central in managing family routines. Mothers used multiple skills to manage busy family life, such as evaluating, planning, accommodating, being patient and resilient. Mothers had to be patient with not only the child with ASD, but also their spouse, other family members, and service providers, in the process of family routine management. "Patience with other people. Because it's me who runs the show … I'm the one who runs around and does everything else" (Participant 6).

Interestingly, some mothers did not seem to have taken this role of family routine management willingly, but rather it was out of necessity and social expectations. "Somebody has to lead all of this and follow things up and make sure things are done. Otherwise things will just coast along" (Participant 15). Socially constructed gendered roles and expectations for domestic responsibility resulted in a sentiment of resentment with some mothers who had little time for leisure occupations. "I wouldn't mind a bit of help … but…, you do 80% and they [men] do 20% … they [men] get to go surfing but women still … don't get to go surfing" (Participant 10).

Theme 3: 'Keeping on track all the time is tiring or frustrating'

Due to the large responsibilities, routine management became too much at times and mothers frequently reported being tired. Participant 13 said, "It's stressful it's very stressful trying to keep up on top of things." Participant 20 echoed this sentiment and said, "I'm tired all the time … the motivation for me to … do these sorts of things (managing family routines) … I don't have it."

Another aspect of this theme is a process that some mothers went through to get used to living a structured lifestyle. This process was more difficult and frustrating for those mothers who identified themselves as a 'free-flow' person, compared with those who identified themselves as a 'structured' person before having their children.

> It's taken me many years to be 'comfortable' with it [structured lifestyle]. There's no point in 'fighting' it, because yes, I'm not autistic and I don't have to 'live' that way. But my son is autistic and he does. (Participant 12)

The mothers went through a lengthy process in finding a practical balance between meeting their children's needs (i.e., predictability in life) and their own needs (i.e., more spontaneous lifestyle). Participant 10 said, "I didn't ever let Julie stay on something … despite the shrieks and protests … I would find something that would have a link to the things [she] loved … it's an evolution … it's a slow sort of incremental process…" Participant 12 shared her experience:

> …it's a matter of trying to bring in my character and the kind of activities that I enjoy and the kind of things that I feel are important. But through the structure and filter of autism world that makes it comprehensible to him [the child with ASD].

Theme 4: 'Looking after my family by looking after myself'

All mothers acknowledged the importance of looking after themselves. They discussed the benefits of having 'me-time' activities for their health and wellbeing, and many mothers in this study were actively ensuring to have some time-off from their responsibilities. "…I will take the book and read my book. That's my 'time-out.' Yes, and they [children] know … If they disrupt it, then they can hear it!" (Participant 1).

Mothers were creative in securing their own time, for example, grabbing moments whenever possible to engage in 'me-time' activities. Participant 3 said, "…when Jackson's playing soccer, I schedule a 5 km walk while he's doing soccer." Participant 9 used everyday activities to have 'me-time' moments, "…my break is getting on my ride-on lawnmower … and I actually like just sitting on it for an hour! … I don't know why but it just seems like meditation to me." Some mothers scheduled their own time-off activities in everyday routines.

> Now, my 'me time' is 9.30 pm. I go to bed at 9.30 pm usually every night. That's my little routine. I'll put the television on and I have my tablet and I play my games and that's my de-stress. (Participant 5)

Mothers recognised the need to re-charge their energy, so they can continue to fulfil their roles in managing family routines. However, mothers frequently discussed difficulty in overcoming a sense of guilt in engaging in 'me-time' activities. "I was always thinking they [children] have to be with me all the time … it wasn't fair to have someone look after them [children]…" (Participant 19).

Most mothers recognised the central role they played in providing support to the family and, in particular, to the child with ASD. This was the main motivator incorporating their time-off into family routines. All participants acknowledged the importance of looking after themselves to fulfil their commitment to supporting their children.

> We do have to kind of come first. Because if you think about it, what would happen if we weren't there? . . . the focus is all on them [children]. But it's the parents – without that base, what happens with the child? Do they not suffer? They do.
> (Participant 2)

Theme 5: 'I am not perfect and it's OK'

Mothers discussed the importance of allowing themselves not to be perfect in fulfilling their roles in managing family routines. Participant 6 said, "It's very important to . . . not try and be 'Wonder-woman' just be who 'I' am." Participant 5 used the metaphor of an engine to explain that role of mothers in managing family routines was not about perfection, but about continuity and sustainability.

> But sometimes the engine is not here, something's going to happen . . . but that's ok. You tend to it and . . . you fix it and then it's good to go again. It's like there's so many moving parts – that when it does break down . . . That's OK. Because that's life.

In allowing themselves not to be perfect, some mothers recognised their limited capacity to cope with all the demands. Mothers had to let go of some tasks, so they could attend to another task. "So I think there's an element of saying "Okay, I'm looking after Jodie. That's all I'm doing" . . . not trying to multi-task" (Participant 8).

In realising that they do not have to be perfect, mothers learnt to ask for help. In the process of learning, mothers had to overcome an internal conflict. "It feels like something that I should be able to do. So you really have to get past it's not a failing as a mother" (Participant 12). Participant 2 echoed:

> I've been 'there' and I was the type of person who never 'asked' for help. I used to put it all on myself. It's about yourself. It's about saying to yourself that "I can do it all" when you can't.

Discussion

This study explored the experiences and perceptions of mothers of children with ASD in managing family routines and its impact on their own health and wellbeing. Unlike previous research in the area of family routines that examined the experiences of the entire family (Bagatell, 2016), this study focused on the personal experiences of mothers.

The demands of constant family routine management may come at a cost to mothers' health and wellbeing

The findings highlight the vital role that mothers have in orchestrating occupations to construct family routines and thus support the results of previous research (Larson, 2006; Larson & Miller-Bishoff, 2014). Many of the participants were responsible for managing family routines, and without their contributions, their family would struggle in maintaining a structured life. Similar to previous research that examined the entire experiences of the family, the results show that family routines benefitted each and every family member, including mothers themselves (Schaaf *et al.*, 2011). The benefits of a structured lifestyle, in turn, ensured that routines were sustained and became 'second nature' to the mothers involved in this study. Perhaps the cognitive demands that mothers experience in orchestrating occupations to construct family routines were somewhat reduced because of the sequenced patterns that occur every day. However, this study found that mothers considered the construction of family routines as an arduous occupation. This experience may be taxing for mothers given previous research suggesting that the lives of families of children with disabilities can be disorganised due to logistic challenges, such as complex scheduling with therapeutic services (Faw & Leustek, 2015). One of the consequences of these maternal efforts may be a cost to mothers' health. Indeed, the participants discussed feelings of exhaustion. This may be of concern as fatigue can be debilitating for parents' abilities to orchestrate family routines to meet the demands of family members (Larson & Miller-Bishoff, 2014). In contrast with previous research which suggest that family routines support the health of the family (Fiese *et al.*, 2002) and provide a platform to participate in meaningful occupations (Bagatell *et al.*, 2014), this study demonstrates that the mother's responsibility for managing family routines is a potential risk to their own health and wellbeing (Bagatell, 2016). Thus, appropriate support should be provided for mothers in managing family routines, not only for their own benefits, but also for their families.

We found that some mothers adopted the role of family routine management because of the necessity to meet everyday demands or social expectations placed upon females. The findings indicate some mothers were hesitant to assume the pivotal role in managing family routines, even though the participants were committed in supporting their children and family. This hesitation may be derived from the participants' dissatisfaction with the traditional household labour division that is commonly found among families of children with ASD

(Hartley, Mihaila, Otalora-Fadner & Bussanich, 2014). Previous research found that when parents of children or adolescents with ASD were not satisfied with their household labour division, they experienced higher levels of stress than those parents who were satisfied with the arrangement (Hartley *et al.*, 2014). Therefore, health professionals, such as occupational therapists, should not overlook the perceived reasons in assuming the key role in managing family routines that may be related to household labour division issues and gender expectations, when considering the health and wellbeing of these mothers.

How mothers cope with the demands in managing family routines

An important finding of the study was that by accepting their own limitations and allowing themselves to be imperfect, mothers found a way to cope with the everyday demands of managing family routines. A study that investigated the relationship between psychological wellbeing and family routines among parents of children with disability found that the parents felt overwhelmed in meeting all family members' needs, and felt a sense of inefficacy as parents when they were unable to meet those demands (Larson & Miller-Bishoff, 2014). Therefore, embracing imperfections in completing everyday tasks and acknowledging own limitations may be helpful; however, it may not come automatically or be an easy process. We found that mothers had to overcome a sense of failure as a mother in allowing themselves to be imperfect. Perhaps, this sense is attributed to the previous finding that mothering is a significant occupation (Larson, 2000a), and thus overcoming this sense would be challenging for any parent. Nonetheless, developing this particular psychological stance through changing perspectives (VanLeit & Crowe, 2002) by allowing themselves to be imperfect to cope with the demands in managing family routines may benefit mothers of children with ASD in supporting their own health and wellbeing.

The study highlighted the importance of engaging in 'me-time' activities for mothers as a way to address their own health and wellbeing. The participants were found to be actively participating in 'me-time' activities, contrary to previous research that found that parents of children with disability did not prioritise their own needs, such as health issues, due to perceived lack of time (Murphy, Christian, Caplin & Young, 2007). We found that the mothers' commitment to support children and family motivated, and even freed them to participate in 'me-time' activities. However, similar to a previous study (Gahagan, Loppie, Rehman, Maclellan & Side, 2007), some of our participants experienced a sense of guilt when engaging in 'me-time' activities. The findings demonstrate the paradox of the occupational role of mothers, where mothers provide support for others over and beyond their own needs, yet they need to stay 'healthy' by looking after themselves to fulfil this meaningful role. The findings indicate that use of family routines may be helpful for mothers of children with ASD in striking a balance to integrate their 'me-time' activities into their everyday life. 'Me-time' activities have been found as a healthy coping strategy to deal with daily demands among parents of children with disabilities (Larson & Miller-Bishoff, 2014). Therefore, 'me-time' activities should be promoted among mothers of children with ASD to enable them in fulfilling their mothering role in managing family routines that, in turn, support their children and family.

Family routines nurturing mothers' spirituality

An interesting finding of the study was that family routines reflected mothers' beliefs, values and needs; hence, nurturing their own spirituality. While previous literature suggest that routines encompass cultural values and beliefs of families (Boyd *et al.*, 2014; Denham, 2003), the finding extends the knowledge of spirituality embedded in family routines by considering mothers' individual beliefs, values and needs, adding to the previously identified spirituality, such as parenting values that are related to the needs of children as well as that of parents (Larson & Miller-Bishoff, 2014). Spirituality is an element commonly considered in occupational therapy theoretical frameworks, such as the Canadian Model of Occupational Performance and Engagement (CMOP-E;Townsend & Polatajko, 2007). Spirituality, such as values and needs, are central to the CMOP-E and provide meaning to occupations (Townsend & Polatajko, 2007), while assisting individual occupational engagement (Strong & Gruhl, 2011). Organising daily activity patterns to meet the family's needs is considered as a way to achieve life balance (Matuska & Christiansen, 2009). A sense of balance that is derived from living in accordance to ones' own values leads to wellbeing (Pentland & McColl, 2009). Therefore, thorough understanding of family routines that entail mothers' spirituality may lead occupational therapists to obtain crucial information that assist occupational engagement and promote wellbeing among mothers of children with ASD.

Limitation

Due to the nature of IPA, the results of this study are reflections of specific participants' experiences in their situations (i.e., mothers of children with ASD who live in Western Australia) at the time of data collection (Larkin *et al.*, 2006). Hence, the current results have a low transferability. However, IPA allowed us to explore the experiences and perceptions of this particular group of mothers more deeply, which was the aim of this study. Although the first author met each participant prior to the interview date, it is possible that there was limited disclosure of information, due to potential lack of rapport. Last, family routines are complex because multiple factors are intrinsically unique to each family, such as the socio-cultural backgrounds of families (Larson & Miller-Bishoff, 2014). Other research methods, such as mixed method, should be considered in obtaining more comprehensive experiences of mothers in managing family routines.

Conclusion

This study highlighted that mothers are pivotal in managing family routines and without their efforts, their family would have limited family routines that provide a structured lifestyle. Their responsibilities are large, and hence, the related challenges may come at the cost of the health and wellbeing of mothers of children with ASD. The psychological stance that allows themselves to be imperfect, while acknowledging their own capacity, may be beneficial to cope with the demand in managing family routines. Furthermore, reasons for these mothers to assume their roles in managing family routines, such as social expectations placed upon female, should not be ignored, as the issues of household labour divisions may be a source of stress among parents of children with ASD. Mothers' commitments to care for their children and family underpin their motivations to participate in 'me-time' activities. Engaging in such activities assists parents to deal with daily demands. Thus, use of family routines to encourage these mothers to participate in 'me-time' activities may be valuable in promoting their health. Family routines that reflect mothers' beliefs, values and needs nurture their spirituality. Therefore, understanding family routines may be a key for occupational therapists in assisting occupational engagement among mothers of children with ASD, as well as fostering their health and wellbeing.

Key points for occupational therapy

- Managing family routines is a major role for mothers of children with ASD.
- Family routines can be used to explore mothers' occupational engagement and promote their health and wellbeing.
- Family routines nurture mothers' spirituality that provide meaning and assist occupational engagement.

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Declaration of authorship

TM conducted the data collection, performed the analysis and interpreted the data, and drafted the final manuscript. YC assisted the analysis, interpretation of the data and drafting the manuscript. RC assisted the analysis, and drafting the manuscript. SV assisted drafting the manuscript. TF assisted the data collection and drafting the manuscript. All authors read and approved the final manuscript.

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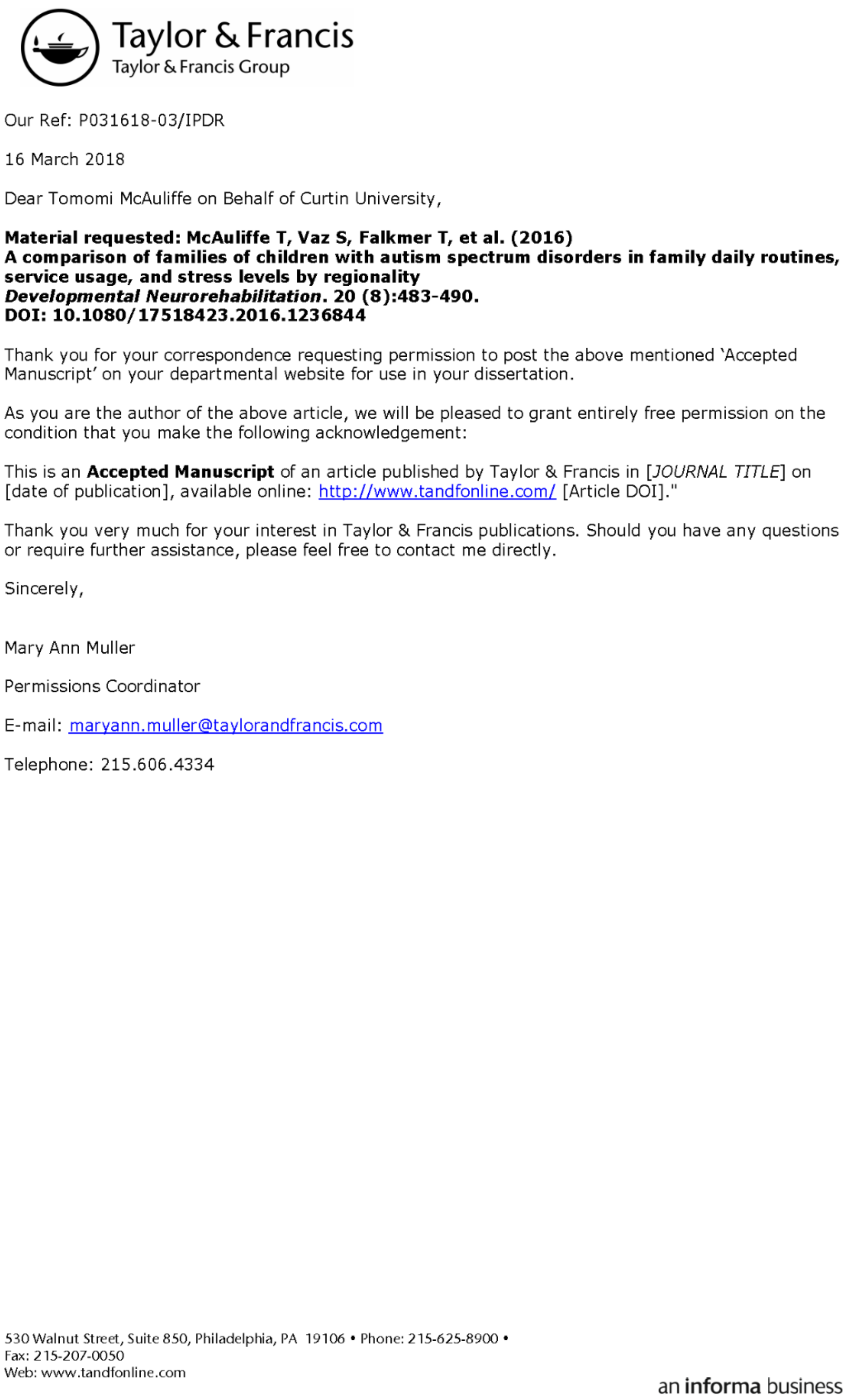

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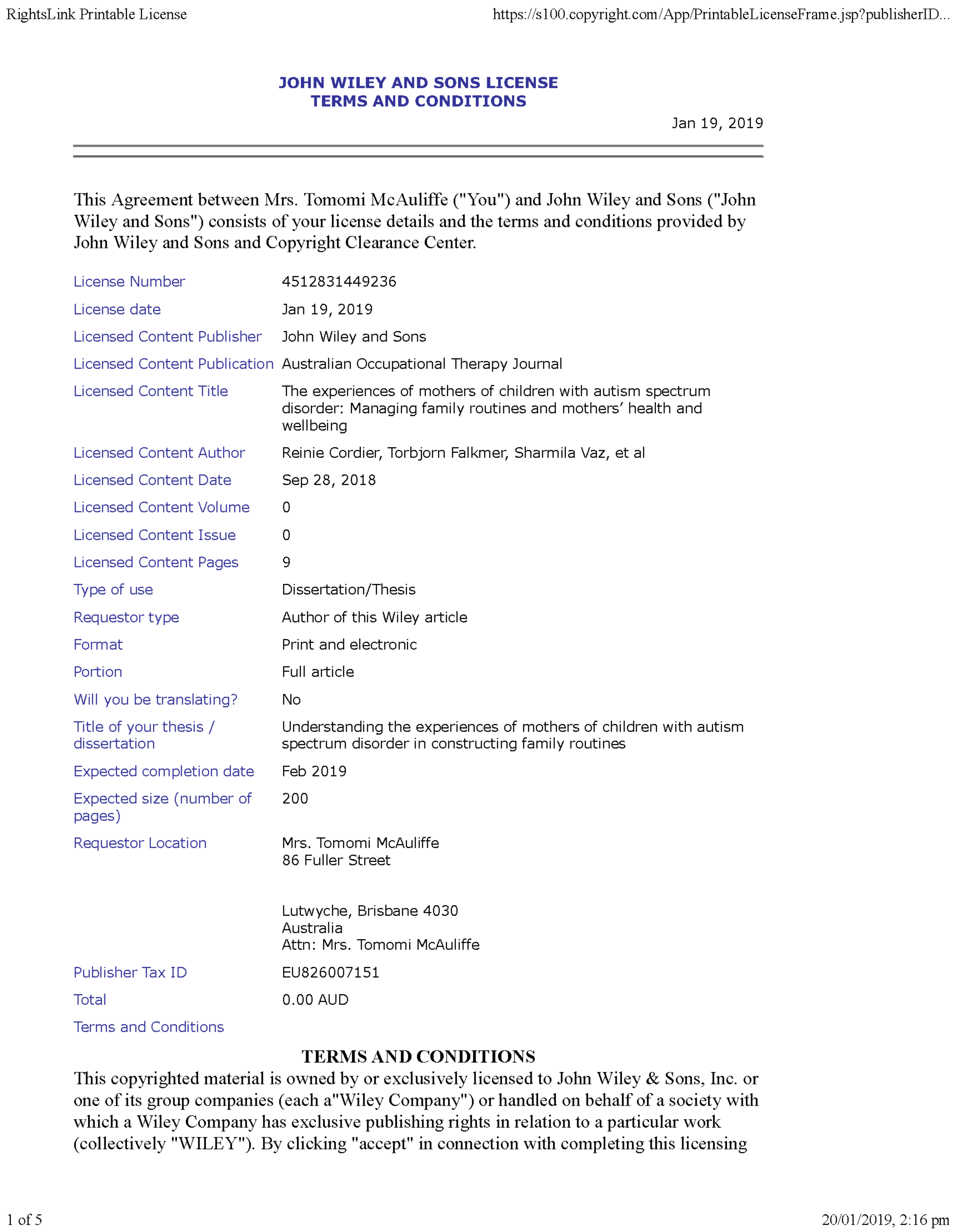

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Appendix H: Additional tables

H1: Table 3.3 Variables that were included in the univariate analyses

Variables	**Total sample (N = 535)** **%**	**Densely populated area (DP) (N = 476)** **%**	**Less Densely populated area (LDP) (N = 59)** **%**
Types of school attended by the child with ASD			
Mainstream private	21.5	22.8	10.7
Mainstream public	44	41.2	67.9
ASD specific program Main stream	5.2	5.6	1.8
Education support centre	24.4	25.2	17.9
Home school	1.9	2.2	0.0
No school	2.9	3.0	1.8
			X^2=13.383, *DF = 1*, *p* = .014
Access to respite			
Day only	46	40.0	82.4
Overnight	4.1	4.8	0.0
Weekends	16.4	17.1	11.8
None	33.5	38.1	5.9
			X^2=10.597, *DF = 1*, *p* = .009
Effects of ASD on employment			
Both parents work less	7.5	8.1	1.9
One parent work less	31.6	29.1	52.8
Single parent work less	9.4	8.8	15.1
One parent cannot work	34.1	35.7	20.8
Both parents cannot work	2.6	2.2	1.9
Unaffected	15.3	16.2	7.5
			X^2=17.446, *DF = 1*, *p* = .002
Number of reduced employment hours			
More than 35 hours	17.6	19.3	6.8
29 to 34 hours	10.0	10.5	6.8
22 to 28 hours	12.4	11.5	18.2
15 to 21 hours	26.2	24.7	36.4
7 to 14 hours	22.1	22.3	20.5
Less than 7 hours	11.8	11.8	11.4
			X^2=3.612, *DF = 1*, *p* = .047
Impact to socialise*			
Severe to worse	54.8	56.4	42.4
Mild to moderate	45.2	43.6	57.6
			X^2=4.132, *DF = 1*, *p* = .042
Distance to medical facility*			
Less than 2km	12.7	13.4	7.0
2 to 5 km	24.9	25.4	21.1
6 to 10 km	19.7	18.9	26.3
11 to 30 km	24.7	25.3	3.5
More than 30 km	17.9	15.0	42.1
			X^2=7.989, *DF = 1*, *p* = .005
Weekly EIT hours*			
Less than 2hours	19.4	18.7	25.6
3 to 6 hours	39.0	37.7	51.3
7 to 14 hours	21.5	22.3	15.4
15 to 20 hours	11.9	12.1	2.6
More than 20 hours	8.7	9.2	5.1
			X^2=5.909, *DF = 1*, *p* = .016

Variables	**Total sample (N = 535)**	**Densely populated area (DP) (N = 476)**	**Less Densely populated area (LDP) (N = 59)**
Frequency to use respite			
Never	68.1	70.3	50.8
Occasionally	17.8	16.5	28.8
Weekly	8.3	7.1	18.6
Fortnightly	1.9	2.1	0.0
Monthly	3.8	4.1	1.7
			X^2=15.269, *DF = 4*, *p* = .003
Levels of social support*			
No support	23.4	24.2	16.9
A little support	81.6	43.3	43.2
Some support	25.0	25.2	23.7
Lots of support	7.8	6.7	16.9
			X^2=3.806, *DF = 1*, *p* = .032
Perceived family stress*			
Very severe stress	20.8	22.8	5.1
Severe stress	24.2	24.7	20.3
Moderate stress	40.5	38.2	59.3
Mild stress	14.4	14.3	15.3
			X^2=14.117, *DF = 3*, *p* = .003
Day care hours for children without ASD			
None	63.1	65.5	45.5
Less than 10 hours	18.9	15.5	45.5
More than 15 hours	17.8	19.0	9.1
			X^2=5.770, *DF = 2*, *p* = .063
Weekly hours the child with ASD spend with friends			
None	48.9	48.0	55.9
Less than 2 hours	31.6	33.1	20.3
Less than 4 hours	12.2	11.2	20.3
Less than 8 hours	5.0	5.5	1.7
More than 9 hours	2.2	2.3	1.7
			X^2=8.562, *DF = 4*, *p* = .073
Visits to non-medical services in a month			
Twice a month	69.5	68.4	78.9
Less than 3 times	9.9	10.1	8.8
Less than 4 times	9.2	9.5	7.0
Less than 6 times	3.1	3.3	1.8
More than 8 times	8.2	8.8	3.5
			X^2=5.770, *DF = 2*, *p* = .063

Categorical demographic variables are presented as proportions due to missing data in some variables.

[*] These variables have been collapsed across categories for the purposes of chi-square analyses.

H2: Table 3.4 Comparison between respondents (N=535) and non-respondents (N=146) on demographics variables that can be derived from the short-form telephone questionnaire

	Non-Respondents (N = 146)	**Respondents (N = 535)**
Age (months)	Mean (SD) 122 (50)	Mean (SD) 119.51 (50.5)
	Median 120	Median 114.5
		t = 0.53 , *p* = 0.59
	Proportion (%)	Proportion (%)
Sex of diagnosed child		
Male	75.50	82.9
Female	24.50	17.1
		X^2 = 4.42, *DF* = 1, *p* = 0.04
ASD diagnosis		
Autism	47.40	55.7
HFA	25.10	21.8
Asperger Syndrome	11.10	7.1
PDD-NOS	15.80	15.4
		X^2 = 5.07, *DF* = 3, *p* = 0.17
How old was your child when you first noticed something was not right?		
Less than 12 months	24.10	24.2
12–18 months	17.10	28.9
19–24 months	18.20	19.9
2–6 years	35.30	24.6
6–18 years*	5.30	2.5
		X^2 =, 13.46, *DF* = 4, *p* <=0.01
How old was your child when formally diagnosed?		
≻12–24 months*	10.30	10.80
2–6 years	50.10	62.70
6–18+ years*	38.70	25.90
		X^2 = 9.43, *DF* = 2 , *p* = 0.01

Categorical demographic variables are presented as proportions due to missing data in some variables.

*These variables have been collapsed across categories for the purposes of chi-square analyses.

H3: Table 4.5 Variables that were found significant in univariate analyses

Household status

				95% CI	
Independent Variables	***B***	***SE***	***p***	**Lower**	**Upper**
WHOQOL BREF physical domain	8.94	2.965	.003	3.10	14.79
WHOQOL BREF psychological domain	6.89	3.124	.028	.73	13.0
WHOQOL BREF social domain	10.46	4.126	.012	2.34	18.59
WHOQOL BREF environmental domain	11.78	2.599	< .001	6.66	16.91
WHOQOL BREF overall	.51	.157	.001	.20	.82
WHOQOL health satisfaction	.38	.182	.039	.02	.73
Factor two (active avoidance coping)	-.55	.17	.001	-.88	-.22
Factor five (acceptance)	.46	.171	.008	-.79	-.12
Estimated hours house duties	.57	.275	.04	.02	1.1
Estimated hours vising family or friends	.36	.187	.049	.01	.73
APSI core autism symptom	-1.72	.687	.013	-3.07	-.36
APSI comorbid behaviour	-1.26	.566	.027	-2.38	-.15
APSI comorbid physical	-1.36	.549	.014	-2.44	-.27
APSI overall scores	-4.42	1.37	.002	-7.14	-1.71