



# Predictors of Satisfaction with Life in Parents of Children with Autism Spectrum Disorder

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## Abstract

This study examined the relationships between autism spectrum disorder (ASD) symptoms, care-related activities, and satisfaction with life (SWL) in 184 parents caring for a child with ASD in New Zealand. The relationships between coping styles and SWL were also examined. The parents' SWL scores indicated they were slightly dissatisfied with their lives. A stepwise linear regression showed three predictors (care-related health problems, carer esteem and financial difficulties) explained 47% of the variance in SWL scores. Several coping styles were associated with lowered SWL, and only emotional support was related to increased SWL. The regression model provides a focus for monitoring parental wellbeing, and stresses the importance of recognition and support for the substantial responsibilities parents of children with ASD face.

**Keywords** Autism spectrum disorders · Parents · Caregiving · Satisfaction with life · Coping

## Introduction

Caring for children with autism spectrum disorder (ASD) is demanding and has broad impacts on family life. ASD is complex and includes an array of deficits, with much of the focus on communication and language difficulties, social impairment and repetitive behaviors (e.g., Strock 2007; Volkmar et al. 2005). However, children with ASD frequently show more than one of these core symptoms, along with a range of comorbidities including hyperactivity (Aman 2004), sleep difficulties (Couturier et al. 2005), sensory issues (Hazen et al. 2014; O'Neill and Jones 1997), and challenging behaviors including aggression and self-injury (Fenton et al. 2003; Simonoff et al. 2008).

The demands and impacts on parents are substantial and multifaceted, yet along with the effects on parental wellbeing they have not been studied extensively (Cappe et al. 2011). Parents of children with ASD typically report higher levels of stress and poorer wellbeing than parents of typically developing children (Bromley et al. 2004; Estes et al.

2009; Hamlyn-Wright et al. 2007). In addition to these health-related impacts, parents also frequently face financial consequences, both as a result of treatment expenses and employment changes (Kuhlthau et al. 2005; Saunders et al. 2015). Priorities may be reassessed to meet care demands (DeGrace 2004), and in the context of substantial intervention costs many parents reduce their working hours to care for their child (Buescher et al. 2014; Cidav et al. 2012). Further, challenging behaviors often require close monitoring and public understanding can be low (Gray and Holden 1992; Sanders and Morgan 1997), thus increasing stress. A response to this can be to reduce participation in social activities, which in turn can lead to a sense of social isolation (Schaaf et al. 2011).

The severity of ASD, ASD-related behaviors, behavior problems, the child's age and gender have all been suggested as factors affecting the wellbeing and coping of parents of children with ASD (e.g., Abbeduto et al. 2004; Gray 2006; Huang et al. 2014; Konstantareas and Papageorgiou 2006; Lecavalier et al. 2006; McStay et al. 2014; Smith et al. 2008). However, these results have been inconsistent. For example, some research has suggested a positive relationship between parenting stress and the severity of ASD-related behaviors (e.g., Konstantareas and Papageorgiou 2006; Mori et al. 2009; Wang et al. 2011); other research has suggested that parents with children showing less extreme ASD-like behaviors experienced more stress (e.g., Huang et al. 2014;

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Pearson et al. 2006); and still further research has suggested it could be behaviors perceived as controllable such as hyperactivity that are associated with most stress (e.g., McStay et al. 2014).

Folkman and Lazarus (1985) proposed that coping is a transactional process, in which strategies might vary across time and context such that the resources committed to dealing with stress appropriately counter the stress (Lazarus 1966). Like others, parents of children with ASD may use a range of coping strategies to assist them in managing the substantial challenges of raising a child with ASD (Lai and Oei 2014) and these may influence the level of parenting stress experienced, the level of parental resilience, and perhaps wellbeing more generally. Lai and Oei's review highlighted that while both adaptive and maladaptive coping strategies were used in response to stress, disengagement and avoidance strategies, which have been associated with greater stress (e.g., Benson 2010; Lai et al. 2015), tended to be used more often by parents of children with ASD than parents of typically developing children (Lai et al. 2015; Obeid and Daou 2015). However, they also noted an overall tendency towards more adaptive approaches which have been linked to positive mental health outcomes or less stress (e.g., Benson 2010).

Within the ASD literature, parental wellbeing has been conceptualised and measured in a variety of ways, most often in terms of an absence of negative outcomes, such as stress or mental health-related symptomology (see Tint and Weiss 2016 for a review). Early research, however, identified three components of subjective wellbeing: positive affect, negative affect, and life satisfaction (Andrews and Withey 1976; Diener 1984). With few exceptions (e.g., Faso et al. 2013; Lu et al. 2015) it is this third component, satisfaction with life (SWL; e.g., Diener et al. 1985), that has been overlooked in favour of more proximal, symptom-oriented components of wellbeing, and as noted earlier, the relationship between coping and parental symptoms and mental health outcomes may be mixed. At the least, global measures of wellbeing can be an important adjunct to specific scales that focus on psychopathology or emotional wellbeing, particularly because they can allow respondents to focus more holistically on positive aspects of their life based on their own particular standards and values (Pavot and Diener 1993).

Thus, the focus in this study was on parent's SWL rather than on their levels of stress or specific psychological outcomes as is more common in the literature. SWL was assessed using the SWL scale first reported by Diener et al., (1985) which allows respondents to weight the life domains in terms of their own values and arrive at a global assessment of life satisfaction (Diener et al. 1985; Pavot and Diener 1993). The SWL scale is a widely used reliable and valid measure (e.g., Diener et al. 2013; Emerson et al.

2017; Pavot and Diener 1993; Whisman and Judd 2016). It has been frequently used in the broader caregiving literature (e.g., Athay 2012; Ergh et al. 2003; Lin et al. 2010), but less commonly with specific reference to caregivers of children with ASD (e.g., Conti 2015; Griffith et al. 2010; Lu et al. 2015).

The relationships between ASD symptoms, care-related activities and overall SWL were examined. In addition, the relationships between coping strategies and SWL were also examined to ascertain whether particular approaches to coping were associated with increased or decreased SWL. It was hypothesised that parent-rated measures of ASD severity, caregiver burden, task stress, and both emotion-focused and maladaptive approaches to coping would be negatively associated with SWL. Whilst social support and problem-focused coping would be positively associated with SWL.

## Method

### Participants

The participants were 184 parents over 18 years of age who were caring for a child with ASD in New Zealand. Their demographic details are summarised in Table 1. The majority (162) of participants were female, 22 were male, and the average participant age was 45.27 years ( $SD = 9.30$ ) ranging from 24 to 62 years old. The sample was relatively well educated, with 81 (44.3%) having a university degree, 32 (17.5%) a qualification from a technical college, and 43 (23.5%) having finished secondary school. Participants reported that they had been caring for their child with ASD for an average of 11.83 years ( $SD = 8.68$ ). The mean age of the children in the present study was 13.30 years ( $SD = 10.96$ ; range 21 months–18 years), and the mean onset of their ASD (i.e., when parents became concerned) symptoms was at 25.8 months ( $SD = 24.58$ ). Ethical approval to conduct the study was obtained from the authors' institutional ethics committee prior to the commencement of the study.

### Materials

A secure online questionnaire probing demographic information, parents' access to support, their SWL, and perceived stress was made available to the participants through an email link. Additionally, the Autism Impact Measure (AIM) to estimate ASD traits of the child, and the Brief COPE to document coping strategies, were administered. The questionnaire took approximately 15–20 min to complete, and was only available in English.

**Table 1** Demographic characteristics of the sample ( $n = 184$ )

Category	$n^a$ (%)
Gender of individual with ASD	
Female	28 (15.30)
Male	155 (84.70)
Gender of caregiver	
Female	162 (88.04)
Male	22 (11.96)
Ethnicity of caregiver	
European	158 (86.30)
Maori	11 (6)
Pacific	4 (2.20)
Asian	7 (3.80)
Other	3 (1.60)
Educational level of caregiver	
Secondary School	43 (23.50)
Tertiary College	32 (17.50)
University Degrees	81 (44.30)
Other	27 (14.80)
Sole caregivers	
Yes	55 (30.10)
No	128 (69.90)
Caregiver relationship with individual with ASD	
Parent	159 (86.90)
Legal guardian	4 (2.20)
Sibling	3 (1.60)
Friend	1 (0.50)
Other	16 (8.70)
Living together	
Yes	156 (86.80)
No	13 (7.1)
Sometimes	11 (6.0)

<sup>a</sup>Totals may differ due to missing data

## The AIM

A parent-rated estimate of the severity of their child's ASD symptoms was obtained using the AIM, which was developed by Kanne et al. (2014) to measure ASD treatment outcome. A total of 25-parent-rated items assessing the impact of ASD symptoms have on the daily functioning of their children were presented using a 5-point Likert-scale ranging from 1 (Not at All) to 5 (Severely). Based on a two week recall period, the AIM inventory measures both the presence of maladaptive behaviors (e.g., “engaged in rituals or routines”) and the absence of skills (e.g., “used gestures”). The AIM scale consists of four subscales, being repetitive behaviors (eight items), odd/typical behaviors (five items), communication/language (five items) and social/emotional reciprocity (seven items). Kanne et al. confirmed the AIM to be a reliable and valid measure of the frequency and impact

of core ASD symptoms and this was also the case in the present data (see Table 2).

## Brief COPE

The Brief COPE consists of 28-items that are collapsed into 14 different coping styles, which themselves are further categorized (*re*: Table 3) into problem-focused (six items), emotion-focused (12 items), and maladaptive (ten items) coping (Carver 1997; Carver et al. 1989). Parents rated how frequently they deployed various coping strategies when faced with a stressful situation based on a 4 point Likert-scale ranging from 1 (I Haven't Been Doing This At All) to 4 (I've Been Doing This A Lot). Reliability analyses have provided evidence that the Brief COPE has good internal reliability, while an exploratory Principal Component Analysis (PCA) exposed a factor structure that is generally consistent with the original COPE inventory (Carver 1997 and Table 4).

## CRA

The CRA consists of 24 items measuring general aspects of a caregiving situation, in this context a parent's negative and positive reactions to caring for a child with ASD. The CRA items are categorised into five subscales, all which measure subjective burden relative to care-related activities (Brouwer et al. 2004): (1) self-esteem (seven items); (2) lack of family support (five items); (3) financial problems (three items); (4) disrupted schedule (five items), and (5) health problems (four items). Parents were required to rate the items using a 5 point Likert-scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). Total scores for each subscale are calculated, with an increase in these scores generally reflecting an increase in care-related burden. However, for the 'self-esteem' subscale, commonly used to measure the positive assessments of caregiving, an increase in total scores reflects an increase in the caregivers' care-related self-esteem (Kim et al. 2007). Studies have shown that the CRA has adequate internal consistency and construct validity (Aranda and Hayman-White 2001; Given et al. 1992).

## SWL

The SWL scale (Diener et al. 1985) is a five-item questionnaire and respondents self-report their level of agreement on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The SWL items are non-specific (e.g., “I am satisfied with my life”, “If I could live my life over, I would change almost nothing”) and allow respondents to weight the life domains in terms of their own values and arrive at a global assessment of life satisfaction (Diener et al. 1985; Pavot and Diener 1993). A total score is computed

**Table 2** Cronbach's alpha ( $\alpha_c$ ), Means ( $M$ ), standard deviations ( $SD$ ) for variables that significantly predict ( $r$ ) SWL

Predictors of SWL	Number of items	$\alpha_c$	$M$	$SD$	$r_{SWL}$
Task stress	13	0.902	40.61	19.74	-0.341**
AIM	8	0.817	23.77	6.82	-0.146*
Restricted/ritualised behavior					
AIM social-emotional reciprocity	7	0.759	18.93	5.99	-0.148*
AIM odd/atypical behavior	5	0.869	13.56	5.19	-0.130*
Caregiver's Reaction Assessment (CRA) carer esteem	7	0.799	26.66	4.67	0.361**
CRA disrupted schedule	5	0.765	18.85	3.90	-0.395**
CRA lack of family support	5	0.781	14.11	4.70	-0.392**
CRA financial problems	3	0.779	10.39	3.08	-0.317**
CRA health problems	4	0.778	11.93	3.36	-0.523**
Maladaptive coping	10	0.849	15.50	5.32	-0.386**
Support partner	1	-	4.24	2.70	0.190*
Support friends	1	-	2.36	2.07	0.273*
Support family	1	-	3.11	2.36	0.259*
Support medical professionals	1	-	2.77	2.05	0.194*

\* $p < .05$ \*\* $p < .001$ **Table 3** Regression statistics for a stepwise regression of predictors on SWL

Variable	$R^2$	$\Delta R^2$	$F$	$B$	SE	$\beta$	$t$
Model 1 (step 1)	0.365	0.365	69.58**				
Constant				34.05	2.02		16.86**
CRA health				-1.33	0.16	-0.60	-8.34**
Model 2 (step 2)	0.420	0.055	11.448**				
Constant				21.51	4.19		5.14**
CRA health				-1.16	0.16	-0.53	-7.24**
CRA esteem				0.39	0.11	0.25	3.38**
Model 3 (step 3)	0.471	0.051	5.724**				
Constant				21.27	4.01		5.30**
CRA health				-0.84	0.19	-0.37	-4.48**
CRA esteem				0.52	0.12	0.33	4.45**
CRA finance				-0.70	0.21	-0.27	-3.38**

\*\* $p < .001$ \* $p < .05$ 

in which lower scores indicate lower life satisfaction. Total scores range from 5 to 35, with particular scores indicating differing levels of SWL: 5–9 extremely dissatisfied, 10–14 dissatisfied, 15–19 slightly dissatisfied, 20 neutral, 21–25 slightly satisfied, 26–30 satisfied, and 31–35 extremely satisfied. The SWL scale has high reliability ( $\alpha > 0.8$ ; e.g., Diener et al. 1985; Eid and Diener 2004), whilst studies support convergent validity with other well-being measures (e.g., Pavot et al. 1991), and concurrent validity with health (e.g., Lyubomirsky et al. 2005). Detailed discussions of the reliability and validity of the SWL scale have been reported by Pavot and Diener (1993) and Diener et al. (2013). The SWL

scale for this study showed good internal consistency, with a Cronbach's alpha of 0.909.

### Support Network

The availability of support to parents was measured using a 7 point Likert-scale ranging from 1 (*Not Supported*) to 7 (*Very Supported*). Participants were required to rate how much support they felt they received from their partner, family, friends and medical professionals. A "not applicable" option was also available for non-relevant sources of support.

**Table 4** Partial correlation coefficients between SWL and the 14 coping subscales

Coping strategy	$\alpha_c$	<i>M</i>	<i>SD</i>	$r_{SWL}$
Problem-focused coping	0.835	17.29	4.34	-0.125
Active coping		5.86	1.72	-0.132
Instrumental support		4.97	1.91	0.020
Planning		6.38	1.73	-0.171*
Emotion-focused coping	0.727	29.59	6.41	-0.097
Acceptance		6.54	1.62	-0.033
Emotional support		4.41	1.83	0.147*
Humour		4.32	2.15	-0.003
Positive reframing		5.95	1.84	-0.052
Religion		6.47	1.82	-0.198*
Self-distraction		4.66	1.95	-0.243*
Maladaptive coping	0.849	15.67	5.68	-0.389**
Behavioral disengagement		2.73	1.39	-0.404**
Denial		2.37	1.10	-0.233*
Self-blame		3.96	1.92	-0.350**
Substance abuse		2.72	1.47	-0.135*
Venting		3.67	1.63	-0.264**

\*  $p < .05$ \*\*  $p < .001$ 

### Task-Related Stress

A second measure of parental stress relating directly to tasks typically undertaken when caring for a child with ASD was also administered. Stressfulness of care-related tasks was measured using a checklist developed by Plant and Sanders (2007). The original checklist contained 22 different tasks, but was condensed to include only the top ten most stressful tasks reported by both males and females. This resulted in a scale of 13 items (Shepherd et al. 2017) as only seven items overlapped across the genders. Participants were required to rate their stress levels when conducting those tasks using a 7 point Likert-scale ranging from 1 (*Not at all Stressful*) to 7 (*Very Stressful*). A “not applicable” option was also available for tasks that were not performed by the caregiver. Scores for each care-giving task were then summed to provide a total score with a higher score indicating more stress. Plant and Sanders’ original checklist was carefully developed from observing and identifying the common caregiving tasks that parents conduct on a typical day. Once a preliminary list was formed, it was reviewed by a board of clinicians and parents. Therefore, this checklist is considered a highly valid index relating to caregivers’ caregiving tasks (Plant and Sanders 2007).

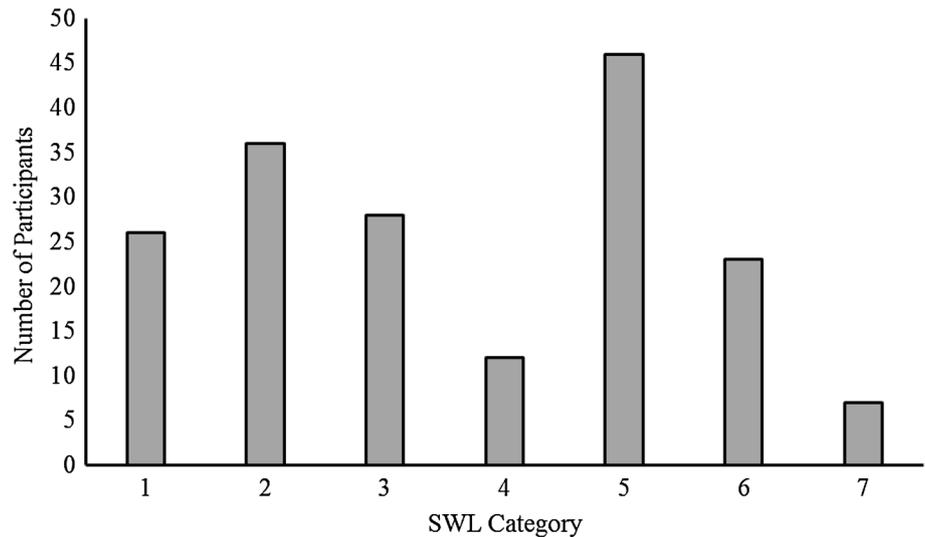
### Procedure

Email invitations to participate in the study were sent to parents of an ASD child via the 16 branches of Autism New Zealand, New Zealand’s largest national autism association. These organisations and their networks provide support, training, advocacy, resources and information on ASD throughout New Zealand. The invitations provided the parents with an URL link to enable them to access and complete the questionnaire online. A Participant Information Sheet was provided as a downloadable attachment. The data collection period was 50 days. Ethical approval required that the investigators were blinded to the dispatching of email invitations, thus it is not possible to calculate an accurate response rate.

### Analysis

All data analyses were undertaken using the Statistical Package for the Social Sciences (SPSS v.23). Missing data, which ranged from 2.17 to 4.35% across the composite scales, was handled using SPSS’s in-built ‘Pairwise deletion’ function. Prior to analysis reverse coding of selective items was undertaken, and then where appropriate the calculation of total scores. Scale consistency was gauged using Cronbach’s alpha ( $\alpha_c$ ) coefficients. Initial correlation analysis (Pearson correlation coefficients) determined which variables significantly co-varied with SWL, and these were subsequently entered into a stepwise regression analysis. The stepwise regression acted to produce a reduced model with fewer predictors of SWL. The data were first scrutinised to ensure that they adhered to the assumptions of regression analyses, including the independence of errors, no heteroscedasticity, and the absence of co-linearity. The stepping-method criterion for entering a variable into the model was set at  $F = 0.05$ , with a removal probability of  $F = 0.1$ . Further analyses were undertaken to examine the relationship between coping strategy and SWL. To this end an exploratory PCA (varimax rotation) was undertaken with the Brief Cope data yielding a clean three factor solution (Carver, 1997, Carver et al. 1989) representing 14 core coping strategies (see Table 4). Partial correlation coefficients, controlling for parent age, education, and age of child, were then calculated between each of the 14 coping subscales and SWL.

**Fig. 1** Percentage of the sample falling into each SWL category: 1 = extremely dissatisfied; 2 = dissatisfied; 3 = slightly dissatisfied; 4 = neutral; 5 = slightly satisfied, 6 = satisfied, and; 7 = extremely satisfied



## Results

The mean SWL total score was 18.42 ( $SD = 7.92$ ), indicating that on average, participants were in the slightly dissatisfied category. Figure 1 shows the distributions of participants across the seven SWL categories.

Table 2 presents those outcome variables that were found to correlate significantly ( $p < .05$ ) with the SWL total scores. Where applicable, Cronbach's alphas are all over 0.7, the cut-off generally considered to represent sufficient scale consistency. The Pearson Product-Moment Correlation coefficients ( $r$ ) presented in the final column indicate that, for positive values, an increase in the predictor variable coincides with an increase in SWL score, while a negative value of  $r$  indicates that as a predictor variable increases, the SWL value decreases. Inspection of Table 2 indicates that the effect of the predictors ranges from small to large. The strongest negative relationship is between perceived care-related health problems and SWL, while the strongest positive relationship is between care-related esteem and SWL.

A stepwise regression with SWL as the dependent variable and those variables listed in Table 2 as the independent variables was performed in order to identify which variables explained the most variability in SWL scores. As per Table 3, the final step of the regression analyses retained three of the fourteen predictor variables: the care-related health problems, carer esteem, and financial difficulties subscales from the CRA. Taken together, these variables explained approximately 50% of the variability in SWL scores, with the weighting for each of three being approximately equal.

To explore the relationship between SWL and coping strategy, partial correlation coefficients were computed using the 14 subscales intrinsic to the Brief-COPE. Table 4 displays the mean and standard deviations for each of the

subscales, and the relationship to SWL after parent age and level of education, and age of their child with ASD, had been controlled for. A positive correlation indicates that greater use of that coping strategy is associated with a higher SWL score, while a negative correlation indicates that greater use of that strategy is associated with a lower SWL score. As reported in Table 4, only one-of-nine statistically significant coefficients was positive (emotional support). Of the significant negative associations, none were associated with large effect sizes, and only two had moderate effect sizes: self-blame and behavioral disengagement (Cohen 1988).

## Discussion

The present study shows parents of children with ASD in general reporting SWL scale scores consistent with being slightly dissatisfied with their lives (Pavot and Diener 1993), although there was substantial variation in SWL scores (see Fig. 1). As hypothesised parent-rated measures of ASD severity, caregiver burden, task stress, and both emotion-focused and maladaptive approaches to coping were negatively associated with SWL. Social support was positively associated with SWL, whilst contrary to hypotheses problem focused coping was negatively associated with SWL. SWL is a particularly useful concept in the context of ASD as it allows the respondents themselves to assign weightings to relevant domains of their lives, and thus may provide additional insight as to the effects of caring for a child with ASD. The SWL scores reported in this study are consistent with those reported in two smaller studies of mothers of children with ASD (Conti 2015; Griffiths et al. 2010).

Many aspects of the caring experience were related to the levels of dissatisfaction reported (Table 2). Our findings support the notion that as task stress increases, evaluation

of one's personal circumstances decreases. This is not surprising given that the impacts of ASD on parents are broad, ranging from limiting career and social opportunities, to higher levels of fatigue and illness (Mugno et al. 2007; Smith and Elder 2010). In relation to quality of life (QoL), a construct generally considered equivalent SWL (Camfield and Skevington 2008), research has reported that families which included a child with ASD had lower QoL than families containing neurotypical children (Khanna et al. 2011). It is also evident that it was general care-related burden items from the CRA that were most strongly related to SWL. The stepwise regression with SWL as the dependent variable showed that three predictor variables: Impact on Health, Impact on Finances, Caregiver's Esteem, accounted for an impressive 47% of the variance in SWL scores. The 'Impact on Finances' and 'Impact on Health' scales were strongly related to reduced SWL, while the 'Caregiver Esteem' scale was strongly related to improved SWL. Further, the results indicated that external support was related to increased SWL although it did not feature in the model.

The fact that the three predictor variables were all from the CRA scale, and that social support was found to be related to increased SWL, highlight the importance of caregiver responsibilities and their effects on the parents' lives. The model provides both a parsimonious approach to monitoring wellbeing in parents of children with ASD, but also indicates key areas: health, finances, and Caregiver Esteem that support services and funders should develop and invest in to provide immediate benefits, or respite for families.

The impacts on the health of parents caring for children with ASD is an area sometimes overlooked given the appropriate focus of parents on supporting the child (Fairthorne et al. 2015). However, there is a range of evidence that demonstrates poorer physical health among parent carers of children with ASD. The evidence ranges from mortality rates (Fairthorne et al. 2014) through poorer antibody responses (Gallagher et al. 2009) to reduced self-rated health (Cantwell et al. 2015), cardiovascular disease (Seltzer et al. 2011) asthma, back problems and migraines (Lach et al. 2009) Yet in spite of these findings, a recent study of 304 general practitioners in the UK, found that less than half had any formal training around ASD, and that they reported a range of problems and barriers in providing appropriate healthcare for affected families (Unigwe et al. 2017). This research along with the findings of the present study suggests that improving levels of support for parents may be significant in terms of reducing health-related costs and burden, and improving parent SWL.

The financial and employment impacts of caring for a child with ASD have been reported extensively (e.g., Buescher et al. 2014; Cidav et al. 2012; Kuhlthau et al. 2005; Saunders et al. 2015) and to some degree are unavoidable if appropriate support and interventions are to be accessed.

Research suggests that early and very intensive intervention constitutes the best demonstrated approach to ameliorating longer-term impacts (e.g., Lovaas 1987), but that necessarily involves a substantial financial commitment and from an early stage. However, it is imperative that interventions are better tailored to support families (e.g., Saunders et al. 2015; Searing et al. 2015). This would naturally be linked with the healthcare interventions noted above, along with therapeutic efforts, and developing strategies to enhance social support. Balancing the individualistic nature of tailored interventions with the financial and resource constraints of many families and their cultural needs is a substantial challenge (Searing et al. 2015).

Carer Esteem, which measures the extent to which the caregiving situation imparts self-esteem, was most strongly associated with higher SWL. The roles and responsibilities of parents of children with ASD are demanding and time-consuming beyond those of parenting a neurotypical child. Items in the carer esteem subscale assess whether the parent finds the caregiver role enjoyable and rewarding, or whether it causes resentment. Intuitively it seems clear that if a major role in one's life confers enjoyment and reward, then a positive link to SWL is unsurprising. Stigma and self-esteem are key issues impacting parents caring for children with ASD and researchers have highlighted the need for targeted interventions to enhance social support and self-esteem (Cantwell et al. 2015; Gray 1993, 2002; Kinnear et al. 2016; Werner and Shulman 2015). The present results suggest that explicit societal, community, and familial recognition of both the importance and the additional responsibilities of caregiving of children with ASD, beyond typical parenting, would likely be beneficial in enhancing carer esteem in parents caring for children with ASD. It is clear that finding the role enjoyable and/or rewarding is a key predictor of more positive outcomes. However, acknowledging the additional aspects of this role beyond those of parenting, provides ongoing challenges and complexities that remain to be clearly documented and understood.

Previous research has shown high levels of maladaptive and emotion-focused coping in parents of children with ASD (e.g., Lai et al. 2015; Piazza et al. 2014; Wang et al. 2011). The present research again demonstrates an association between maladaptive coping and poorer SWL. With respect to specific coping styles, all five maladaptive coping styles (behavioral disengagement, denial, self-blame, substance use and venting) were associated with poorer SWL, with behavioral disengagement, self-blame and venting most strongly linked. Somewhat surprisingly, neither problem nor emotion-focused coping were associated with improved SWL.

Yet while problem and emotion focused coping strategies overall were unrelated to SWL, specific subscales were. However, these associations tended to be negative—among

the problem-focused approaches, planning was associated with poorer SWL. This is of interest as planning is often considered a useful and adaptive approach to coping in a variety of situations. Whether it is a result of the relatively unpredictable nature of ASD, or perhaps reflects very engaged parents who become exhausted or burnt out is not clear. Given the sample was recruited from parents engaged with support agencies, the latter is worthy of further investigation.

Indeed, an interesting finding was that just a single coping strategy, emotional support, was associated with higher SWL in this sample. This, along with the apparent ineffectiveness of planning and other problem focused approaches resonates with Lazarus' (1966) original conceptualisation of coping styles, and matching them to the issue at hand. The very nature of ASD and its unpredictability likely renders planning ineffective to some degree. Thus, in a largely uncontrollable situation, acknowledging and accessing support for one's emotional responses may be useful in ameliorating some impacts.

The present findings should be considered in the context of some limitations. The study is cross-sectional, and it has been noted elsewhere that ASD symptoms, coping strategies and the caring environment are all subject to change across time (Benson 2010). Moreover, it is important to note that the ASD symptoms reported here were determined by parents and not clinicians and ASD diagnoses were not independently verified. However, as noted, the AIM scale is a reliable and valid measure of the frequency and impact of core ASD symptoms (Kanne et al. 2014). Further, the current sample size might have been too small to enable detection of small effects ( $r < .03$ ) thus potentially raising the risk of a Type II error. Finally, the present participants were recruited through ASD-related support organisations in New Zealand and their websites and newsletters. Families not connected to these national organisations were unlikely to be aware of the study, and thus not unlikely to have participated. Whether the results are generalizable to a broader range of parents of children with ASD is not clear. A nationally conducted longitudinal study of parents of children with ASD could address many of these issues (Benson and Karlof 2009; Lai et al. 2015).

In conclusion, the present results show SWL scores in parents caring for children with ASD indicating a degree of dissatisfaction with their lives consistent with recent research (Conti 2015; Griffith et al. 2010; Lu et al. 2015). A parsimonious three factor model accounts for a substantial proportion of the variance in SWL scores, and provides clear direction in terms of investment socially and clinically to better support families with children with an ASD. Explicitly recognising and valuing the importance of caregiving beyond parenting is perhaps a useful first step. Interventions designed with the broader impacts on health and finances

of families as a focus are important. Careful consideration of the variable and unpredictable nature of ASD and its impacts, and tailoring interventions to individual families, are key in providing appropriate support (e.g., Saunders et al. 2015; Searing et al. 2015).

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**Author Contributions** All authors conceptualized the study. JL drafted the manuscript and DS carried out the analyses. All authors reviewed the manuscript critically, and approved the final version.

## Compliance with Ethical Standards

**Conflict of interest** The author declares 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 and/or national research committee 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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