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**Manuscript title: In-the-moment experiences of mothers of children with Autism Spectrum Disorders: A comparison by household status and region of residence**

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**Abstract**

**Purpose:** This study compared the *in-the-moment* experiences among mothers of children with Autism Spectrum Disorders (ASD) 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:** Limited but significant differences between single and coupled mothers, as well as mothers from regional and major city areas, were found. Future research direction and service provisions were suggested.

**Keywords**

Autism Spectrum Disorders, Caregiver, Ecological momentary assessment, Everyday experience, Lone mothers, Mothers of children with disability, Real-life experience, and Time-use

## **Introduction**

The 2018 Survey of Disability, Ageing and Carers (SDAC) identified that there were 861,600 primary carers in Australia, providing care to their spouses, children and parents [1]. The majority of primary carers in Australia are females, constituting 71.8% [1], and this tendency that the primary carers are mainly females is also observed in other countries, such as the United Kingdom and Sweden [2]. About 27% of primary carers provide care to their children and nearly 90% of primary carers who care for their children are mothers [1]. The trend that mothers are more likely to assume this carer's role has remained unchanged since at least 2012 [3]. In families of children with Autism Spectrum Disorders (ASD), the trend is similar with the majority of primary carers being mothers [4].

Previous research indicates that providing care for children with ASD is a more demanding experience than providing care for typically developing children [5, 6]. Parents of children with ASD have been found to spend on average 43 hours per week in childcare activities (e.g., assisting children's personal care) [7]. It is well documented that domestic tasks add to the everyday demands for mothers in addition to childcare [8, 9]. Similarly, some child-related factors, such as having young children [10] or children with disabilities [6, 9, 11, 12], increase the intensity of everyday parental activities.

To investigate the demands and intensity that mothers of children with disability experience, their time-use and daily patterns have been commonly examined [6, 12, 13, 14]. 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 [12, 13, 15, 16]. Mothers of children with disabilities have been found to spend most of their time in childcare [12, 15], and this tendency remains the same even their children grow older [6]. 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 [6, 15, 17, 18].

Various data collection methods have been used to investigate the time-use among parents of children with disability. These include: 1) daily diary entry [15, 17, 19, 20], 2) time estimation [7], and 3) instruments to record daily activities and parental perceptions, such as satisfaction [6, 12, 13, 21]. Although these methods are valuable, they may be prone to recall bias [22] and can be burdensome for parents of children with disability who commonly experience increased time pressure [23]. 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 [22, 24]. Although this method is underutilized in the field of disability [25], through ESM, researchers can identify patterns of activities and explore participants' feelings while engaging in activities [26, 27, 28]. Use of ESM can potentially minimize recall bias [22, 24] and requires less cognitive demand than those traditional methods due to short completion time [27]. ESM has not been widely used with mothers [29, 30]; however, it has been employed to examine time-use with a variety of populations [31, 32, 33]. Previous research that examined the emotional experiences in managing multiple roles among public health nurses reports good usability of this method [34].

While some previous studies have investigated the experiences of single mothers of children with ASD [35, 36], empirical studies that compared the time-use of mothers based on their household status (i.e., single versus couple) are limited [37]. Previous studies commonly investigated whether mothers' time-use differ depending on the presence of children's disability [6, 12] or children's diagnosis [13]. The lack of focus on single mothers' experiences is problematic as single parent households are projected to increase globally [38]. Receiving support, such as spousal support, is an essential coping strategy in managing daily life among mothers of children with disability [39].

However, single mothers of children with disability face increased time pressure to manage family care responsibilities without day-to-day spousal support [40]. 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 [41]. Subsequently, families of children with disability who live in regional and remote areas may have difficulty in accessing therapy services on a daily basis [42]. 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 [43]. 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***

Mothers who had children aged 2-19 years with ASD, living in Western Australia, were eligible to participate in this study and 40 mothers were recruited using convenience sampling. In 2016, the study was promoted through a wide network of community organisations. Prospective participants who were interested in participating in the study were asked to contact the first author via email or phone. 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” [44, 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 [45]. 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 Accessibility/Remoteness Index of Australia (ARIA+) grid, which is a one square kilometer grid covering all of Australia, is used to calculate scores for road distances to the service centers [46]. The five categories are as follows: 1)

major city (scores between 0 and 0.2), 2) inner regional (scores greater than 0.2 and less than or equal to 2.4), 3) outer regional (scores greater than 2.4 and less than or equal to 5.92), 4) remote (scores greater than 5.92 and less than or equal to 10.53), and 5) very remote (scores greater than 10.53) [45]. 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 1 presents a comparison of participants' characteristics by household status and region of residence.

<Insert table 1 here>

### ***ESM Survey***

An iOS application, Participation in Everyday Life Survey Application (PIEL<sup>©</sup> survey) was used to conduct the ESM survey. This application was developed to assist researchers to collect ESM data [47]. 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 [6, 12, 13]. 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 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.



<Insert table 2 here>

## ***Procedures***

We asked participants to download the PIEL<sup>®</sup> survey application [47] 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<sup>®</sup> 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. During the time of data collection, all mothers were carrying the main childcare responsibility. 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 [REDACTED] 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 [48] 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 [22]. Six activity categories were created (see table 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.

### ***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 [49, 50]. Adapting other analyses, such as general linear model (GLM), to manage this dependency is problematic as the adjustment made by GLM for the covariance structure of the data in estimating models assumes that the data is independent [51]. Therefore, use of multilevel analyses that account for this dependency is considered to be appropriate to examine the associations between activities and *in-the-moment* feelings [49, 51, 52, 53]. 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 [49, 52, 54]. If variability between and within different levels is not accounted for, misleading conclusions may be drawn [49, 51]. Thus, multilevel analysis is better suited to analyze ESM data than conventional ordinary least squares (OLS) [51, 55] or analysis of variance that cannot account the complexities of ESM data [52] in increasing statistical power [56]. 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 [49, 54]. However, a previously suggested guideline is a minimum sample of 30 for both level 1 and 2 (i.e., a total of 900 rows of data with 30 participants, where each row corresponds to a time that a participant responds to the survey) [57]. Given that recent studies that analyzed ESM data using multilevel analysis had sample sizes of between 25 and 40 participants [58, 59, 60, 61, 62], a sample size of 40 with over 1300 rows of data in the current study would be considered acceptable. Hierarchical Linear and Nonlinear Modelling software (HLM 6.08) [63] 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) ASD diagnosis (HFA, AS, PDD-NOS versus autistic disorder), 2) age of child with ASD (5 to 11 years old versus older than 11 years old), and 3) total number of children (two or more children versus one child) [9, 10, 64, 65]. A fixed regression coefficient ( $\beta$ ) 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, regional versus major city region of residence, ASD diagnosis, age of child with ASD and total number of children) 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 [49, 54]. For all analyses, the critical  $\alpha$ -level was set at .05.

## **Results**

### ***Time-use and participants' characteristics***

In accordance with previous research that used ESM [27], 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 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.

<Insert table 3 here>

### ***Multilevel analyses***

The results of the step one multilevel analyses are presented in Table 4. Figures which summarize the results of both steps one and two multilevel analyses are created and presented by each dependent variable (i.e., five *in-the-moment-feelings*). Each figure depicts the following results as per each dependent variable: 1) the relationship between activities (level 1 independent variables) and *in-the-moment* feelings (dependent variables); 2) the relationship between participants' characteristics (level 2 independent variables) and *in-the-moment* feelings; and 3) moderating effects of participants' characteristics on the relationships of activities and *in-the-moment* feelings (Figures 1 to 5). The lower section of figures depicts the relationships between activities and *in-the-moment* feelings. The upper section of Figures shows participants' characteristics and the relationships between participants' characteristics and *in-the-moment* feelings. These two types of relationships are illustrated using a solid black line with a symbol of 'plus/minus' sign with a dotted pattern on the line to illustrate positive/negative relationships. Moderating effects of participants' characteristics are presented using a wide grey line that stretches downwards from the upper section to the lower section, crossing the relationships between activities and *in-the-moment* feelings. Strong/weak moderating effects were presented in the Figures with a black symbol of a 'plus/minus' sign on the wide grey line.

<Insert table 4 here>

### ***Multilevel analysis of 'felt supported' in activities***

Overall, mothers were less likely to feel supported when engaging with childcare and domestic tasks (Table 4). However, mothers were more likely to feel supported while participating in leisure activities. As per participants' characteristics, coupled mothers were more likely to feel supported than single

mothers. There were no other significant relationships between participants' characteristics and 'felt supported'. These findings are presented in Figure 1.

Single versus coupled household status moderated the relationship between feeling supported and domestic tasks ( $\beta = -0.17, SE = 0.09, p < .05$ ). This means that coupled mothers were less likely to feel supported in domestic tasks than single mothers. In addition, children's age had a moderating effect on the relationship between feeling supported and productivity, self-care and leisure ( $\beta = 0.21, SE = 0.08, p < .05$ ;  $\beta = 0.16, SE = 0.08, p < .05$ ;  $\beta = 0.14, SE = 0.06, p < .05$  respectively). This means that mothers who had children between the ages of 5 and 11 years felt more supported in those activities than those mothers who had children older than 11. Although productivity and self-care were not significantly associated with 'felt supported' in level 1 multilevel analysis, relationships were established when the moderation effects of participants' characteristics were found to exist. These relationships were shown as a dotted line between activities and 'felt supported'.

< Insert figure 1 here >

#### *Multilevel analysis of 'felt challenged' in activities*

Mothers were more likely to feel challenged when engaging in childcare and productivity activities (Table 4). There were no significant relationships between participants' characteristics and a dependent variable of 'felt challenged. Regional versus major city region of residence had a moderating effect on the relationship between feeling challenged and childcare, productivity and self-care activity ( $\beta = 0.14, SE = 0.06, p < .05$ ;  $\beta = 0.16, SE = 0.07, p < .05$ ;  $\beta = 0.19, SE = 0.08, p < .05$ ). This means that those mothers who lived in major city areas felt more challenged while engaging in childcare, productivity and self-care activities. Further, children's age had a moderating effect on the relationship between feeling challenged and domestic tasks ( $\beta = 0.11, SE = 0.05, p < .05$ ). This means that mothers who had children between the ages of 5 and 11 years felt more challenged in domestic tasks than those mothers who had children older than 11. The level 1 multilevel analysis did not find a relationship between

domestic task and ‘felt challenged’; however, the relationship was established when the moderation effects of participants’ characteristics were found to exist. These findings are presented in Figure 2.

< Insert figure 2 here >

#### *Multilevel analysis of ‘felt in control’ in activities*

Mothers were less likely to feel in control with childcare and productivity. Additionally, mothers with two or more children were less likely to feel in control (Table 4). There were no other significant relationships between participants’ characteristics and ‘felt in control’. Moderating effects of participants’ characteristics on the relationships between activities and ‘felt in control’ were not found. These findings are presented in Figure 3.

< Insert figure 3 here >

#### *Multilevel analysis of ‘felt engaged’ in activities*

Mothers were more likely to feel engaged while participating in productivity and leisure activities (Table 4). There were no significant relationships between participants’ characteristics and ‘felt engaged’.

Children’s age had a moderating effect on the relationship between feeling engaged and productivity, domestic tasks, and self-care ( $\beta = 0.21, SE = 0.06, p < .01$ ;  $\beta = 0.24, SE = 0.06, p < .01$ ;  $\beta = 0.17, SE = 0.07, p < .05$  respectively). This means that mothers who had children between the ages of 5 and 11 years felt more engaged in those activities than those mothers who had children older than 11. The relationships between ‘felt engaged’ and domestic tasks as well as self-care were not found significant in the level 1 multilevel analysis; however, these relationships were established when the moderation effects of participants’ characteristics were found to exist. Total number of children had a moderating effect on the relationship between feeling engaged and productivity ( $\beta = 0.24, SE = 0.08, p < .01$ ). This means that mothers with two or more children felt more engaged in productivity than those mothers with one child. Figure 4 presents these findings.

<Insert figure 4 here>

#### *Multilevel analysis of 'felt stressed' in activities*

Mothers were more likely to feel stressed with childcare, productivity, and domestic tasks (Table 4). There were no significant relationships between participants' characteristics and 'felt stressed'. No moderating effects of participants' characteristics on the relationship between activities and 'felt stressed' was found. These findings are presented in Figure 5.

<Insert figure 5 here>

### **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 [66, 67]. Perceived control is an important construct to consider when investigating the experiences of parents of children with ASD [68]. 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 [69, 70, 71]. Conversely, when mothers felt they were in control in managing children's behavior, they were found to hold positive perceptions of their children [70]. 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 [72]. 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 [73]. However, previous research suggests that given the characteristics of ASD, such as rigidity, and related parental stressors, learning to control situations may be counterproductive [74]. 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 [75, 76]. Mothers are required to constantly engage in both direct childcare activities, such as assisting a child during meal time [77], and indirect childcare activities, such as coordinating children's therapy appointments [78]. 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 [13, 78, 79, 80]. Moreover, indirect childcare activities can be time-consuming that they may lead to mothers having less time available for personal activities [13, 79]. Previous studies found that mothers of children with a disability create extra time by reducing their own time to meet the childcare demands [17, 18, 19]. 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 [9]. Previous research suggests that mothers prioritize their time based on meaningfulness of activities [13]. 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 [81], 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 [39, 82, 83]. Although the benefits of receiving informal support from other sources, such as extended family, have been well documented for parents of children with ASD [18, 84, 85], there is a tendency that levels of informal support received by these parents are generally low [86]. 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 [76, 87]. 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 [88]. Therefore, spouses who share everyday experiences might be perceived as a more valuable source of support among parents of a child with ASD [89].

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 [90]. 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 [13, 91]. 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 [92]. A higher level of perceived support has been found to be related to decreased burden [93] and lower stress levels among parents of children with ASD [94]. It should be noted that the current study did not investigate the types of support, such as instrumental support, that the mothers received [95]. However, received support is an element of the complex construct of perceived support [96]. 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 [97], 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 [10]. 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 [10]. 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 [98]. 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 [99]. 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 [100]. Receiving adequate social support that alleviates adverse health issues [101, 102] is particularly important to single mothers, as earlier research suggests that they experience more negative health outcomes than coupled mothers [103]. 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 [104, 105]. Our results indicate that further investigation into children's fathers' involvement relating to the outcomes for both single mothers and children with ASD is required.

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 [9, 64], presence of intellectual disability [65], and number of children [17, 64], 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, domestic tasks and self-care 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 [6, 12]. Productivity tasks, such as paid work, can provide respite for parents of children with disability from their childcare responsibilities [9]. 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 childcare, productivity and self-care tasks than their counterparts. Lifestyle demands associated with city life, such as traffic congestion and extended travel time, may have limited time available for these mothers to spend time in these activities. This potential limitation, in turn, may have attributed to these mothers to feel more challenged when engaging in these activities. However, the proportion of time spent on these three activities did not differ between mothers who lived in major city areas and those who lived in regional areas. The result of the study suggests that mothers’ perceptions of insufficient time may have led them to feel more challenged while completing everyday activities. However, the current study did not collect qualitative data to clarify the findings. Future research should consider employing a mixed method, combining ESM and individual interviews, to obtain a better understanding of the experiences of these mothers.

Another way to consider the current finding would be a potential difference in social support between these two areas. 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 [106]. The availability of social support may allow mothers who live in regional areas to find it easier to participate in everyday activities than their counterparts. In support of this notion, the current study found that mothers who lived in regional areas spent a longer time in personal leisure of 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.

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 to this current study. The participants were recruited in Western Australia only using convenience sampling, 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 relatively small sample size and thus we did not examine interactions between household status and region of residence. Future research should consider recruiting a larger sample size. However, it should be noted that the number of participants in the current study meets the minimum guideline of 30 [57] and the results of this study were based on the analysis of over 1300 rows of survey entries. Although previous research that used ESM show that it is a reliable method to study individual time-use [27], 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. 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. Mothers were asked to report their children's official ASD diagnosis; however, specific information, such as diagnostic levels, was not collected. It should be noted that the demographic survey included a page with a diagnostic checklist of DSM-IV-TR/ICD10 symptoms of ASD [108] to validate that child meets diagnostic criteria at the time of completing the study. The study was promoted by several community organizations and thus the researchers did not have access to the potential number of participants that were approached. Therefore, the researchers were unable to calculate the response rate. 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.

### **Implications for rehabilitation**

- This study shows that all mothers spent the most time on childcare and the least amount of time on self-care activities.
- *In-the-moment* experiences between single and coupled mothers, as well as mothers from major cities and mothers from regional areas, differ somewhat; however, this study builds evidence to support that these mothers' experiences are similar.
- The result of the study indicates that single mothers require extra support as they carry similar levels of responsibilities as coupled mothers, but without the support of a partner.
- Promoting a sense of control may assist all mothers to fully engage in parenting activities.

### **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, future research should consider investigating separated father's involvement in relation to mothers' outcomes. 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 [REDACTED] Human Research Ethics Committee.

Word count 6947

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