



# The quality of life of parents of children with autism spectrum disorder: A systematic review<sup>☆</sup>



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## ABSTRACT

**Background:** Previous research has raised concerns about the quality of life (QoL) of parents of children with autism spectrum disorder (ASD). A better understanding of parental QoL can inform clinicians and policymakers and lead to improved outcomes for both parents and children.

**Aims:** This review aimed to systematically examine studies measuring the QoL among parents of children with ASD (<18 years) and to investigate its parental, child-related and contextual associated factors.

**Methodology:** An electronic database search was conducted using Medline, Psycinfo, Embase, CINAHL, Biosis, ASSIA, Social Services Abstracts, Sociological Abstracts and Open grey.

**Results:** This review indicated poorer QoL among parents of children with ASD compared to parents of typically developing children or to population norms. Variables associated with lower parental QoL within this group included child behavioural difficulties, unemployment, being a mother and lack of social support.

**Conclusion:** This review verified previous reports on lower QoL among parents of children with ASD and highlighted potential areas of support. Implications for future research, policy and practice are discussed.

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## Contents

1. Introduction	37
2. Methodology	38
2.1. Inclusion and exclusion criteria	38
2.2. Search procedures	38
2.3. Data extraction and appraisal of study quality	38
2.3.1. Data extraction	38
2.3.2. Quality appraisal	38
3. Results	39
3.1. Database search	39

**Abbreviations:** ASD, autism spectrum disorder; QoL, quality of life.

<sup>☆</sup> **Note:** While preparing this manuscript for publication, this study was published: Dardas and Ahmad (2014). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? *Research in Developmental Disabilities*, 36, 620–629.

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3.2.	Participants and settings	39
3.3.	Quality of life definition and measurement	40
3.4.	Study quality	41
3.5.	Findings	42
3.5.1.	Data synthesis	42
3.5.2.	Questions 1 and 2: results from the comparative studies	42
3.5.3.	Question 3: correlation between QoL and other factors	42
4.	Discussion	43
4.1.	Question 1: how does the QoL of parents of children with ASD compare to the QoL of parents of typically developing children or to population norms?	44
4.2.	Question 2: which QoL dimensions were mostly affected?	44
4.3.	Question 3: which factors are associated with QoL?	44
4.3.1.	Parental factors	44
4.3.2.	Child related factors	45
4.3.3.	Contextual factors	45
4.4.	Limitations and recommendations for future research, policy and practice	46
5.	Conclusion	46
	Conflict of interest	47
	Funding	47
	Acknowledgement	47
	References	47

## 1. Introduction

Autism spectrum disorders (ASD) are a group of life-long neurodevelopmental conditions characterised by significant deficits in the social and communication domains and by restrictive, repetitive and ritualistic patterns of behaviour, interests or activities (American Psychiatric Association (APA), 2013). In recent years, there has been a marked increase in ASD prevalence with UK and US population estimates reaching 1.7% and 2.0%, respectively (Blumberg et al., 2013; Russell, Rodgers, Ukoumunne, & Ford, 2014). The increasing levels of ASD stress the need for early identification of the disorder and for targeted interventions in order to improve children's prognosis.

Treatment for ASD typically involves interventions aimed at improving children's adaptive skills and at symptom reduction. In these areas, parent mediated interventions as well as parent training have been receiving increasing support (Diggle & McConachie, 2013; McConachie, Randle, Hammal, & Le Couteur, 2005; Sofronoff, Leslie, & Brown, 2004). Previous studies have demonstrated the effectiveness of parental interventions in improving children's responsiveness, expressive language and functional play as well as in significantly reducing children's behavioural difficulties and sleep problems (Anan, Warner, McGillivray, Chong, & Hines, 2008; Elder, Valcante, Yarandi, White, & Elder, 2005; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Siller, Hutman, & Sigman, 2013; Weiskop, Richdale, & Matthews, 2005). Moreover, parental involvement in the treatment of anxiety in children with ASD has also been found effective and is considered a core modification when adapting CBT for children on the spectrum (Moree & Davis, 2010; Sofronoff, Attwood, & Hinton, 2005). Further advantages of parental involvement include increased generalisation and long-term maintenance of treatment gains, as well as cost effectiveness and better allocation of resources (Matson, Mahan, & Matson, 2009; Solomon, Necheles, Ferch, & Bruckman, 2007). Taken together these results suggest that parent mediated interventions could be an efficacious alternative to one-to-one clinician support.

However, the literature suggests that parental capacity to promote the health and overall adjustment of their children may be affected by their own emotional state and wellbeing. For example, parental stress can compromise both parents' and children's coping resources and affect their ability to problem-solve (Friedman & Chase-Lansdale, 2002). Research on the challenges entailed in raising a child with ASD has raised concerns regarding parental wellbeing. Several common factors have been identified in this population including impaired mental and physical health, social isolation and lack of family coherence (Giallo, Wood, Jellott, & Porter, 2013; Silva & Schalock, 2012; Singer & Floyd, 2006; Tsuno, Besset, & Ritchie, 2005).

While previous research in this field has exclusively focused on the negative aspects of caregiving such as stress and caregiving demands (Hastings & Taunt, 2002), a number of recent studies have examined parental QoL in an attempt to provide a more comprehensive assessment of parental adaptation. Quality of life (QoL) is a complex and multidimensional concept that allows for a detailed evaluation of adaptation, both positive and negative, across several domains of functioning. QoL refers to an "individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (WHOQOL Group, 1998, p. 11). QoL measurement has played a paramount role in evaluating the quality and outcome of health care and in influencing the allocation of resources by policymakers (Moons, Budts, & DeGeest, 2006).

Studies examining the QoL of parents of children with ASD have revealed a predominately negative picture. A number of studies have shown the QoL of parents of children with ASD to be lower compared to that of parents of typically developing children. However, the literature lacks a systematic understanding of parental QoL and its associated factors.

Such an understanding is paramount in order to identify parents at risk, clarify areas in need of support and inform the allocation of appropriate services for this population. Steps towards improving parental QoL could also enhance their capacity to provide adequate care for their children and might lead to better outcomes for the whole family.

This review aimed to systematically examine and analyse studies measuring parental QoL and to highlight parental, child and contextual QoL associated factors. Three key questions provide a focus for this review: (a) How does QoL in parents of children with ASD compare to QoL in parents of typically developing children or in general population norms? (b) Which dimensions of QoL are affected most? (c) What parental, child, and contextual factors influence parental QoL?

## 2. Methodology

### 2.1. Inclusion and exclusion criteria

The present review included quantitative studies based on the following inclusion and exclusion criteria: First, studies had to include parents of children with ASD. This included parents of children with a diagnosis of Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder–Not otherwise specified. Second, the age of the child had to be below 18 years. While parents of children and parents of adults with ASD have often been treated together in the literature, research suggests that parental adaptation might vary across different age groups (Duarte, Bordin, Yazigi, & Mooney, 2005; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). Thirdly, studies had to use distinct QoL questionnaires to (a) compare the QoL of parents of children with ASD to a control group or to population norms or to (b) examine the interaction of parental QoL with child-related, parent or contextual factors. In an attempt to avoid propagation of studies with ethical insufficiencies, only studies which mentioned having obtained ethical approval were included in the review.

Studies that assessed parents of children with conditions such as comorbid learning disability, Fragile X, Down syndrome or cerebral palsy were excluded from the review. Such comorbidities were excluded due to additional difficulties, specific to the aforementioned conditions that might influence the overall assessment of parental QoL (Abbeduto et al., 2004). Studies that addressed the impact of interventions on parental QoL were also excluded. Finally, the search was limited to studies published in English after the 1st of January 2000.

### 2.2. Search procedures

An initial search of the Cochrane Database of Systematic Reviews (CDSR) and the Database of Abstracts of Reviews of Effects (DARE) was performed to ensure the absence of similar reviews. Following this, a systematic database search was conducted to identify relevant studies. The search included studies published after January 1st 2000 and was run on three separate occasions: June 1st 2014, July 1st 2014 and July 31st 2014. The dates the search was run defined the end points of each search. In order to avoid publication bias, databases containing unpublished material were included. The search included the following databases: Medline, Psycinfo, Embase, CINAHL, Biosis, ASSIA, Social Services Abstracts, Sociological Abstracts and Open grey.

A combination of different keyword searches was conducted in each database. The keywords referring to ASD were "ASD", "Autism", "Autism Spectrum Disorders", "Asperger's" and "Pervasive Developmental Disorder". The key words "Quality of life" and "QoL" were used for the quality of life. These were combined with the keywords "parent"; "mother"; "father" and "caregiver". A combination of index and mesh terms were used according to the requirements of each database.

### 2.3. Data extraction and appraisal of study quality

#### 2.3.1. Data extraction

Details from eligible studies were extracted by the first author using a pre-designed data extraction form which is available upon request. The following data were extracted: (a) participant demographics, such as age, gender, employment status, ASD diagnosis and comorbidity; (b) participant inclusion and exclusion criteria; (c) the total number of participants in each study group; (d) information on the measures used; (e) data collection and data analysis procedures; (f) main results and (g) conflict of interest/source of funding. A second reviewer independently checked the data extraction forms for accuracy.

#### 2.3.2. Quality appraisal

A number of quality criteria were defined to evaluate each study in a systematic and unbiased manner. These criteria were created based on the 'STROBE Statement: Checklist of items that should be included in reports of cross-sectional studies' (Strobe Initiative, 2008), in addition to elements from other existing tools (McLean, Maxwell, Platt, Harris, & Jepson, 2008; Scottish Intercollegiate Guidelines Network, 2012). Recommendations on how to critically appraise observational studies for systematic reviews were also taken into consideration (Abalos, Carroli, Mackey, & Bergel, 2001; Carlson & Morrison, 2009). The criteria addressed a number of quality factors including background information, participant selection, assessment and measures, confounding variables, statistical analysis and generalisability of findings. All studies were rated independently by

two reviewers. Initial review found exact agreement on 99.1% of quality ratings. Cohen's Kappa coefficient was calculated, producing an inter-rater reliability of  $\kappa = 0.97$ . Deviating evaluations were discussed in order to reach a consensus rating.

### 3. Results

#### 3.1. Database search

Database search elicited 449 records, of which 321 remained after the removal of duplicates. After screening of title and abstract, 88 studies were identified as possible relevant studies. From those remaining studies twelve were excluded because full-text articles were not available at our institutes and could not be obtained within the time frame of this study, despite contacting the authors where possible. As a result, 76 studies were examined for eligibility. Of those, 12 studies fulfilled the inclusion criteria and were included in the review. At this stage the reference lists of identified papers were searched manually to identify possible omitted studies. However, no studies that met the inclusion criteria were identified.

As a result, 12 studies were selected for the review. All studies were cross-sectional studies published in English. Two publications described the same sample (Dardas & Ahmad, 2014a, 2014b) and therefore metadata for these studies, for example when presenting the combined number of individuals involved in all studies, were only calculated once. The literature search is outlined in more detail in Fig. 1.

#### 3.2. Participants and settings

The reviewed studies collectively involved 1529 parents of children with ASD. The majority of the participants were mothers ( $n = 1031$ ; 67.4%), whereas fathers constituted a smaller percentage of the sample size ( $n = 315$ ; 20.6%). Two studies (Kuhlthau et al., 2014; Tung, Huang, Tseng, Yen & Tsai, 2014) did not report the gender of the participants ( $n = 183$ ; 12%). The parent's age at the time of the study ranged from 18 to 69 years. Six studies stated the participants employment status, with 54.2% of the participants being on paid employment ( $n = 608$ ). Children in the reviewed studies had a range of ASD diagnoses, including Autism or Autistic Disorder, Asperger's Syndrome (AS) and PDD-NOS. Four studies included children with the broader diagnosis of ASD. The age of children with ASD ranged from 0 to 18 years. The participants' demographic characteristics are presented in Table 1.

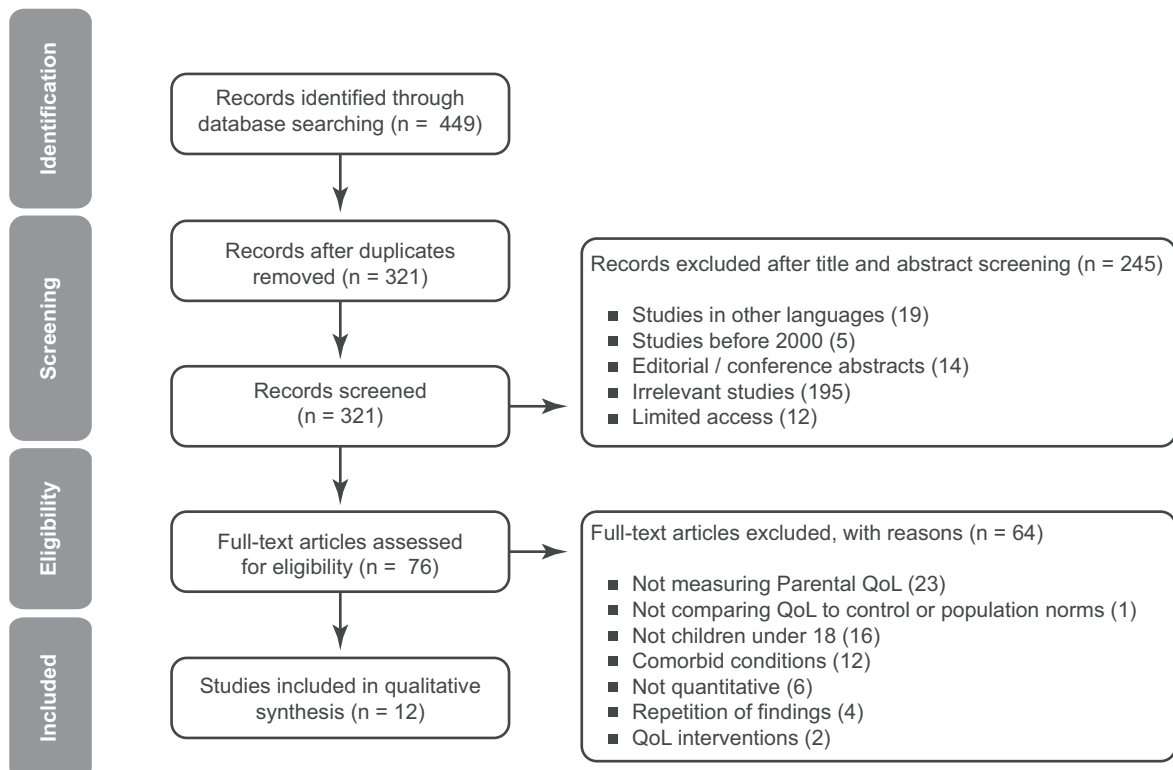


Fig. 1. QUOROM flow chart for literature search (Moher, Liberati, Tetzlaff, & Altman, 2009).

**Table 1**

Study and participant characteristics.

Studies marked with ✓ identified support from services and/or comorbidities as confounding variables and adjusted statistically for their impact. M: mothers; F: fathers; ND: Not Determined. MOS SF-36 (V.1): The MOS 36-Item Short-Form Health Survey (SF-36), Volume 1. SF-36v2: Short Form 36 Health Survey Version 2. SF-12: 12 Item Short-Form Health Survey. SF-12v2: Medical Outcomes Study Short-Form Health Survey version 2. SF-8: SF-8 Health Survey. SF-6D Six Dimension Short-Form Health Survey. WHOQOL-BREF: The World Health Organization Quality of Life Assessment-BREF self-administered instrument. FQoL: Family Quality of Life Survey. EQ-5D: Five Dimension EuroQoL. AD: Autistic Disorder. AS: Asperger's Disorder. ASD: Autism Spectrum Disorder. HFA: High Functioning Autism. PDD-NOS Pervasive Developmental Disorder—not otherwise specified.

Study	Design	n (cases/ control)	Mothers/ fathers	Full or part- time employment	Type of ASD	Age (yrs)	Age of child with ASD (yrs)	QoL measure	ASD diagnosis	Support from services	Comorbidities
Allik, Larsson, and Smedje (2006) Sweden	Cross-sectional control group	120 (61/59)	ASD: 31/30. Control: 30/29	M: 74.1%. F: 93.3%	AS, HFA	M: 28–54. F: 35–64	8.5–12.8	SF-12	By a professional	ND	✓
Bourke-Taylor, Pallant, Law and Howie (2012) Australia	Cross-sectional	94 (94/0)	94/0	ND	Autism, AS	41.7 ± 5.4	5–18	SF-36	Self-reported	✓	✓
Dardas & Ahmad (2014a, 2014b) Jordan	Cross-sectional	184 (184/0)	114/70	54%	AD	21–69. 37 ± 7.6	2–12. 6.3 ± 3	WHOQOL-BREF	By a professional	ND	ND
Hu (2008) Taiwan	Cross-sectional	280 (280/0)	233/47	35.80%	ASD	28–57	6–14. 9.8 ± 2.1	WHOQOL-BREF	By a professional	✓	ND
Khanna et al. (2011) USA	Cross-sectional	304 (304/0)	283/21	49.70%	AD, AS, PDD-NOS	38.9 ± 8.0	0–18	SF-12v2	By a professional	✓	ND
Kheir et al. (2012) State of Qatar	Cross-sectional control group	98 (56/42)	ASD: 33/23. Control: 38/4	71.40%	ASD	ND	3–17	SF-36v2	ND	ND	✓
Kuhlthau et al. (2014) USA	Cross-sectional	101 (101/0)	ND	ND	ASD	39.4	4–17	SF-6D. EQ-5D	By a professional	✓	ND
Lee et al. (2009) USA	Cross-sectional control group	135 (89/46)	ASD: 63/26. Control: 32/14	ND	HFA	42.2 (median)	7–13	MOS SF-36 (V.1)	By a professional	✓	ND
McStay, Trembath, and											

Dissanayake (2014) Australia Cross-sectional 196 (196/0)(98/98) M: 91.8%. F: 96.8 AD, AS, ASD, PDD-NOS M: 41.8 ± 6.0 F: 44.2 ± 6.23–16 FQoL By a professional ✓ ✓ ✓  
 Totsika, Hastings, Emerson, Berridge, and Lancaster (2011) UK Cohort design control group 14,526 (82/14,444) ASD: 82/0. Control: 14,444/ONDAD, AS34. 18–585 ± 0 SF-8 Self-reported ND ✓  
 Tung et al. (2014) Taiwan Cross-sectional 82 (82/0) ND ND AD 38.7 ± 4.63–12 WHOQOL-BREF By a professional ND ✓

### 3.3. Quality of life definition and measurement

The reviewed studies included similar definitions of QoL, all of which reflected the multi-dimensional character of the QoL construct. Although the measured dimensions varied between studies, all included a range of domains such as physical health, mental health and social functioning.

Standardised measures were used to gather quantitative data on QoL in all studies. With regards to the questionnaires used, seven of the studies used different versions of the Short Form Health Survey (SF) for the quality of life measurement. This measurement assessed different QoL dimensions including, general health, physical functioning, mental health and social functioning. These were synthesised in two components: Mental Component Summary and Physical Component Summary

Six studies measured all subscales of the SF survey and reported them in their analysis. Bourke-Taylor et al. (2012) only reported the Mental Health Component. Four studies used the WHOQoL instrument (Taiwanese and Arabic versions). This instrument has a broader focus than the SF, as it also examines environmental QoL. Finally, two studies used different measures to examine parental QoL: the Family quality of life Survey (Hoffman, Marquis, Poston, Summer, & Turnbull, 2006) and the EQ-5D (EuroQoL Group, 1990) (See Table 1).

### 3.4. Study quality

Two of the reviewed studies met the majority of the aforementioned quality criteria for cross-sectional studies (~90%) and were rated 'High Quality' (Kuhlthau et al., 2014; Totsika et al., 2011). The remaining studies were rated "Good quality", meeting more than 70% of the included criteria. All reviewed studies were characterised by a well-defined research question, objectives and rationale. Control groups were clearly defined and adequately matched to the ASD groups. All correlational studies provided multiple regression or multivariate analyses to examine which variables were related to parental QoL and to examine relationships among variables. Moreover, all studies used measures with good psychometric properties.

The main area of weakness was found in the external validity of the reviewed studies. With regards to the sampling process, all studies, with the exception of Totsika et al. (2011) used convenience clinical or self-referred samples and only two studies provided power calculations on how the sample size was reached. In addition, few studies failed to obtain an adequate response rate (>50%) which could further limit the generalisability of the findings. Lack of verification of the ASD diagnosis by a professional as well as unreported confounding variables, such as comorbidity and service support, were additional methodological quality considerations. Finally, with regards to the statistical analysis, the majority of studies did not explain how missing data were handled (See Table 1).

**Table 2**

Results from comparative studies.

Black areas indicate significantly lower QoL scores; grey areas indicate no significant differences between parents of children with ASD and the comparison group. White areas were not tested. Statistical significance is indicated by asterisks when available (\* for  $p < 0.05$ , \*\* for  $p < 0.01$  and \*\*\* for  $p < 0.001$ ). MOS SF-36 (V.1): The MOS 36-Item Short-Form Health Survey (SF-36), Volume 1. SF-36v2: Short Form 36 Health Survey Version 2. SF-12: 12 Item Short-Form Health Survey. SF-12v2: Medical Outcomes Study Short-Form Health Survey version 2. SF-8: SF-8 Health Survey. SF-6D Six Dimension Short-Form Health Survey. EQ-5D: Five Dimension EuroQoL. WHOQOL-BREF: The World Health Organization quality of life Assessment-BREF self-administered instrument. MCS: Mental Component Summary. PCS: Physical Component Summary. VT: Vitality. SF: Social Functioning. RE: Role Emotional. MH: Mental Health. PF: Physical functioning. RP: Role Physical. BP: Bodily Pain. GH: General Health perceptions. PSY: psychological. PHY: physical. SOC: social. ENV: environmental (Allik et al., 2006; Bourke-Taylor et al., 2012; Dardas & Ahmad, 2014b; Khanna et al., 2011; Kheir et al., 2012; Kuhlthau et al., 2014; Lee et al., 2009; Totsika et al., 2011; Tung et al., 2014).

Study	Setting / Recruitment	Compared to	QoL measure	Results	MCS		SF		PCS		WHOQOL								
					VT	SF	RE	MH	PF	RP	BP	GH	PHY	PSY	SOC	ENV			
Allik, Larsson & Smedje (2006), Sweden	Parents registered at three PDD-habilitation centres	Control group	SF-12	Mothers in the ASD group reported lower PCS-12 scores than mothers in the control group. No difference in fathers' scores between fathers in the ASD and control groups.															
Bourke-Taylor, Pallant, Law & Howie (2012), Australia	Recruitment via advertising in non-profit disability state agencies	Population QoL scores	SF-36	Mothers of a child with a disability reported poorer mental health (Mean = 31.8) when compared to other Australian adults (Mean = 52.9). Within this group, parents of children with ASD had the lowest QoL (Mean = 30.03, $p < 0.05$ ).		*													
Dardas & Ahmad (2014b), Jordan	Parents recruited from ASD centre	Population QoL scores	WHOQOL-BREF	When compared to population means QoL was acceptable for the physical and social domains (Mean = 65.69 and 66.09, respectively), borderline for the psychological (Mean = 61.12) and lower for the environmental (Mean = 55.84) domains.															
Khanna, Madhavan, Smith, Patrick, Tworek & Becker-Cottrill (2011), USA	Parents recruited from autism centre	Population QoL scores	SF-12v2	Significantly lower QoL scores were attained by participants when compared to their age-matched counterparts in the general US population. Results for age groups 25-34 yrs (top) and 35-45 yrs (bottom) are presented.	***	**	***	***		**	**	***							
Kheir, Ghoneim, Sandridge, Al-Ismail, Hayder & Al-Rawi (2012), State of Qatar	Parents registered in two paediatric clinics	Control group	SF-36v2	No difference in the overall QoL score. However, parents in the Autism Group scored lower than controls in the general health domain.									*						
Kuhlthau, Payakachat, Delahaye, Hurson, Pyne, Kovacs & Tilford (2014), USA	Parents recruited from two autism treatment networks	Population QoL scores	SF-6D, EQ-5D	The parent average QoL score as measured by the SF-6D (Mean = 0.74) was significantly lower than the general USA population (Mean = 0.80). Parent EQ-5D scores were similar to population means.										Overall QoL score					
Lee, Lopata, Volker, Thomeer, Nida, Toomey & Smerbeck (2009), USA	Parents recruited from social skills program	Control group	MOS SF-36 (v.1)	Parents in the ASD group scored lower than controls in both the PCS (Mean 81.66 vs 87.68) and MCS (72.04 vs 81.16).		*				*									
Totsika, Hastings, Emerson, Berridge & Lancaster (2011), UK	British population, representative sample	Control group	SF-8	Low PCS was more prevalent in mothers of children with ASD (14.70%) than in the control group (5.24%). No significant differences were reported in the MCS between mothers of children with ASD and controls.															
Tung, Huang, Tseng, Yen & Tsai (2014) Taiwan	Recruitment from hospitals, paediatric clinics & developmental centres	Population QoL scores	WHOQOL-BREF	Poorer QoL was reported among parents of children with ASD when compared to general population means. This was observed in all QoL domains.												***	***	***	***

### 3.5. Findings

#### 3.5.1. Data synthesis

A systematic qualitative synthesis was used to summarise the characteristics and findings of the reviewed studies. Findings are synthesised in order by research question. To answer the first two research questions, studies which compared the QoL of parents of children with ASD to parents of typically developing children or to population norms are presented (text and Table 2). To answer the third research question, studies are then synthesised based on the parental, child-related and contextual factors which were associated with QoL (text).

#### 3.5.2. Questions 1 and 2: results from the comparative studies

Nine studies provided outcomes which compared the QoL of parents of children with ASD to population scores or to parents of typically developing children. All of these studies found a negative association between ASD and parental QoL in at least one QoL domain. Specifically, four of these studies showed a broad impact on QoL, three specifically on the physical domain, one on the mental health domain (the physical domain was not reported), and one only on the environmental domain. The results are summarised in Table 2.

#### 3.5.3. Question 3: correlation between QoL and other factors

**3.5.3.1. QoL and parental characteristics.** Four studies provided separate results regarding the gender of the parent. Significant differences were found between mothers and fathers in McStay et al. (2014) with mothers reporting significantly lower levels of QoL than fathers ( $p < 0.01$ ). Similarly, in Allik et al. (2006) mothers demonstrated significantly lower physical QoL than fathers ( $p < 0.05$ ). Kheir et al. (2012) reported that mothers demonstrated poorer mental health and had more bodily pain and more fatigue and tiredness than fathers ( $p < 0.05$ ). In addition, mothers had more difficulties with work and demonstrated decreased participation rates in social activities due to emotional problems ( $p < 0.05$ ). In contrast, no significant differences between mothers and fathers arose in the subscales or total score of QoL in Dardas and Ahmad (2014b).

Of the parental mental health variables the relationship between stress and QoL was examined in two studies. Both studies showed that stress was significantly associated with lower QoL. In Lee et al. (2009) stress was significantly associated with the mental and physical health summary scales of the MOS 36-Item Short-Form Health Survey ( $\beta = -0.330$ ;  $p < 0.05$ ). Furthermore, in Tung et al. (2014), stress was negatively correlated with all aspects of QoL including physical, psychological, social and environmental HRQOL, explaining 42%, 46%, 47%, and 42% of the total variance.

Parental individual coping strategies were also associated with QoL among parents of children with ASD. In Khanna et al. (2011) self-distraction, denial, venting, behavioural disengagement and self-blame, as measured by the Brief Coping Orientation to Problem Experiences (Carver, 1997) were associated with lower QoL ( $p < 0.001$ ). In Dardas and Ahmad (2014a) two coping styles negatively influenced QoL, namely 'accepting responsibility' ( $p < 0.05$  in fathers and  $p < 0.01$  in mothers) and 'escape-avoidance' ( $p < 0.01$ ). 'Accepting responsibility' referred to accepting responsibility for a problem and obligation to solve it (Folkman & Lazarus, 1988), while escape avoidance included strategies aimed at denying and forgetting the situation. In contrast to these findings, no association between coping strategies and QoL was found in Lee et al. (2009).

Only one study sought information on the relationship between QoL and parental self-efficacy (Bourke-Taylor et al., 2012). Self-efficacy refers to people's beliefs in their ability to influence their lives and reach their goals (Bandura, 1994). Parental self-efficacy in managing their children's disability as well as in dealing with wider family matters was seen as an important factor associated with QoL ( $r = 0.40$ ;  $p < 0.001$ ).

**3.5.3.2. QoL and child characteristics.** An association was found between parental QoL and child behavioural problems in all five of the reviewed studies. In Khanna et al. (2011), the physical QoL dimension of the SF-12v2 significantly correlated with the child's behavioural problems as measured by the short form Developmental Behavioural Checklist (Taffe et al., 2007). ( $r = -0.19$ ;  $p < 0.05$ ). Mothers who perceived greater behavioural difficulties in their children demonstrated lower physical QoL. Similarly, in Tung et al. (2014) the hyperactivity/inattention domain of the Strengths and Difficulties Questionnaire (Goodman, 1997) correlated with the physical domain of the HRQOL scale ( $r = -0.23$ ,  $p < 0.05$ ). In addition, McStay et al. (2014) reported lower QoL among parents of children demonstrating higher levels of externalising difficulties. Similar results were demonstrated by Allik et al. (2006). In this study lower scores of prosocial behaviour, and higher scores of hyperactivity and conduct problems in the child as measured by the Strengths and Difficulties Questionnaire-parent report indicated poorer maternal mental health. These results were corroborated by Totsika et al. (2011): Maternal QoL was correlated with the existence of conduct problems in the child ( $OR_{interaction} = 1.51$ ).

Four studies assessed the impact of emotional problems on parental QoL. However, only half of these studies indicated a significant correlation between the child's emotional problems and maternal mental health (Bourke-Taylor et al., 2012; Totsika et al., 2011).

Conflicting results were also obtained regarding the relationship between ASD severity and QoL. In Tung et al. (2014) and Khanna et al. (2011), severity of autism as measured by the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980) was negatively associated with psychological QoL ( $r = -0.35$ ;  $p < 0.001$  and  $r = -0.16$ ;

$p < 0.05$  respectively). In contrast, four studies did not reveal a correlation between ASD severity and parental QoL, using different measures (Hu, 2008; Kuhlthau et al., 2014; Lee et al., 2009; McStay et al., 2014).

Finally, only one out of four studies indicated a relationship between the child's age and parental QoL. In Tung et al. (2014) parents of older children with ASD had lower environmental HRQoL than parents of younger children.

**3.5.3.3. QoL and contextual factors.** Three studies examined the impact of employment status on parental QoL. Part- or full-time paid employment was consistently associated with higher parental QoL. In Dardas and Ahmad (2014a) parents who were in paid employment rated their overall QoL more positively ( $r = 0.21$ ;  $p < 0.01$ ). In Hu (2008) occupational status showed small but significant correlations with all QoL dimensions, including psychological ( $r = 0.13$ ;  $p \leq 0.05$ ), social ( $r = 0.13$ ;  $p \leq 0.05$ ), physical ( $r = 0.16$ ;  $p \leq 0.01$ ) and environmental ( $r = 0.16$ ;  $p \leq 0.01$ ). Finally, in Bourke-Taylor et al. (2012) mothers in paid employment rated their mental health more positively than those who were unemployed ( $p < 0.05$ ).

Household income also correlated with parental QoL in four out of five reviewed studies. In Dardas and Ahmad (2014a) household income was associated with maternal ( $r = 0.28$ ;  $p \leq 0.01$ ) but not paternal QoL, whereas in Hu (2008) family monthly income was the strongest associated factor of the psychological ( $r = 0.18$ ;  $p < 0.01$ ), social ( $r = 0.25$ ;  $p \leq 0.01$ ) and environmental domains of QoL ( $r = 0.37$ ;  $p \leq 0.01$ ). Consistent with these results, Lee et al. (2009) reported that having a higher income in the home was associated with better physical ( $\beta = 0.377$ ;  $p < 0.05$ ) and mental health ( $\beta = 0.427$ ;  $p < 0.001$ ). Finally, Totsika et al. (2011) found that socioeconomic position was significant and mediated the relationship between child conduct problems and physical QoL ( $OR_{\text{interaction}} = 0.68$ ). In Tung et al.'s (2014) study however, the relationship between income and QoL was not significant ( $p > 0.05$ ).

Four studies examined the relationship between QoL and family variables, such as family composition, functioning, and coherence. Family composition was examined in terms of number of children in the family. Having more children was associated with better QoL for mothers in Dardas and Ahmad (2014a) ( $\beta = 0.13$ ;  $p < 0.01$ ) and for both parents in Lee et al. (2009) ( $r = 0.31$ ;  $p < 0.05$ ). Family functioning was assessed by standardised measures aiming to examine problems in the family. Parental physical and mental HRQoL were negatively associated with problems in family functioning in Khanna et al. (2011) ( $r = -0.12$  and  $r = -0.39$ ;  $p < 0.05$ ). Finally, in McStay et al. (2014) family coherence as assessed by the Sense of Family Coherence Scale (Sagy, 1998) was significantly associated with QoL ( $r = 0.72$  and  $r = 0.67$  for mothers and fathers respectively,  $p < 0.01$ ).

Five studies discussed the relationship between availability of social and professional support and QoL. Social support was discussed in terms of parental engagement in reciprocal social interaction with others, including friends, family or others in the community. A significant positive association was found between social support and QoL in all studies (Hu, 2008; Khanna et al., 2011; McStay et al., 2014). Parents who experienced more social support demonstrated higher QoL. In contrast, the availability of service support was not as consistently associated with increased parental QoL. Although two studies showed that support from services was significantly associated with QoL (Bourke-Taylor et al., 2012; McStay et al., 2014), one failed to demonstrate such a relationship (Lee et al., 2009).

Finally, one study assessed the relationship between QoL and participation in health promoting activities such as time out of the home, exercise and healthy lifestyle choices (Bourke-Taylor et al., 2012). Results from this study indicated that participation in health promoting activities was the strongest associated factor of QoL among mothers of children with ASD ( $r = 0.46$ ;  $p < 0.001$ ).

## 4. Discussion

The present review systematically examined the quality of life (QoL) of parents of children with ASD in an attempt to provide a more thorough assessment of parental adjustment and to highlight areas that may benefit from the development of enhanced and focussed supports. Three main questions were addressed: (a) How does the QoL of parents of children with ASD compare to parents of typically developing children or to general population norms? (b) Which QoL dimensions are affected most? (c) What parental, child, and contextual factors are associated with parental QoL? The main findings are discussed below along with practice implications and recommendations for further research.

### 4.1. Question 1: how does the QoL of parents of children with ASD compare to the QoL of parents of typically developing children or to population norms?

All studies showed that parents of children with ASD scored lower than parents of typically developing children or than the general population in at least one QoL dimension. Most parents of children with ASD demonstrated lower subjective physical and mental health as well as poorer social functioning and lower satisfaction with their environment' compared to the other groups. These findings are in line with previous research indicating decreased health and general wellbeing among this population (Bromley, Hare, Davison, & Emerson, 2004; Davis & Carter, 2008; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Schieve, Blumberg, Rice, Visser, & Boyle, 2007).

Parental QoL deficits could be understood in the context of the challenges that these parents face. Increased levels of stress, sleep deprivation and fatigue have been associated with parents of children with ASD and are likely to compromise their mental and physical functioning (Giallo et al., 2013; Seymour, Wood, Giallo, & Jellett, 2013). Furthermore, stigmatisation, increased caregiving responsibilities and the high financial demands of caring for children with ASD might



reduce parental opportunities to socialise with others and may inhibit their capacity to make positive changes in their environment (Gray, 2008; McCann, Bull & Winzenberg, 2012; Sawyer et al., 2010; Sharpe & Baker, 2007). However, it is important to keep in mind that the quality appraisal raised a number of issues around the internal and external validity of the reviewed studies, for example with respect to selection bias, sampling error and generalisability. Therefore, although these results are indicative of a negative association between parenting a child with ASD and parental QoL, future research should seek to improve methodologically upon these factors to enhance the quality and validity of the available findings.

#### 4.2. Question 2: which QoL dimensions were mostly affected?

This review highlighted that QoL was rated low more consistently in the physical domain than in the mental health domain with three studies demonstrating only physical QoL deficits among this population. This is an interesting finding which might suggest a more immediate impact of ASD on parental physical wellbeing. Although the reasons behind this are largely unknown, a possible explanation could be found on the positive aspects of raising a child with disabilities. Parental rewards of raising a child with ASD such as increased spirituality and personal growth (Myers, Mackintosh, & Goin-Kochel, 2009; Pakenham, Sofronoff, & Samios, 2004) could potentially safeguard parents against emotional distress but not against the more 'objective' aspects of caregiving such as lack of sleep and physical exhaustion (see also Green, 2007). The measures used in the reviewed studies allowed for a positive evaluation of caregiving, for example by including questions such as 'To what extent do you feel your life to be meaningful?' This may have accounted for the higher scores in the mental health dimension. However, more research is warranted to explore this area in detail in the future. Further research could allow for a more thorough understanding of the physical health domains in need of support and may help design specific health promotion programmes for this population.

#### 4.3. Question 3: which factors are associated with QoL?

##### 4.3.1. Parental factors

**4.3.1.1. Gender.** Among the parental QoL associated factors, the gender of the parent was found to be associated with QoL, with mothers demonstrating significantly lower QoL than fathers in most studies (75%). This is consistent with a large body of literature which suggests that mothers of children with disabilities experience lower QoL and wellbeing (Mugno et al., 2007; Yamada et al., 2012), greater distress (Olsson & Hwang, 2001) and higher anxiety levels than fathers (Hastings, 2003).

The QoL differences observed across genders could be explained in light of the maternal caregiving responsibilities. Parenting a child with ASD involves additional challenges due to the children's communication difficulties, self-care limitations as well as their unpredictable and aggressive behaviours. Mothers are most commonly reported as the primary caregivers of children with ASD and might therefore absorb the majority of caregiving burden (Montes & Halterman, 2008). This interpretation is supported by research showing greater health difficulties and role restriction among mothers who report more childcare responsibilities (Roach, Orsmond, & Barratt, 1999).

However, it is important to note that paternal sample sizes in most of the reviewed studies were relatively small ( $n \leq 30$ ). Moreover, a study with a larger paternal ( $n = 70$ ) sample (Dardas & Ahmad, 2014b) failed to find gender differences in QoL, and some findings suggest similarities in parental experience when there is a child with a disability (Davis & Carter, 2008; Hastings, 2003). Further research in this area would be beneficial in gaining a better understanding of the role of gender in QoL as well as of the unique experiences of fathers in families affected by ASD.

**4.3.1.2. Mental health factors.** Stress, coping style and parental self-efficacy emerged as important factors associated with QoL. First, results from this review suggested that parental stress was negatively associated with QoL. Although both reviewed studies examining this relationship used convenience samples which might affect the validity of their findings, these results are in agreement with research in different populations (Masthoff, Trompenaars, Van Heck, De Vries, & Hodiament, 2005). Research has also shown that parents of children with ASD may be more likely to experience high levels of stress (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). These findings highlight the importance of assessing parental stress levels in order to intervene when appropriate.

Although most included studies emphasised the role of coping in parental adjustment, conflicting results were demonstrated on the specific coping strategies that were associated with QoL. Variation in the measurements used and in the theoretical conceptualisation of coping could have in part accounted for these differences. A study by Hastings et al. (2005) identified four key coping dimensions which are relevant to parents raising a child with ASD: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. Further research on the relationship between these coping dimensions and QoL would be beneficial in ascertaining which coping styles are helpful when adapting to the challenges of raising a child with ASD. Only one of these studies (Dardas & Ahmad, 2014a, 2014b) reported the presence of co-morbidities in their sample. As co-morbidity in ASD has been found to be associated with maternal coping (Abbeduto et al., 2004), future studies should aim at distinguishing between ASD and other conditions when examining parental coping and QoL.

Given the wide amount of research linking self-efficacy to improved parental wellbeing (Jones & Prinz, 2005), it was surprising that only one reviewed study addressed the impact of parental self-efficacy on QoL (Bourke-Taylor et al., 2012).

Although this study had a number of limitations such as the existence of convenience samples and the lack of confirmation of the ASD diagnosis by a professional, it verified previous reports on the relationship between self-efficacy and QoL, showing self-efficacy to be a significant QoL associated factor. These results are promising, however, more research would be beneficial in order to further explore the relationship between QoL and self-efficacy among this particular population.

#### 4.3.2. Child related factors

With regards to child-related factors, externalising difficulties were consistently associated with lower parental QoL. Parents who perceived greater conduct difficulties in their children demonstrated lower physical and mental QoL. This concurs with previous research on parents of children with ASD and comorbid learning disability (Davis & Gavidia-Payne, 2009). As Bekhet, Johnson, and Zauszniewski (2012) noted, the relationship between child behavioural difficulties and parental wellbeing could turn into a vicious cycle in which the child's difficulties decrease parental wellbeing which, in turn, exacerbates the child's symptoms. Interventions which provide parental support may help disrupt this vicious cycle and improve psychological outcomes for the whole family. It may therefore be beneficial for services and professionals to adopt a systemic approach in the presence of such issues and to assess the needs of both parents and children. This is further supported by the association between QoL and family coherence reported in this review.

This review showed conflicting results in the relationship between ASD severity and QoL, with more than half of the studies that examined this relationship (66.6%) failing to detect such an association. Variation in measures used and in the definition of autism severity might account for the reported differences. More research in this area could help assess this relationship further.

Finally, the majority of the reviewed studies which explored the relationship between the child's age and parental QoL did not indicate a statistically significant association. However, in the absence of longitudinal studies these results should be interpreted with caution. Future longitudinal studies are needed to assess the long-term impact of having a child with ASD across different age groups and to evaluate the specific needs of parents at each stage.

#### 4.3.3. Contextual factors

**4.3.3.1. Household income.** The majority of studies (80%) examining the association between income and QoL showed a significant positive association between these variables. Higher income could improve parental physical environment and increase both child and parent access to health services (DeVoe et al., 2007). Even in countries where there is free access to health care, such as the UK, low income families still seem to be underrepresented among those seeking health care advice (Knowles, Munro, O'Cathain, & Nicholl, 2006). In addition, low-income parents' experiences of service support are often negatively reported and parents may appear reluctant to seek help for themselves or for their children (Attree, 2004). Developing and implementing therapeutic interventions which are sensitive to the needs of low-income families might be beneficial. For example, building on community-based interventions which rely on mutual support and promote parental empowerment could help to support these families (Minkler, Wallerstein, & Wilson, 1997). In addition, financial support and provision for the child's future financial security, depending on parental economic resources, might be useful in enhancing the QoL of parents and their children.

**4.3.3.2. Employment status.** Paid full or part-time employment was associated with higher parental QoL in most reviewed studies. Although the presence of convenience samples might raise questions about the validity of these findings, the relationship between employment and QoL is verified by research in different populations (Miller & Dishon, 2006). This could be partly because employed parents are more likely to improve their familial income (see Section 4.3.3.1). However, in Hu (2008) a path analysis indicated that employment status and income were associated with distinct QoL domains and literature suggests that the benefits of employment transcend income levels (McKee-Ryan, Song, Wanberg, & Kinicki, 2005). For example, parental employment may be personally rewarding and increase the availability of their social support resources. Although low QoL might make it hard for parents to find employment, research suggests that the main barrier in parental workforce participation is service limitations, such as lack of skilled childcare (Bourke-Taylor, Howie, & Law, 2011). Thus, service provision to improve parental workforce participation might be beneficial in safeguarding parental QoL outcomes. In an attempt to address this policy makers and organisations could foster programs designed to reduce conflict between work and family such as flexibility of working hours, wider accessibility of respite support and/or the provision of medical appointments out with the working day.

**4.3.3.3. Social support and participation in health promoting activities.** Results from this review highlighted the importance of social resources and of participation in activities outside the home. Specifically, higher levels of social support was positively associated with parental QoL. Similarly, participation in health promoting activities such as time out of the home, exercise and healthy lifestyle choices was associated with better perceived mental health among parents. However, the fact that in most industrialised countries the care needs of children with disabilities are met at home, in addition to high caregiving demands, can reduce parental opportunities to spend time outside the home and to socialise with others. Therefore, ensuring that parents have the time and resources to be able to participate in social and other health promoting activities could be beneficial in promoting their QoL. The provision of respite care, experienced child-care at home, as well as support

in planning outdoor activities with or without the child might be useful steps towards this direction (Murphy, Christian, Caplin, & Young, 2007; Yantzi, Rosenberg, & McKeever, 2007).

**4.3.3.4. Support from Services.** In contrast to social support, support from services was not consistently associated with higher QoL. A failure to detect a relationship between QoL and service support may be understood in the context of certain methodological limitations (e.g. lack of measure sensitivity in the measurement of support in Lee et al., 2009). However, previous research could provide an alternative explanation for these findings. While some studies have demonstrated the positive effect of child- or family-oriented support on parental outcomes when there is a child with a disability (Blackledge & Hayes, 2006; Chiang, 2014), others have reported no effect of service involvement and dissatisfaction with services (Renty & Roeyers, 2006; Shu & Lung, 2005). More research into parental interventions may therefore be required to enhance acceptability and efficacy of services and to provide interventions tailored to the needs of this population.

#### *4.4. Limitations and recommendations for future research, policy and practice*

A number of limitations need to be borne in mind when examining the results of this study. First, all studies in the review were cross-sectional and therefore inferred an association and not a causal relationship (Sedgwick, 2014). Furthermore, study weaknesses, such as the presence of convenience samples, lack of the assessment of confounding variables as well as the lack of verification of ASD diagnosis by a professional were likely to have affected the internal and external validity of the studies and to have influenced the review findings. A further consideration would include the definition of QoL. QoL is a complex construct with multiple definitions and measurement approaches. The reviewed studies included a variety of measures which differed slightly in the theoretical conceptualisation of quality of life. These issues must be considered when interpreting the existing findings as this makes between study comparisons difficult. However, restricting the search to studies using the same QoL definition and measurement would have significantly narrowed the focus of the review and would have excluded relevant research.

The small percentage of fathers included in the sample rendered it difficult to infer conclusions for this population. In addition, the participants in the included studies were diagnostically, geographically and culturally diverse making it hard to compare across studies. Moreover, since the purpose of this review was to examine the QoL of parents of children with ASD, studies that assessed parents with children with other conditions such as comorbid learning disability, Fragile X, or Down syndrome were excluded. However, given that only few studies in the review reported the comorbidity of their sample, it is possible be that a separation between parents of children with ASD, and parents of children with ASD and the aforementioned comorbid conditions was difficult to control for. Finally, a number of possibly eligible studies could not be accessed within our institutes. We are therefore unaware what the findings of these unobtainable studies might have contributed to the results.

Notwithstanding these limitations, the present systematic review is the first to examine the QoL in parents of children with ASD and can provide some preliminary evidence on the relationship between ASD and parental QoL. Despite its limitations, this review supports an appreciation that this population may experience impoverished QoL through highlighting some of the factors that have been identified within the existing literature which could improve or impede parental QoL. While there remains research to be done on the relationship between parenting a child with ASD and QoL, this study provides recommendations on areas where future interventions and policy decisions should focus on. For example, disability related support such as respite and child-care as well as the development of psychosocial interventions aimed at reducing stress and at enhancing social support and parental self-efficacy could be beneficial in promoting parental QoL outcomes. Moreover, the provision of financial support and of services that address the needs of low income families might be useful in supporting this specific subgroup.

Future research should seek to evaluate parental interventions targeting these factors to determine whether they lead to positive QoL outcomes. Moreover, replications in independent larger cohorts as well as longitudinal studies are required, in order to obtain more reliable results on parental QoL and its correlates and to assess the long-term impact of parenting a child with ASD. It might also be beneficial to focus on parental physical health and ways in which to promote it. Of the studies reviewed none examined the impact of cultural differences on parental QoL, and future studies may benefit from exploring this relationship. In addition, further research is needed to address the impact and experiences of fathers in families where there is a child with ASD in order to identify potential differences in the support services offered. Finally, future research would benefit from the use of a consistent measurement of QoL which would allow a quantitative analysis of future studies. Given the potentially pervasive impact of having a child with ASD across all QoL domains, the implementation of a broader instrument such as the WHOQoL-Bref might be more useful when assessing the QoL of this population.

## **5. Conclusion**

This review underlined the complexity of raising a child with ASD and its potentially adverse effect on parental QoL. Three main findings emerged from this review: (a) Parents of children with ASD had lower QoL when compared to other populations (e.g. parents of typically developing children or general population norms); (b) The physical dimension of QoL was more consistently affected; and (c) Several child, parent and environmental variables influenced parental QoL within

this group. Findings from this review may inform the development of future interventions and influence health care, policy and funding decisions.

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None.

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