

Abstract

Objectives: The present study aimed to explore whether regionality is associated with differing stress levels, coping, QOL and daily routines for parents and families of a child with ASD (aged 2 - 18 years) in Western Australia using validated outcome measures and compare the stress levels and QOL of this group to population norms.

Methods: A sample of 278 families living in Western Australia who have a child or adolescent (2-18 years old) with a clinical diagnosis of ASD participated in a cross-sectional survey. Multivariate logistic regression modelling was conducted to determine key factors associated between regionality and demographic variables, quality of life, coping styles, time use, and stress levels.

Results: Parents living in low densely populated areas were more likely to adopt avoidant coping mechanisms, compared to those living in densely populated areas. Fathers with children on the autism spectrum were less likely to be educated above diploma level in regional and remote areas. Stress, QOL or daily routines did not differ by regionality; however, the total sample (i.e., parents from both LDP and DP areas) experienced significantly higher levels of stress and lower QOL when compared to the general population.

Conclusion: The findings suggest that despite having higher levels of stress and lower QOL compared to the general population, residing in a geographically LDP area in Western Australia has a small association on preferred coping style preference and has no association on stress levels, QOL or daily routines for parents who have a child with ASD.

Keywords: Autism Spectrum Disorder, Quality of Life, Parents, Psychological Adaptation

Autism Spectrum Disorders (ASD) include a life-long spectrum of conditions characterised by deficits in social communication and behaviour, including problems interpreting non-verbal gestures, difficulty developing age-appropriate friendships, adherence to rigid routines, and adapting to environmental change (American Psychiatric Association, 2013; Happé & Ronald, 2008). In the absence of pharmaceutical intervention, intensive early intervention delivered by trained clinicians is recommended to ameliorate core symptomology and thereby improve functional outcomes (Dawson et al., 2010; Whalen, Liden, Ingersoll, Dallaire, & Liden, 2006). The symptoms and concomitant challenging behaviours associated with ASD present parents and children with many adverse outcomes, including but not limited to, higher parental stress, poor sibling adjustment, family functioning, disruptive behaviour, and social isolation (Gray, 1994; Rao & Beidel, 2009).

Parents of a child with ASD experience higher levels of stress compared to parents of typically developing children, as well as parents of children with other disabilities (Dabrowska & Pisula, 2010; Duarte, Bordin, Yazigi, & Mooney, 2005; Hayes & Watson, 2013; Higgins, Bailey, & Pearce, 2005; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Frequent contributors to parental stress in ASD include, social behaviour challenges of children with ASD, parents' reduced ability to socialise, reduced access to individual therapy, negative co-parent relationships and high out of pocket costs (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Johnson, Frenn, Feetham, & Simpson, 2011; Lecavalier, Leone, & Wiltz, 2006; Sim et al., 2018). Higher levels of stress have also been found to be a predictor of lower quality of life (QOL) (Khanna et al., 2011; Lee et al., 2009). A recent systematic review by Vasilopoulou and Nisbet (2016) concluded that parents of children with ASD are more likely to experience poorer QOL when compared with parents of typically developing children or to population norms. The authors concluded that variables associated with lower parental QOL were child behavioural difficulties, unemployment, being a mother and a lack of social support. Furthermore, the QOL of parents with a child with ASD has been shown to directly impact the QOL of their children, with lower QOL experienced by parents associated with lower QOL in their children (Burgess & Gutstein, 2007). Given the bi-directional nature of the parent-child relationship, consideration of the QOL of parents is an essential factor when working with this population.

The transactional model of stress and coping proposed by Lazarus and Folkman (1984) viewed stress as the outcome of the interaction between the environment and the individual. When environmental stressors/demands exceed individual resources, coping mechanisms are recruited to restore function.

According to Lazarus and Folkman (1984), if the coping mechanisms cannot meet the demands or are maladaptive, the outcome is stress. Subsequently, if stress is the outcome of inadequate coping mechanisms, it would be remiss not to investigate individual preferences for coping in parents of children with ASD.

Parents of children with ASD utilise a range of coping strategies when stressed and the use of these coping strategies are variable compared to parents of typically developing children or children with other disabilities (Hastings et al., 2005; Lai, Goh, Oei, & Sung, 2015). Hastings et al. (2005) explored the structure of coping strategies used by parents of children with ASD living in the United Kingdom. The authors reported four distinct coping dimensions: 1) active avoidance coping, such as self-blame; 2) problem-focused coping, such as planning and taking action to address the problem; 3) positive coping, such as humour or positive reframing; and 4) religious/denial coping, such as prayer. A review paper by Lai and Oei (2014) reported that parents of children with ASD recruit both adaptive (seeking social support and problem-focused) and maladaptive (active-avoidance) coping strategies to manage stress related to caregiving. Furthermore, Lai and Oei (2014) concluded that maladaptive coping strategies contributed to higher levels of stress and mental health problems, while adaptive coping strategies are associated with lower levels of stress and fewer mental health problems - such as depression. A gap remains in the research regarding the nature of parental coping in ASD across different individuals and situations. Specifically, broad coping frameworks for parents with ASD may not be generalisable to all parents and caregivers of children with ASD from different cultural, demographic and environmental contexts.

Carver, Scheier, and Weintraub (1989) suggested that coping is context-dependent and primarily influenced by the constraints of the situation. The unique context of living in regional and remote Australia and the comparison between parents living in these areas and those living in more densely populated areas in relation to their stress levels is poorly understood and further investigation is warranted. In this paper, regionality is defined in terms of the difference in population density. Terms of densely populated (DP) and low densely populated (LDP) are used to differentiate between highly populated areas and regional and remote areas, respectively (McAuliffe, Vaz, Falkmer, & Cordier, 2016).

The challenges of raising a child with ASD can be magnified for families living in regional and remote areas in Australia, where access to timely and appropriate health and therapeutic services can potentially create unique barriers (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017; Chen, Liu, Su, Huang, & Lin, 2008; Hutton & Caron, 2005; Murphy & Ruble, 2012), which, in turn, may impact on the type

of coping strategies used by parents. Specifically, families of children with ASD living in regional and remote areas in Australia attempting to access appropriate health services can encounter: 1) widely dispersed services requiring parents to travel vast distances to access services; 2) lower levels of screening and delayed diagnosis; and 3) difficulties in retaining skilled health professionals in these settings (Iacono, Humphreys, Davis, & Chandler, 2004; Smith, Humphreys, & Wilson, 2008; Struber, 2004). These are unique stressors to families living in LDP areas, which could negatively influence stress levels and coping strategies adopted by parents living in these areas (Elgar, Arlett, & Groves, 2003). Moreover, there is a scarcity of literature investigating the difference in stress levels and coping strategies between families living in DP areas compared to those living in LDP, even in families who do not have a child with ASD. Given the importance of early intervention in reducing the child's ASD related behaviours; limited access to adequate health services and a shortage of adequately trained early intervention health and education professionals are of particular concern for this population, serving to increase parental stress (Hayes & Watson, 2013; Hutton & Caron, 2005; Iacono et al., 2004; Smith et al., 2008; Struber, 2004).

The unique nature of stress and the interaction between stressors and the environment of parents of children with ASD living in regional and remote areas in Australia could affect the coping strategies recruited by this population (Hastings et al., 2005; Hoogsteen & Woodgate, 2013b). Furthermore, there is evidence to suggest that coping strategies used by parents of children with ASD could be different when compared to parents of typically developing children or children with other disabilities, due to the differences in social environments (e.g., poorer social supports and limited access to service) often experienced by this group (Hastings et al., 2005; Lai et al., 2015). Few studies have defined and categorised different types of coping strategies used by parents who have a child with ASD (Benson, 2010; Hastings et al., 2005; McAuliffe, Cordier, Vaz, Thomas, & Falkmer, 2017) and none have done so with families living in regional or remote areas in the Australian context. It is plausible that people living in regional areas in Australia may exhibit different coping mechanisms due to the unique context in which they live, such as limited social support and poorer access to services. However, an extensive literature search indicates a scarcity of research having been undertaken to investigate this.

Synthesising the findings from studies that investigated the impact of regionality on study outcomes is, however, a challenge, due to heterogeneity in classification systems, geographical topographies, poor sampling methods within studies and differences in local government policy and resourcing (Hoogsteen &

Woodgate, 2013b; Murphy & Ruble, 2012; Parsons, Cordier, Vaz, & Lee, 2017). To date, only one empirical study has explicitly investigated the role of regionality in Australia in the lives of parents of children with ASD. McAuliffe et al. (2016) compared family daily routines, service usage and stress levels of parents of children with ASD living across Western Australia by regionality and concluded that families living in low densely populated areas experience reduced employment hours, travel greater distances to access medical facilities and report less severe stress levels when compared to families living in urban areas. However, McAuliffe et al. (2016) did not use validated assessments to measure the study outcomes and did not investigate the phenomena of coping or QOL. The current study extends the knowledge base by: 1) Exploring whether regionality is associated with differing stress levels, coping, QOL and daily routines for parents and families of a child with ASD (aged 2 - 18 years) in Western Australia using validated outcome measures; and 2) Comparing stress levels and QOL of parents and families of a child with ASD (aged 2 - 18 years) in Western Australia with population norms.

Methods

Participants

Families living in WA who had a child or adolescent (2 - 18 years old) with a clinical diagnosis of ASD determined by a team of qualified health professionals using the DSM-V or DSM-IV criteria (if diagnosed prior to the DSM-V) were recruited (American Psychiatric Association, 2013). Families were recruited through the Disability Services Commission (DSC) of WA by contacting every parent of children with ASD on their register; by the research team contacting service providers, such as general practitioners, paediatricians, speech pathologist and occupational therapists working with families of children with ASD; related events run through Curtin University, community organisations, such as the Southwest Autism Group (SWAN); and ASD service providers in WA. A list of families who have agreed to be contacted for research studies, housed at Curtin University and the Telethon Kids Institute, were also invited to participate.

Survey responses from 278 families of children with ASD were received, with 91% of respondents ($n = 255$) female and 9% ($n = 24$) male. The characteristics of the families who responded to the survey are summarised in Table 1. There were no significant differences between families living in DP areas to those living in LDP areas except for the father's education in the family, with fathers in LDP having lower education levels compared to fathers living in DP areas. The characteristics of the children with ASD

collected in the survey are displayed in Table 2. The age when the children first accessed therapeutic services was the only significant difference between those children living in DP areas and those living in LDP areas.

<Insert Table 1 Here>

<Insert Table 2 Here>

Procedure

A cross-sectional survey design was used. Ethics approval was received from the Curtin University Human Ethics Committee (HR123/2014) for this study. Potential participants had one of three possible options to participate in the survey: 1) online, 2) via telephone, or 3) using pencil and paper. The online survey was available from January 2015 to December 2016. Consent for the online version was provided by ticking a box at the start of the survey. If participants elected to complete the survey over the telephone, a member of the research team would call at a nominated time convenient for the participant. The researcher sought consent to participate and then followed on to screen for eligibility using the following pre-determined inclusion criteria: having a child or adolescent (2 - 18 years old) with ASD; their child having no other major medical or psychiatric conditions (e.g., Fragile X syndrome); and resided in Western Australia (WA). Once consent to participate was obtained and the participant deemed eligible, the researcher administered the survey. Finally, if the participants elected to complete the survey using the paper and pencil method, a pack was sent in the post; including a consent form to be returned via an enclosed envelope separate to the survey. All data whether entered directly by participants online or by researchers from the paper copies were housed on password protected Curtin University's Qualtrics Web Server.

Measures

To create the survey, the authors undertook a literature search of studies investigating the lived experience of living regionality with ASD, researched measures with robust psychometrics for this population, and incorporated feedback from representatives of local government and support groups. Survey data were collected on: 1) ASD identification and diagnostic procedures; 2) availability and accessibility of services and support; 3) parent satisfaction with services and supports; 4) direct financial costs of parenting a child with ASD; and 5) emotional stress and physical barriers to receiving professional input. The following

validated instruments were incorporated: Autism Parenting Stress Index (APSI) (Silva & Schalock, 2012a; Silva & Schalock, 2012b); Brief COPE (Carver, 1997); and World Health Organisation Quality Of Life - BREF (Skevington, Lotfy, & O'Connell, 2004).

Autism Parenting Stress Index

The Autism Parenting Stress Index (APSI) is a valid and reliable instrument for measuring parenting stress in relation to the core and co-morbid symptoms of ASD (Silva et al., 2015). The measure is intended for use by clinicians to identify areas where parents need support with parenting skills and to assess the effect of the intervention on parenting stress (Silva & Schalock, 2012a). A validation study of the measure reported internal consistency for parents of children with ASD was acceptable with Cronbach's α scores .76, .76 and .67 on the factors of core autism behaviours, co-morbid behaviours and co-morbid physical issues. Test-retest reliability coefficient was .88 at a 4-month interval (Silva & Schalock, 2012a; Silva, Schalock, & Gabrielsen, 2011). The APSI uses a five-point Likert scale and respondents are asked to rate aspects of their child's health according to how much stress it causes them or their family. Some example items include "Your child's ability to communicate" and "Difficulty making transitions from one activity to another"(Silva & Schalock, 2012a)

Brief COPE

The Brief COPE is an abbreviated version of the COPE inventory. The Brief COPE uses a 4-point Likert scale to determine how frequently they employ 28 different behaviours and cognitions across 14 scales when coping with stressful situations (Benson, 2010; Carver, 1997). Although not specific to measuring stress in the context of parenting children with ASD, the Brief COPE is a useful tool in identifying poor coping outcomes and has been used extensively as an outcome measure with this population (Benson, 2010; Hastings et al., 2005; Lai & Oei, 2014). Except for three scales, Venting (.50), Denial (.54) and Acceptance (.57), Cronbach's α scores are an average of .72 (range .52 - .93) across the 14 scales (Benson, 2010). Some example items include "I've been taking action to try to make the situation better" and "I've been getting emotional support from others" (Carver, 1997)

World Health Organisation's Quality Of Life-BREF (WHOQOL-BREF)

The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100 assessment clustered into four domains; 1) physical health; 2) psychological; 3) social relationships; and 4) environment (Skevington et al., 2004). The measure consists of quality of life items that are concerned with the meaning of

different aspects of life to the respondents, and how satisfactory or problematic their experience is of them. The assessment covers a broad range of facets and has been cross-culturally validated for several languages (Skevington et al., 2004). Internal consistency for the total sample is acceptable (Cronbach's $\alpha > .70$) for three out of the four domains for physical health (.82), psychological (.81), and environment (.80), but marginal for the social relationships domain (.68). Test-retest reliability is generally high ranging from .56 to .84 for individual items over an interval from 2-8 weeks. Domain test-retest are .66 for physical health, .72 for psychological, .76 for social relationship and .87 for the environment domains (Skevington et al., 2004; WHOQOL Group, 1998). The measure's domain scores have been shown to correlate at approximately .90 with the WHOQOL-100 domain scores, which has itself demonstrated sound criterion validity. The domain scores have also been shown to demonstrate content and discriminate validity (WHOQOL Group, 1998). Some example items include "To what extent do you feel that physical pain prevents you from doing what you need to do?" and "How would you rate your quality of life?". (WHOQOL Group, 1998)

Daily Routines

Participants were asked to complete a 24-hour format table to describe their average weekday and weekend day by providing estimated hours on each of the 14 activities presented. These 14 activities were chosen based on published literature investigating daily routines of parents of children with a disability (Gevir, Goldstand, Weintraub, & Parush, 2006; McCann, Bull, & Winzenberg, 2012). The 14 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.

Data Analyses

Data were managed and analysed using IBM SPSS[®] Statistics version 24 (IBM Corp., 2016). Descriptive statistics were used to describe the demographic characteristics of families living in low densely populated (LDP) and families living in densely populated (DP) areas. Independent *t*-tests for continuous variables and Pearson's χ^2 for categorical variables were performed to determine between-group differences using the dependent variable of regionality with the independent variables of key child factors (e.g., age, diagnosis, comorbidity), and parent factors (e.g., demographic factors, stress, coping, quality of life, impact on routine). Binary logistic regression analysis was conducted on significant variables using the backward

elimination method to develop the final model to determine key factors associated with demographic variables, quality of life, coping styles, time use, and stress levels, using the dependent variable of regionality. Finally, unequal variance *t*-tests were performed to compare the total sample (DP and LDP combined) with published general population normative data for the WHOQOL-BREF and APSI outcome measures (Hawthorne, Herrman, & Murphy, 2006; Silva & Schalock, 2012a).

For this study, regionality was defined using the Australian Bureau of Statistics (ABS) five-category classification based on the Australian Standard Geographical Remoteness Classification System (ASGC) (Australian Bureau of Statistics, 2011a). The aim of ASGC remoteness structure is to divide Australia into broad regions for comparative statistical purposes. There is no widely accepted standard to determine when city becomes country; the ASGC remoteness classification system simply groups areas where all members of that remoteness area (RAs) have similar, but not identical, characteristics of remoteness (Australian Bureau of Statistics, 2003). The ASGC remoteness structure is classified into five RAs (Australian Bureau of Statistics, 2011a). The categories include: 1) major cities; 2) inner regional; 3) outer regional; 4) remote; and 5) very remote. 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, 2011b; McAuliffe et al., 2016). Participants' postcodes in the current study were recoded based on this classification.

The RAs were further collapsed into a dichotomous variable due to the small number of respondents from remote and very remote areas. In doing so, the DP category ($n = 230$, 82.7%) was formed by collapsing the major city ($n = 136$, 48.9%) and inner regional city ($n = 94$, 33.8%) postcodes and LDP category ($n = 48$, 17.3%) was formed by collapsing the outer regional ($n = 29$, 10.4%), remote ($n = 15$, 5.4%) and very remote postcodes ($n = 4$, 1.4%). The rationale for this dichotomisation was based on people living in outer regional, remote and very remote areas having to travel significantly greater distances to access services compared to those living in major cities and inner regional areas (Australian Bureau of Statistics, 2011b). Analyses were also conducted with the DP category ($n = 136$, 48.9%) comprising only of participants from major cities and the LDP category ($n = 142$, 51.1%) consisting of participants from inner regional, outer regional, remote and very remote regions. No difference in findings was observed, regardless if inner regional data were dichotomised with DP or LDP categories.

An exploratory factor analysis was conducted to best fit the current study's participants (see Table 3) as the studies by Benson (2010) ($n = 113$) and Hastings et al. (2005) had smaller sample sizes ($n = 113$; $n = 135$ respectively) than the current study ($n = 278$) and did not contain such a large proportion of participants from regional and remote areas. A principle component analysis using an oblimin rotation was completed for the 28 items used in the measure. The scree-test was used to determine the number of factors with the eigenvalue greater than 1.0 (Field, 2013; Osborne & Costello, 2009) and factor loading greater than .40. Following the initial examination of the correlation matrix, the two items, which form a subscale of substance use and another two items, which form a subscale of use of religion, were highly correlated ($r > .8$) and therefore excluded. Eigenvalues greater than two indicated that the first three factors explained 20%, 15%, and 8%, of the variance, respectively (Table 3). The fourth, fifth and sixth factors had eigenvalues under 2, explaining 8%, 5% and 5% of the variance, respectively. The scree plot was ambiguous showing inflections on factors three and five, justifying retaining both of these factors; however, the components did not fit the theoretical framework validated by Hastings et al. (2005) or Benson (2010), hence were excluded. The Kaiser-Meyer-Olkein measure indicated good sampling adequacy ($KMO = .768$) and Bartlett's test of sphericity ($\chi^2 = 2213.23$, $df = 276$, $p < .001$) indicated sufficient correlation between each item (Field, 2013). As a result, the three-factor solution explaining 43% of the total variance was used in the current study. Cronbach's α -values are reported for all three factors in Table 3. In contrast to the studies by Benson (2010) and Hastings et al. (2005) – each had four factors – our analysis yielded three factors with one item dropped: 1) problem-focused; 2) active avoidance; and 3) positive coping. The item dropped was an item for the self-distraction subscale, '*I have been turning to work or other activities to take mind off things*'. Due to the similarities between our extracted factors and those of Hastings et al. (2005) with the exception of religious/denial coping, we elected to use their factor labels in this study. The problem-focused factor refers to the proactive coping styles to deal with stressors, including items of the planning, use of instrumental support, active coping, and acceptance subscales. Active avoidance described coping styles that avoided physical and emotional stressors, including items of self-blame, behavioural disengagement, denial and venting in addition to one item from the self-distraction subscale. Finally, positive coping described coping by perceiving stressors through a constructive lens. This included items of the humour, positive reframing and use of emotional support subscales.

<Insert Table 3 Here>

Results

Factors predictive of regionality

Chi-square tests for categorical outcomes and *t*-tests for continuous outcomes were used to determine univariate differences as a function of regionality. A multivariate logistic regression model of factors that significantly predicted living in low-density areas (LDP) was developed by including factors that approached significance at univariate level ($p < .10$). The following factors were included in the multivariate model: 1) number of children with ASD in the family; 2) age the child first accessed therapy; 3) level of fathers education; 4) avoidance coping factor cluster in the Brief COPE; 5) Social domain in the WHOQOL-BREF; 6) Environmental domain in the WHOQOL-BREF; 7) Co-morbid behaviour domain in the Autism Parenting Stress Index; 8) hours sleeping on the weekend; and 9) hours spent studying on the weekend.

The final multivariate model is presented in Table 4. Backward elimination was used to build the model as there was no a priori rationale to enter variables into the model (Field, 2013). Goodness of fit of the model was tested against a constant only model and found to be statistically significant ($\chi^2(5) = 28.58, p < .001$). The final model explained 20% of the variability in regionality (Nagelkerke's $R^2 = .20$). The overall accuracy of the model was 83.8%. The Wald criterion and Exp (β) were used to predict the strength of individual factors. Parents who lived in LDP areas were 1.1 times more likely to adopt avoidance coping strategies ($p = .004, Exp(\beta) = 1.14$) when compared to parents living in DP areas. Fathers who lived in LDP were 3.4 times more likely to have achieved a qualification up to a diploma or lower ($p = .017, Exp(\beta) = 3.44$).

The multivariate logistic regression analysis detected no significant difference for associations between the dependent (regionality) and the following independent variables: 1) number of children with ASD in the family; 2) age the child first accessed therapy; 3) Social domain in the WHOQOL-BREF; 4) Environmental domain in the WHOQOL-BREF; 5) co-morbid behaviour domain in the Autism Parenting Stress Index; 6) hours sleeping on the weekend; and 7) hours spent studying on the weekend. Lastly, sensitivity analyses were conducted by including parent gender, parent's age, child gender, and time since the diagnosis was made as covariates in the model; however, no significant differences in these independent variables were detected and they did not change the final model.

<Insert Table 4 Here>

Comparison to General Population

Respondent scores from the overall sample (DP and LDP combined) on the WHOQOL-BREF and APSI outcome measures measuring quality of life and stress levels respectively, were compared with published normative data based on the general population (see Table 5). Normative data from the WHOQOL-BREF was obtained from a random sample of residents with respondents being 54% female and 46% male, with an average age of 48.2 years (SD = 17.3) living in Victoria, Australia (Hawthorne et al., 2006). Participants were recruited through random telephone selection and stratified including a broad range of health conditions from full health to terminal illness in addition to socioeconomic status (Hawthorne et al., 2006). Normative data for the APSI was obtained from 139 parents of typically developing children completing a survey in Oregon, USA (Silva & Schalock, 2012a). Inclusion criteria for the typically developing children were: 1) between the age of three to six; 2) no diagnosis of ASD; 3) no developmental delay; 4) no chronic illnesses or medical conditions (Silva & Schalock, 2012a). Results demonstrated highly significant differences ($p < .001$) in all domains for both measures. Parents of children with ASD experience four times more stress overall when compared to parents of typically developing children. Furthermore, parents of children experience 14%, 25%, 37% and 18% poorer quality of life compared to parents of typically developing children across the physical, psychological, social and environmental domains of their lives, respectively.

<Insert Table 5 Here>

Discussion

The aim of this study was to: 1) Explore whether regionality is associated with differing stress levels, coping, QOL and daily routines for parents and families of a child with ASD (aged 2 - 18 years) in Western Australia using validated outcome measures; and 2) compare the stress levels and QOL of this group to population norms. The higher use of avoidant coping strategies and fathers being more likely to have lower education levels were the only significant differences between parents living in LDP areas compared to DP areas. Stress, QOL or daily routines did not differ by regionality; however, the total sample (i.e., parents from both LDP and DP areas) experienced significantly higher levels of stress and lower QOL when compared to the general population. The findings suggest that despite having higher levels of stress and lower QOL compared to the general population, residing in a geographically LDP area in Western Australia has a small

association on preferred coping style preference and has no association on stress levels, QOL or daily routines for parents who have a child with ASD.

Coping

Despite experiencing similar levels of stress and QOL, parents who live in LDP areas were significantly more likely to use avoidant coping strategies compared to those living in DP areas, however, the strength of the association at the group level was small ($Exp(\beta) = 1.14$). Given the lack of research into parents' experiences of having a child with ASD while living in regional Australia, interpretation of this finding presents some challenges. On the one hand, parents from LDP areas may be more likely to adopt avoidant coping strategies due to poor access to formal support options. On the other hand, the magnitude of the difference between parents living in DP and LDP areas was minimal. Thus factors other than regionality may better explain differences in the coping strategies of parents of children with ASD.

A study investigating the lived experience of having a child in regional Canada reported parents felt isolated regarding how to best support and parent their child with ASD (Hoogsteen & Woodgate, 2013a). People living in LDP areas may lack viable formal support options, such as limited access to: adequately trained support professionals, mental health services, and information, and increased travel time to obtain necessary supports due to having to travel vast geographical distances. These factors may restrict parents' ability to adopt problem-focused and positive coping strategies and encourage the use of avoidant coping strategies (Hoogsteen & Woodgate, 2013a; Lai et al., 2015; McAuliffe et al., 2017; McAuliffe et al., 2016). Lastly, coping and emotional regulation are context bound; hence, avoidant coping strategies may be culturally normative and valued differently across contexts. That is, parents from LDP areas may place a high value on avoidant coping strategies, such as distraction, and find them effective in reducing their depressive symptoms, thus explaining the higher preference for using distraction in this population (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008).

Current evidence suggests parents who use avoidant coping styles may, over time, be at higher risk of experiencing mental health difficulties, such as depression and poor emotional regulation, given the higher incidence of these mental health conditions in people who adopt maladaptive coping strategies compared to more positive and active approaches (Benson, 2010; Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001; Hastings et al., 2005; Pisula & Kossakowska, 2010). Although avoidant coping strategies may be helpful in decreasing stress in the short term, the likelihood of experiencing depression and emotional

dysregulation in parents with a child with ASD are increased if avoidant coping strategies are recruited in lieu of more positive coping strategies, such as engagement and positive reframing (Benson, 2010; Dardas & Ahmad, 2015). Therefore, practitioners working with families of children with ASD should be cognisant of the coping styles within their unique context used by parents to deal with the demands of parenting and implement evidence-based strategies accordingly, regardless of geographical location.

The small likelihood in preferring avoidance coping styles and the absence of significant differences in other coping style preferences between parents living in LDP and DP areas may indicate regionality has little association with the coping styles used by parents of children with ASD. Factors other than regionality may have a more substantial association with the preferred coping strategies for parents of children with ASD. A review by Lai and Oei (2014) reported parent gender and age, child age, the magnitude and changing nature of their child's challenging behaviours, time since diagnosis and cultural effects are the most important factors that influence the way parents with ASD cope. Notably, respondents to the survey were mostly mothers (91%); however, between-group differences were not significant for gender when comparing DP and LDP groups. Furthermore, when sensitivity analyses were conducted by including parent gender, parent's age, child gender, and time since the diagnosis was made as covariates in the model, no statistically significant associations were evident between DP and LDP areas. Future studies investigating coping strategies in parents of children with ASD living in LDP areas should aim to capture mental health issues, in addition to experiences of stress and QOL. Further investigation into the association between coping mechanisms, psychological adjustment and impact on mental health is warranted for parents of children with ASD, regardless of geographical location. Finally, there is a need for longitudinal studies to examine the impact of raising a child with ASD on mental health, in addition to stress levels, QOL, coping mechanisms and daily routines of families living in LDP over time. Longitudinal studies will better capture the dynamic nature of raising a child with ASD as they transition through various life stages, from the time a diagnosis is made, to school entry, entering puberty, and entering the workforce.

Stress and Quality of Life

Findings from this study provide further support for the notion that parents of a child with ASD experience higher levels of stress and poorer QOL than parents with typically developing children (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Higgins et al., 2005; Montes & Halterman, 2007). Despite parents of children with ASD experiencing higher levels of stress and lower QOL than the general population,

findings from this study suggest no overall difference in the stress levels between the parents of children with ASD living in LDP areas when compared to those living in DP areas. Limited between-group differences suggest that while it can be challenging for parents of a child with ASD living in LDP areas, these challenges do not increase stress or reduce QOL when compared to parents of a child with ASD living in DP areas who may have better access to services (Farmer & Reupert, 2013).

This is a positive finding, suggesting the barriers to accessing services for parents living in LDP areas may be decreasing when compared to parents living in DP areas, although it is acknowledged that some families living in very LDP areas may still experience challenges in accessing services (Dew et al., 2013; Dew et al., 2012). There has been a proliferation of innovative intervention models for children with ASD and their parents, such as parent-mediated, telehealth-delivered and information communication technology-based interventions to address challenges for LDP communities to access services (Antezana et al., 2017; Parsons, Cordier, Lee, Falkmer, & Vaz, 2019; Parsons et al., 2017). Furthermore, the impact of having limited services on stress and QOL could be ameliorated by other factors unique to living regionally, such as an increased sense of community and informal social supports (Hoogsteen & Woodgate, 2013a). Future research investigating why no difference was detected between families living in DP and LDP areas stress levels and QOL is warranted. There is a need to understand better the factors that mediate the stress levels and QOL for families with a child with ASD living in LDP areas.

Father's Education and Disruption to Family Routine

The finding that fathers of children with ASD living in more DP areas tended to have achieved more advanced education compared to those living in LDP areas mirrors the broader social trends in Australia (Australian Bureau of Statistics, 2008). Therefore, it is plausible to assume the difference in father's education levels between families living in DP and LDP is representative of the broader Australian population, as opposed to a unique characteristic of families with a child with ASD living in low-densely populated areas. Finally, our findings indicate that disruptions to family routines are not associated with the geographical location of families of a child with ASD.

Limitations

This study has several limitations. Firstly, an analysis of non-responders could not be conducted, which may cause possible sample bias as the survey was distributed widely through numerous networks. Additionally, a drop-out analysis could not be completed despite a dedicated drop-out section in the online

survey, as no responses were received. This prevented any comparison between parents who completed the survey and those who chose not to. Secondly, the study sample reflects the geographical distribution of the general population living in remote (5.4%) and very remote (1.4%) Western Australia (Australian Bureau of Statistics, 2008). To better understand the unique experience of parents of children with ASD living in remote and very remote locations, a disproportionate amount of participants from these areas would be needed to have been recruited into the study. While the researchers made targeted effort to recruit more participants from remote areas, the numbers were small. As a result, the study may not fully capture the experience of families living in remote and very remote regions of Western Australia. Finally, the heterogeneity of regional areas in Western Australia may not be adequately expressed in the study. While all effort was made to distribute the survey to all the regions of Western Australia, particular regions were over-represented. Therefore, care should be taken in generalising the findings to all regional and remote areas in Australia.

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Author Contributions

DP conceived of the study, participated in its design and coordination, performed the measurement, performed the statistical analysis, interpreted the data and drafted the manuscript; RC participated in the design and coordination, assisted with statistical analysis and interpretation of the data, and helped to draft the manuscript; HL participated in the design and coordination of the study, and interpretation of the data; TF conceived of the study and participated in its design and coordination, and SV conceived of the study, participated in its design and coordination, assisted with statistical analysis and interpretation of the data.

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Compliance with Ethical Standards

Conflict of Interest:

The authors declare that they have no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee (Curtin University Human Ethics Committee; Approval: HR123/2014) and 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 the study.

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Table 1

Characteristics of the families of children with ASD living in Densely Populated (DP) areas vs Low Densely Populated (LDP) areas

Characteristics	Total sample		Living in DP areas		Living in LDP areas	
	N	%	N	%	N	%
Total	278	100	230	82.1	48	17.1
Number of children with ASD						
1	238	85.9	200	87.3	38	79.2
More than 1	39	14.1	29	12.7	10	20.8
$X^2 = 2.20, df = 1, p = .139$						
Household comp						
Two parent	195	74.4	159	73.6	36	78.3
Single	48	18.3	40	18.5	8	17.4
Other	19	7.3	17	7.9	2	4.3
$X^2 = .785, df = 2, p = .675$						
Total number of children						
1	39	14.9	36	16.7	3	6.7
2 or more children	222	85.1	180	83.3	42	93.3
$X^2 = 2.93; df = 1, p = .087$						
Mother's education						
Up to diploma	159	60.9	131	60.6	28	62.2
Undergraduate Degree or higher	102	39.1	85	39.4	17	37.8
$X^2 = .039; df = 1, p = .844$						
Father's education						
Up to diploma	170	69.1	132	65.3	38	86.4
Undergraduate Degree or higher	76	30.9	70	34.7	6	13.6
$X^2 = 7.475; df = 1, p = .006^{**}$						
Employment status of household						
Employed	211	89	171	89.1	40	88.9
Unemployed	26	11	21	10.9	5	11.1
$X^2 = .001, df = 1, p = .973$						
Household Income¹						
Up to \$51,999	31	13.9	26	14.4	5	11.9
\$52,000 and over	192	86.1	155	85.6	37	88.1
$X^2 = 1.72, df = 1, p = .678$						

¹The cut-off point was set based on the median household income in Western Australia at the time of the study

*Significant result $p < .05$

**Significant results $p < .01$

Table 2

Characteristics of children with ASD living in Densely Populated (DP) areas vs. Low Densely Populated (LDP) areas

Characteristics	Total sample		Living in DP areas		Living in LDP areas	
	N=	%	N=	%	N=	%
Children's Age (month):						
Mean (standard deviation)	116.5 (54.9)		116.4 (54.0)		115.2 (58.9)	
	<i>t</i> = .184, <i>p</i> = .85					
Gender						
Boy	230	82.7	192	83.5	38	79.2
Girl	48	17.3	38	16.5	10	20.8
	$X^2 = .52, df = 1, p = .47$					
Age when first sign of 'something not right' noticed						
Less than 3 years old	225	80.9	187	81.3	38	79.2
3 years old and older	53	19.1	43	18.7	10	20.8
	$X^2 = .52, df = 1, p = .47$					
Age when formally diagnosed						
Less than 4 years old	119	62.2	99	43.2	20	42.6
Between 4 and 6 years old	70	19.4	58	25.3	12	25.5
Older than 6 years old	87	18.3	72	31.4	15	31.9
	$X^2 = .01, df = 2, p = 1.00$					
Age when therapy first accessed						
Less than 3 years old	82	29.6	71	30.9	11	23.4
Between 3-4 years old	72	26.0	52	22.6	20	42.6
Between 4-6 years old	71	25.6	63	27.4	8	17.0
Older than 6 years old	52	18.8	44	19.1	8	17.0
	$X^2 = 8.44, df = 3, p = .038^*$					

*Significant result $p < .05$

**Significant result $p < .01$

Table 3*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	.77	.78	.74	.75	.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 isn't 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

Note. Significant loadings are highlighted in bold.

Table 4*Variables associated with living in Low Densely Populated areas.*

Variables	B	SE	Wald	p	Exp (β)	95 % CI for Exp (β)	
						Upper	Lower
Constant	-5.07	1.45	12.20	< .001	< .01		
Number of Children with ASD	-1.02	.59	3.03	.082	.36	.12	1.14
Father's Highest Education Level	1.24	.51	5.69	.017*	3.44	1.24	9.48
Avoidance Coping	.13	.04	8.33	.004**	1.14	1.04	1.24
Acceptance Coping	.17	.01	3.18	.075	1.19	.98	1.43
Hours study weekend	-.68	.40	2.97	.085	.50	.23	1.10

*Significant result $p < .05$ **Significant result $p < .01$

Table 5*Comparison of total sample with general population*

	Total Sample (n = 278)	General Population¹	<i>t</i> -score	<i>p</i> -value	Cohen's <i>d</i>
WHOQOL-BREF Domains²					
Physical					
Mean	63.13	73.50	-8.61	< .001**	.59
SD	17.26	18.10			
Psychological					
Mean	52.62	70.60	-18.94	< .001**	1.30
SD	13.70	14.00			
Social					
Mean	51.10	81.50	-19.82	< .001**	1.46
SD	23.41	18.20			
Environmental					
Mean	61.56	75.10	-12.86	< .001**	.94
SD	15.93	13.00			
APSI Factors³					
Stress overall					
Mean	20.84	5.41	20.81	< .001**	-2.04
SD	9.96	5.18			
Core ASD behaviours					
Mean	10.06	1.32	26.58	< .001**	-2.62
SD	4.81	1.86			
Co-morbid behaviours					
Mean	6.16	2.42	12.59	< .001**	-1.24
SD	3.83	2.22			
Co-morbid physical issues					
Mean	5.22	1.67	12.70	< .001**	-1.25
SD	3.54	2.15			

¹General population sample sizes: WHOQOL-BREF (n = 866), APSI (n = 139)

² Higher scores indicate higher QOL

³ Lower scores indicate lower levels of stress

*Significant result $p < .05$

**Significant results $p < .01$