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

## **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 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., 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, 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, 2014).

Empirical studies that explored mothers' own experiences in orchestrating family routines among families of children with disability are limited (Kelleghrew, 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 1.

### **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 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). 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 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 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, Mihaila, Otolara-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. 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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