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Does family quality of life get better as the years go by? A comparative mixed-methods study between early years and school-aged children with disability in Australia

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Abstract

This Australian study compared perspectives of family quality of life (FQOL) of parents of preschool children attending early childhood intervention services (ECIS) with parents of school-aged children with disability. It examined the relationships between disability-related services, parent occupations, and FQOL. Two mixed-methods studies with 122 participants and 24 in-depth interviews were conducted. The first study included 72 parents attending ECIS. The second study included 50 parents of school-aged children with disability. The quantitative aspect ($N = 122$) used the Beach Center FQOL survey and a demographic questionnaire. Twelve semistructured interviews were conducted for each study. Spearmann's Rho correlations for quantitative data analysis and thematic analysis for qualitative data were used for each study. A two-way analysis of variance along with a qualitative comparative analysis were conducted to compare the findings from both studies. Results indicated lower scores on FQOL in parents with school-aged children when compared with the ECIS group. Loss of work, lack of time for caregiver health, lack of respite, and interim residential care had detrimental impacts on parents' long-term well-being. Based on the results, it can be concluded that the hardships and challenges of caregiving increase as the child gets older; however, positive adaptations, beliefs, and positive transformations help FQOL. Family-centered care and supportive practitioners assist FQOL and are highly recommended.

KEYWORDS

carer, childhood disability, developmental disability, early intervention, family quality of life, intellectual disability, parent

Abbreviations: ABS, Australian bureau of statistics; BC-FQOLS, beach center family quality of life survey; CWD, child with disability; ECIS, early childhood intervention services; FCP, family centred practice; FQOL, family quality of life; NDIS, national disability insurance scheme; QoL, quality of life; WB, well-being.

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INTRODUCTION

Most families are unprepared for the long-term caregiving when a child with disability is born. They constantly adapt and transform, coping with arising challenges. Despite families trying to feel positive, having a child with disability affects daily routines, occupations, and family quality of life (FQOL), more so than when a child is born without a disability (Bhopti et al., 2020a, 2020b; Rillotta et al., 2012; Zuna et al., 2014). Loss of employment, lack of time for self-care, poor health, and financial struggles are some other consequences that parents/caregivers experience. Regardless of the hardships associated with caregiving for a child with disability, most parents stay positive and report that their FQOL is reasonable (Bhopti et al., 2020a). Many families focus on strengths and try to "normalize" their experiences especially in the early years of having a child with disability (Bhopti et al., 2020a). "Normalization" has been reported in previous literature where parents/caregivers compare, adapt to, and accommodate the needs of their child with chronic conditions, leading to a positive influence on FQOL (Deatrick et al., 1999; Knafl et al., 2010). FQOL focuses on positive development, strengths, and coping mechanisms that families use rather than negative factors like stress or depression (Chiu et al., 2013).

A good depiction of what constitutes FQOL is presented in a gearbox model of FQOL showing the direct and indirect predictors impacting FQOL (see Figure 1) (Zuna et al., 2010). Family members accommodate, adapt, and use their beliefs and characteristics (direct predictors), and benefit from services, policies, and programs (indirect predictors). The interaction of these predictors produces new strengths, needs, and priorities that influence FQOL throughout the life course of the family (Zuna et al., 2010).

This article compares FQOL data from two studies (Bhopti et al., 2020a, 2020b). Perspectives of parents of children with disability from preschool (Study 1; 0–7 years) are compared with perspectives of parents of school-aged children (Study 2; 8–18 years). The preschool group included children in the age group of 0–7 years receiving early childhood intervention services (ECIS) and not yet in school (consistent with Australian ECIS) and the school-aged group included children from the ages 8 - 18 years who were attending school. The main aim of this research was to investigate whether FQOL is better in the families of children in the older age group.

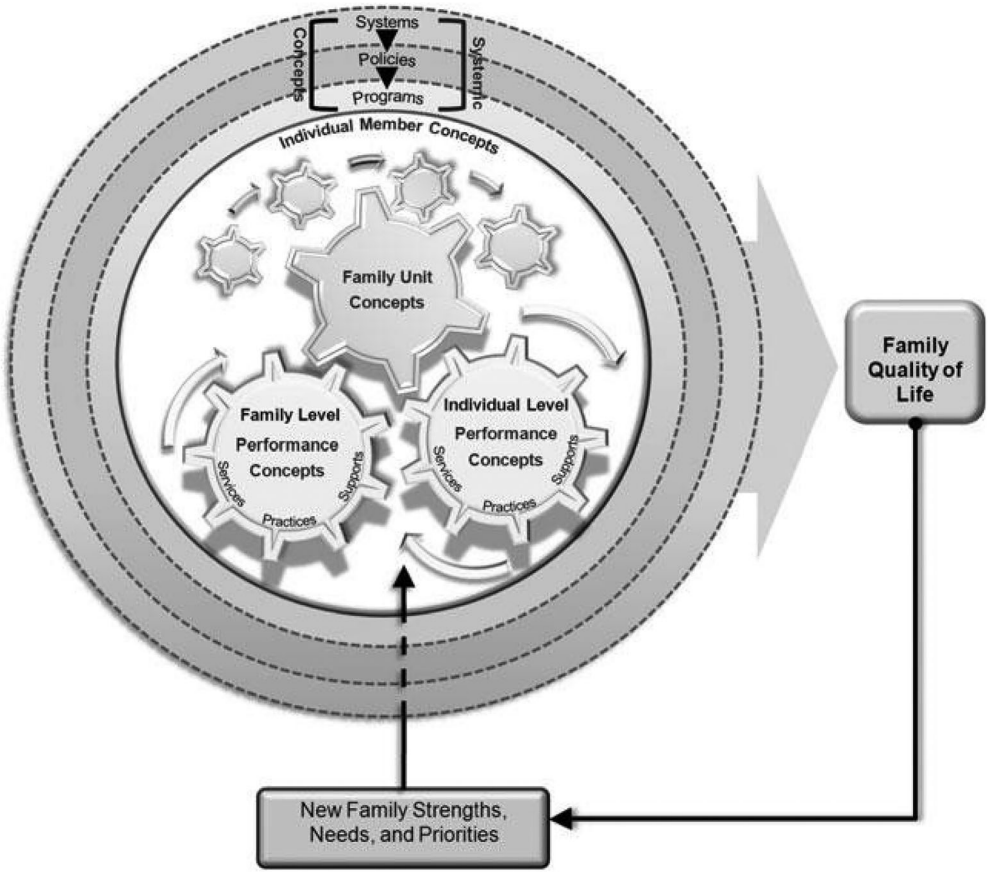

FIGURE 1 Unified theory of family quality of life (FQOL). *Source*: Zuna et al. (2010), p. 268

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A further aim was to establish whether parents/caregivers were able to return to their previous occupations as their child grew older. As such, this study also considered the impact of having a child with disability on parent occupations. A classification of occupations proposed by Harvey and Pentland (2004) using four categories was used to gain an understanding of how parents allocate their time for occupations. These four categories are (i) necessary occupations, (ii) contracted occupations, (iii) committed occupations, and (iv) free-time occupations. Necessary occupations comprise necessary time, aimed at meeting basic self-maintenance needs, such as eating, sleeping, sex, and personal care activities. Contracted occupations occur in contracted time and involve paid productivity or formal education. Committed occupations have a productivity or work character. However, they are typically not remunerated, and the duration of work is diffuse and unspecified, such as housework, childcare, home and vehicle maintenance or shopping (Bhopti, 2016).

The final overarching aim was to use the results and findings to guide policy and practice to advocate for better FQOL. The research questions guiding this article are: (i) Are there any differences in perceived FQOL between preschool years and school-aged groups of children with disability? (ii) Are there any differences between parent occupations and services and supports received? and (iii) Does perceived FQOL get better as the child with disability gets older?

Brief overview of the two studies

Studies 1 and 2 were mixed-method studies and applied the same protocol and methods of data collection and analyses (Bhopti et al., 2020a, 2020b). The Beach Center FQOL Survey (BC-FQOLS) and a demographic questionnaire were used to collect quantitative FQOL data. Qualitative data were collected via 12 semi-structured in-depth interviews in each study. Both studies investigated FQOL and relationships between FQOL, parent occupations, and disability-related supports/services (no informal supports were considered). The quantitative and qualitative data from Studies 1 and 2 were analyzed and compared and are presented in this article.

Instrumentation

The BC-FQOLS is a 25-item survey comprising five subscales (family interaction, parenting, emotional well-being, physical-material well-being, and disability-related support) and was designed and psychometrically tested at the Beach Center on Disability (BCD) in Kansas (BCD, 2002; Hoffman et al., 2006). In the current study, the Cronbach alpha coefficient was 0.94, indicating good internal consistency reliability for use of the scale with this sample ($N = 122$).

The demographic questionnaire included sections on age, sex, relationship to the child, diagnosis of child, languages spoken at home, educational levels of main carer and partner, duration of ECIS, type of school (special or mainstream), and annual income.

TABLE 1 Interview questions

Study 1	Study 2
1. How would you describe your family quality of life at present?	1. How would you describe your family quality of life at present?
2. What are some of the things that you think have impacted or influenced your current family quality of life? Can you explain why?	2. What are some of the things that you think have impacted or influenced your current family quality of life? Can you explain why?
3. Do you think that your family quality of life was different before having (name of child with disability)?	3. Do you think that your family quality of life was different before having (name of child with disability)?
4. Did you work?	4. Did you work?
5. Or are you able to do things you did before? Can you give me some examples?	5. Or are you able to do things you did before? Can you give me some examples?
6. Has receiving ECIS had any influence on you or your family? Could you tell me a bit more about that?	6. Has receiving disability-related supports/services had any influence on you or your family? Could you tell me a bit more about that?
	7. Do you recall if receiving ECIS had any influence on you or your family? Could you tell me a bit more about that?
	8. Could you comment on the differences between your FQOL now when your child is at school compared to when in ECIS?

Abbreviations: ECIS, early childhood intervention services; FQOL, family quality of life.

Procedure

Study 1: Following ethics approval for both studies, nine sites from a single large family-centered ECIS organization

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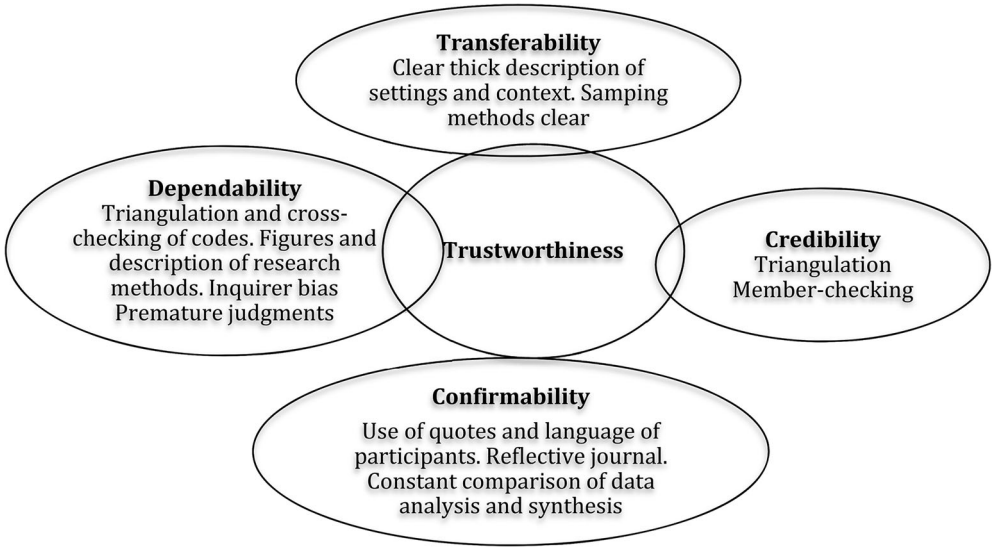

FIGURE 2 Trustworthiness. *Source*: Adapted from the work of Lincoln and Guba (1985)

were provided with 300 information packs for distribution to families within their service. All responses were returned to a locked bag or via postal mail to the first author over 9 months. An estimated 200 packs were distributed out of the 300 packs and 72 responses were collected. Twelve participants from this sample who consented to participate were purposefully selected for the interviews to ensure perspectives from mothers, fathers and varying socio-economic status and as per availability. *Study 2*: A convenience sampling method was used and participants for the second study were recruited via privately run parent support groups within metropolitan Melbourne, Australia, via their group facilitators and snowball sampling (Liamputtong, 2013). The first author attended the group sessions at preorganized times to distribute the information packs to parents within the group and provided reply paid envelopes or a locked mailbox for collection. An estimated 75–100 surveys were distributed, and 50 responses were received. Twelve participants from this sample who consented to participate were purposefully selected for the interviews as per above considerations. The interview questions for both studies are listed in Table 1.

Data analysis

For the quantitative analysis in both studies, descriptive statistics from the demographic questionnaires, mean values of the total raw scores from the BC-FQOLS, and its subscales of FQOL were inputted into the Statistical Package of Social Sciences (IBM Corp., 2013). Spearman's Rho correlation was chosen as the statistic for the analysis of relationships between FQOL, parent occupations, and disability-related supports. For the qualitative aspect, Creswell's (2009) six steps of qualitative analysis for generating codes and themes were utilized. All interviews were transcribed verbatim and measures to ensure trustworthiness were maintained by examining the four criteria of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). See Figure 2.

Detailed data analysis for each study is available in previous publications and a summary of the two studies with results and findings is provided in Table 2 (Bhopti et al., 2020a, 2020b).

METHODS

Quantitative method

The quantitative data from the two studies were compared using "between-groups" analysis of variance (ANOVA). The variables for ANOVA included age-group of the child as the independent variable and total family quality of life (TFQOL) as the dependent continuous variable. A one-way between groups analysis of variance was conducted to explore the impact of age on the level of satisfaction with total FQOL. The other continuous variables used were the subscale mean scores of FQOL, namely "family interaction," "parenting," "emotional well-being," "physical/material well-being," and "disability-related support."

The total participants from the two studies ($N = 122$) were divided into four groups (Group 1 = 0–2 years; Group 2 = 3–6 years; Group 3 = 7–10 years; Group

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TABLE 2 Results and findings from Studies 1 and 2

Description	Study 1—ECIS	Study 2—School-aged children
Inclusion criteria	Parents of a child/ren with disability attending an ECIS service -Working knowledge of English -Informed consent received	Parents of a school-aged child/ren with disability -Working knowledge of English -Informed consent received
Exclusion criteria	Parents/caregivers who did not fit within the definition of "family" were excluded (e.g., a birth father with no custody or relationship with the child or family)	Parents/caregivers who did not fit within the definition of "family" were excluded (e.g., a birth father with no custody or relationship with the child or family)
Quantitative sample	$N = 72$ BC-FQOLS Demographic questionnaire	$N = 50$ BC-FQOLS Demographic questionnaire
Qualitative sample	$N = 12$ Six questions for semistructured interviews used	$N = 12$ Six questions for semistructured interviews used
Diagnosis of child	Developmental delay: 15.3% Cerebral palsy: 13.9% Down syndrome: 6.9% Autism ASD: 26.4% Congenital issues: 11.1% No clear diagnosis: 11.1% Speech and language delay: 6.9% Other: 8.3%	Cerebral palsy: 12% Down syndrome: 18% Autism/ASD: 46% Congenital conditions: 16% No clear diagnosis: 4% Other: 4%
Quantitative results	High score for Total FQOL (M = 100.56, SD = 14.15) Highest association for subscale "parenting" (rho = 0.86, $p = 0.01$) and lowest for subscale "physical/material well-being" (rho = 0.61, $p = 0.01$) Strong positive correlations between "disability-related support" (ECIS) with TFQOL satisfaction (rho = 0.70, $p = 0.01$). Strong correlations between duration of ECIS and relationship with ECIS provider and between committed, necessary and free-time occupations, and "disability-related support"	High score for Total FQOL (M = 90.96, S = 16.90) Highest association for subscale "total family interaction" (M = 22.26, SD = 5.09); lowest for "disability-related support" (M = 14.96, SD = 3.21) Strong positive correlations between committed occupations, and free-time occupations with "disability-related support." No significant correlation between necessary occupations and contracted occupations with "disability-related support"
Qualitative themes	Theme 1: My family quality of life is okay, but...different, difficult at times, with constant ups and downs Theme 2: Family quality of life is better when we feel hopeful and supported Theme 3: Family quality of life is challenged during difficult times Theme 4: Having a child with disability has consequences for the family and for family quality of life	Theme 1: Our FQOL is hard, limited, dreadful, terrible, challenging, fluctuating; however, there are positives about having a child with disability. Theme 2: Sharing good times as a family supports FQOL Theme 3: Services and supports are valued and help FQOL Theme 4: Caregiving is for the long term, affects parent occupations and challenges FQOL

Abbreviations: BC-FQOLS, Beach Center FQOL survey; ECIS, early childhood intervention services; FQOL, family quality of life.

4 = 11–18 years). Three sets of ANOVA analyses were conducted: comparing FQOL and its subscales as the independent variables, to parent occupations; and services and supports between the four groups as dependent variables. An F-ratio was also calculated that represents the variance between the groups divided by the variance within the group (Pallant, 2013). To understand which groups differ, post hoc tests were also conducted to protect against the likelihood of Type 1 error.

Qualitative method

The qualitative comparative approach (Bradley et al., 2007; Ragin, 1999) was used to compare the findings

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TABLE 3 Analysis of variance (ANOVA) scores between groups—ECIS and school age—Studies 1 and 2 ($N = 122$)

ANOVA—Total FQOL and subscales of BC-FQOLS—between groups					
	Sum of squares	***Df***	**Mean square**	***F***	**Sig.**
TFQOL	4385.921	3	1461.97	6.500	0.00*
TParenting	217.907	3	72.64	4.363	0.00*
TPhysmaterialWB	122.511	3	40.84	6.117	0.00*
TEmotionalWB	162.470	3	54.16	4.190	0.00*
TDisabSupport	144.025	3	48.00	6.926	0.00*
TFamInteraction	207.128	3	69.04	2.842	0.041*

Abbreviations: DisabSupport, Disability-related support; Fam, Family; TFQOL, Total Family Quality of Life; T, Total; Physmaterial WB, Physical Material Well-being; WB, Well-being.
*$p < 0.01$.

between the parents' perspectives in Studies 1 and 2 of FQOL, parent occupations, and disability-related supports. Themes were generated by analyzing concepts coded in the two participant groups (ECIS and school-aged) to assess whether certain concepts and perspectives were more apparent or experienced differently in one group than the other (Bradley et al., 2007). In both Studies 1 and 2, the codes and themes were comparable. Color coding was used to group common findings. Three final categories were created in response to the research question about comparing the two studies: comparing FQOL between groups; comparing parent occupations between groups; and comparing disability-related supports between groups.

Along with the above comparisons, two questions were added to the interview guide in Study 2 to obtain longitudinal data from parents living with disability and their FQOL. These questions were "Do you recall if receiving ECIS had any influence on you or your family?" and "Could you comment on the differences between your FQOL now when your child is at school compared to when in ECIS?" The responses to these two questions were also coded and included in the final themes.

RESULTS AND FINDINGS

Comparing FQOL between groups

An ANOVA was conducted to explore the impact of age as the independent variable (comparing ECIS to school-aged children) on the level of satisfaction with total FQOL (dependent variable), as measured by the BC-FQOLS (see Table 3). Mean scores for Total FQOL and the five subscales were computed via SPSS used as the dependent variables throughout the data analysis. There was a statistically significant difference in the BC-FQOLS scores for total FQOL for the groups: $F(3, 118) = 6.5$, $p < 0.01$. The effect size calculated using eta squared was 0.141 and is considered a large effect size (Cohen, 1988). There was a statistically significant difference in the scores for the dependent variable "Total Family Interaction" for the groups: $F(3, 118) = 2.842$, $p = 0.04$ with a moderate effect size of 0.06; post hoc comparisons using the Tukey HSD test indicated significant different mean scores for Group 1 ($M = 24.63$, $SD = 4.78$) and Group 4 ($M = 21.77$, $SD = 5.30$). There was a statistically significant difference in the scores for the "Total Parenting" dependent variable for the groups: $F(3, 118) = 4.36$, $p < 0.01$ with a moderate effect size of 0.09 and significantly different post hoc comparison mean scores for Group 1 ($M = 24.56$, $SD = 3.6$) from Group 4 ($M = 21.48$, $SD = 4.98$). There was a statistically significant difference on the scores for the dependent variable "Total Emotional Well-being" for the groups: $F(3, 118) = 4.19$, $p < 0.01$ with a moderate effect size of 0.09 and significantly different post hoc comparison mean scores for Group 1 ($M = 14.70$, $SD = 3.63$) from Group 4 ($M = 12.32$, $SD = 3.57$). There was a statistically significant difference in the dependent variable "Total Disability-Related Support" for the groups: $F(3, 118) = 6.93$, $p < 0.01$ with a large effect size of 0.15 and significantly different post hoc comparison mean scores for Group 1 ($M = 17.11$, $SD = 2.07$) from Group 4 ($M = 14.55$, $SD = 3.40$). There was a statistically significant difference in the scores for the dependent variable "Total Physical/Material Well-being" for the groups: $F(3, 118) = 6.11$, $p < 0.01$ with a large effect size of 0.13 and significantly different post hoc comparison mean scores for Group 1 ($M = 17.12$, $SD = 2.50$) from Group 2 ($M = 14.44$, $SD = 1.42$) and Group 4 ($M = 15.22$, $SD = 3.19$). Group 3 ($M = 17.21$, $SD = 2.07$) did not differ significantly from any other groups. For all other variable comparisons conducted above, Group 2 and Group 3 did not differ significantly from any other groups.

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TABLE 4 Comparing services and supports

What best describes the services and supports you receive for your child's needs ($N = 50$)	Frequency	Percent
I get more services now than ECIS	14	28
I get less services now than ECIS	31	62
Other	5	10
Total	50	100
Service provision: Are you able to afford services and supports for your CWD (child with disability)?	**Frequency**	**Percent**
Yes, fully	4	8
To some extent but that's OK	22	44
To some extent but that's not OK	21	42
No, I am unable to	3	6
Total	50	100

Comparing the results from the demographic questionnaire, nearly 62% of the participants reported that they received fewer services at school, as compared to when their child was in ECIS, while 14% said that they received more. For data comparing services and supports please refer to Table 4.

Qualitative comparisons

The qualitative findings complemented and illuminated the quantitative results. Contrary to parents of school-aged children, parents within ECIS reported better FQOL and used words such as "okay" and "different" to describe their FQOL compared to school-aged parents who used words such as "limited," dreadful," "terrible," and "challenging." Parents of school-aged children reminisced about the early years as being raw and hard. The new diagnosis and the grief attached to the diagnosis were hard and they remembered it as being a most difficult time. The parents in ECIS confirmed the time of diagnosis as being hard and the unknown journey ahead was described as stressful and devastating, impacting their FQOL in a negative way. However, both groups of parents said that despite the hard times and challenges, their overall FQOL was good, or "reasonable," and that there were many positives that helped their FQOL.

Parents in the ECIS group expressed that their inherent values about being a parent, and doing the parent role well, helped them feel good about their FQOL. They used *normalization* (that their life in the early years is similar to a family with a typically developing child) and *stability* (that their child will continue to progress and develop skills into the future) to stay positive, and this helped their FQOL.

In contrast, parents in the school-aged group did not talk about *normalization* and did not compare their lives to parents of children without disability. They acknowledged and accepted the disability as being long term and tried to find positives in the transformation of their role as a parent of a child with disability, within their family, and within their community. They also accepted the fact that their life was different to others who did not have a child with disability. Many of them reported that they felt courageous and stronger and were able to advocate for their child with disability better. Some of the parents moved toward helping and nurturing other parents, and some also took up roles of educating the community (advocates). This transformation and acceptance helped their FQOL.

Comparing parent occupations between groups

For this category only qualitative data were compared between the groups due to lack of a rigorous tool to measure parent occupations.

Caregiving (committed occupation) was an accepted yet most time-consuming parent occupation in both groups. Parents in the ECIS group were not expecting the caregiving to be long term. Behaviors of concern/challenging behaviors and high medical support needs were recognized as having the most impact on caregivers' time in both groups. The impact of caregiving was apparent on the physical health and well-being (necessary occupation) of parents in both groups. Parents within ECIS said they felt that they would be able to find time for their own health needs in the future; however, according to parents of school-aged children this did not happen, and they continued to neglect their own needs and were exhausted and unwell. Many parents had been diagnosed with chronic health conditions since the early years including breast cancer, cardiovascular problems, depression, chronic back pain, and high levels of stress that were left untreated due to lack of time or finances. Parents in both groups were unable to spend time in leisure activities or pursue their hobbies (free-time occupations).

In terms of contracted occupations, both groups of parents were unable to return to work in the same capacity as before having a child with disability. Parents in the early years were expecting to return to work when their child went to school. However, the parents of school-aged children confirmed that they were unable to return to full-time work even though some of their children were almost

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reaching adulthood. Most of the parents missed their jobs and careers. Some of the fathers reported that they were not able to pursue career choices because of the caregiving needs at home. However, most of the parents had accepted that they would not be able to work in a full-time capacity or would not be career people again. Both groups reported that the loss of income impacted their financial well-being and increased their financial burdens.

Comparing services and supports between groups

An ANOVA was conducted to explore the differences in services and supports between the groups. There was a statistically significant difference in the BC-FQOLS scores for the item "the relationship they had with their service providers" for the groups: $F(3,118) = 7.07$, $p < 0.01$ (large effect size of 0.15) and significantly different post hoc comparison mean scores for Group 1 ($M = 4.46$, $SD = 0.59$) from Group 3 ($M = 3.89$, $SD = 0.99$) and Group 4 ($M = 3.81$, $SD = 0.91$).

Qualitative findings

Parents in both groups reported that services and supports helped their FQOL. However, most parents of school-aged children missed the ECIS support, the coordinated care of services, and the funding. Some parents also said that inclusion of their child in mainstream schools was difficult, and they missed the inclusive settings from the early days.

In contrast to parents of school-aged children, early childhood parents did not expect services such as ECIS to look after their family needs and were more focused on child-specific outcomes. Funding for services, particularly therapy needs, was more important to them than family outcomes or their own needs. They did not seek respite care or support groups. As opposed to parents within ECIS, parents of school-aged children used more respite care and parent support groups and found these two supports helpful. On looking back, they said that they were child-focused because it was difficult for them to see the future, and they just wanted their child with disability to progress to the best of his or her ability, so they put all their efforts into therapy. However, on reflection, most of the parents of school-aged children emphasized the importance for long-term well-being of parents looking after their own needs during the early years.

Both groups valued respectful and trusting workers and preferred consistency in the workers (therapist, keyworkers, or respite care workers) who were involved in caregiving for their child with disability. Please refer to Table 5 for detailed qualitative comparisons.

DISCUSSION

This study concludes that perceived FQOL declines as parents age and children get older. We say this firstly due to the quantitative scores that clearly indicate that FQOL was significantly lower in the school-aged group. But more importantly our qualitative findings tell us that many parents in the preschool (ECIS) group reported about their FQOL using terms consistent with positive psychology such as "normalization" and "stability" and these hopeful beliefs, helped them feel good about their FQOL versus the school-aged group who reported more challenges.

However, it was harder for the school-aged group because they were concerned about their child's future as an adult, they were run down due to prolonged caregiving, and they were unsure about what would happen to their child when they die. Yet many of the school-aged group parents coped by feeling positive about the transformation of their role as a parent of a child with disability, and started to see the positives in their life, were hopeful, and drew on their faith and beliefs for experiencing a sense of positive FQOL. Some even became strong advocates for disability. Jess et al. (2017) reported similarly that despite the elevated levels of stress and depression reported by mothers of children with intellectual disability, they also experienced a sense of positive well-being that helped with their satisfaction of life and family. Studies on positive psychology affirm that specific positive strategies such as positive coping, belief systems, values, and faith help FQOL (Brown et al., 2016; Chiu et al., 2013; Seligman & Csikszentmihalyi, 2000).

Qualitative findings also showed us that engaging in free-time and leisure occupations with family members and family relationships were important for parents and helped their FQOL even if they had lost their careers and had financial struggles. These findings are consistent with the literature across countries. In an Australian study that included 42 caregivers, family relationships were reported as having high importance (Rillotta et al., 2012). In a Slovenian study, 20 parents of school-aged children with disability reported that family relationships contributed most to their FQOL (Čagran et al., 2011). Previous studies by Caples and Sweeney (2010) and Clark et al. (2012) have also reported that loss of work or wages is not associated with a positive FQOL even if it impacts on financial well-being for a family. It is possible that caregivers feel committed to caregiving as a priority over their career roles. Necessary occupations such as sleep, health, and self-care were impacted for most parents across the

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TABLE 5 Comparative analysis of qualitative Studies 1 and 2

Comparisons Final categories	Study 1	Study 2	Analyses
Comparing family quality of life (FQOL) between groups	Code 1: My family quality of life is okay... different, reasonable, however is **hard** and difficult at times. It is **constant adaptation, ups and downs**	Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating	Code 1: Our FQOL is **hard**, limited, dreadful, terrible, challenging, difficult, **fluctuating, adjusting**, however there are positives about having a CWD
			2.1 Family time is important for FQOL
			Theme 2.1: Comparing ECIS and now... about FQOL then and now ... It was harder in the early years, but it is still challenging, stressful and difficult
	Both groups reported that they were making constant adjustments.		
	In ECIS, families reported that their FQOL was more reasonable than in school-aged parents.		
	Spending time together with family was important to parents of school-aged children but parents in ECIS did not seem to feel that this was important for their FQOL as they were too busy adapting to their parenting roles.		
	Both groups looked at the positives of having a CWD and this helped their FQOL.		
	The parents of school-aged children reminisced about the early years as being raw and hard and that later they adapt to the needs of their CWD and it gets slightly easier to manage the disability despite the grief.		
		Code 1: Early years are raw and hard but now families have adapted to living with disability, so it is easier than before.	
		6.5: Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being	The parents in ECIS confirmed that the time of diagnosis and the unknown journey ahead was stressful and devastating

(Continues)

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TABLE 5 (Continued)

	Beliefs and values	Beliefs and values	
	Code 4: Early years are similar to having a typically developing child	Code 1: There are positives about having a CWD	Difference in thinking that helps FQOL. In early years *normalization* (that their life is similar to a typically developing child) and *stability* (that their child will continue to progress and develop skills into the future) helps FQOL. Parents try to stay positive and use their belief systems, values of being a parent, and faith to help their FQOL
	Code 8: Progress and development of child is energizing and uplifts parents and helps FQOL		
	Code 12: Positive attitudes, beliefs, religion, faith, and family values help families		In later years, parents acknowledge and accept the disability as long-term and find positives in the transformation of their role as a parent of a CWD within their family and in their community
		Theme 2.2: Caregiving, then and now...did not expect caregiving to be long-term in the early years	
Comparing parent occupations between groups	Caregiving: Committed occupation	Caregiving: Committed Occupation	Caregiving was an important parent occupation in both groups due to their commitment to their CWD
	Code 14: Severity of disability **especially challenging behaviors impact FQOL**	3.1: **Behaviors of concern** of a CWD add to the challenges of caregiving and impact siblings	Parents in the ECIS group were not expecting the caregiving to be long term. Both groups reported that behaviors of concern/challenging behaviors and children with high support needs required high amounts of time in caregiving
	Physical well-being: Necessary occupation	Physical well-being: Necessary occupation	Both groups reported that caregiving impacts parental physical well-being. ECIS families reported that they would be able to find time for their own needs in the future; however, according to parents of school-aged children this does not happen. They continued to neglect their own needs and were exhausted and unwell. Parents of school-aged children commented on their poor health and neglecting their health care due to caregiving

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TABLE 5 (Continued)

	Code 3: Physical well-being of parent/ caregiver is not a priority, due to the child's needs and financial responsibility	3.1: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being	Many parents in both groups had been diagnosed with chronic health conditions since the early years that were left untreated. Some conditions included breast cancer, cardiovascular problems, depression, chronic back pain, and high levels of stress that were left untreated due to lack of time or finances.
	Return to work: Contracted occupation	Return to work: Contracted occupation	Both groups of parents were unable to return to work in the same capacity as before having a CWD. Parents in ECIS were adapting and accepting their role of becoming a parent. They were not concerned about returning to work. They were expecting to return to work in the future when their child went to school. However, the school-aged parents confirmed that they were unable to return to full-time work even now. Both groups reported that loss of income impacted their financial well-being and increased their financial burdens. Parents in ECIS said that they felt privileged that they were able to care for their child and did not have to return to work and this attitude helped their FQOL. Parents of school-aged children said that they had become advocates and researchers for disability and were happy with this change of occupation and this helped their FQOL.
	Code 5: Ownership and adoption of parenting role comes about after having a child	3.1: **Caregiving for a CWD impacts parent occupations.** Parents are unable to return to paid work, with lack of time for self-care, or meaningful occupations	
	Code 6: Adaptations are made/**previous parent occupations change**	Code 4: Having a CWD impacts financial/ material well-being due to extra costs and reduced income	
	Code 3: Physical well-being of parent/ caregiver is not a priority, due to the child's needs and financial responsibility	6.6: Parents become advocates for their CWD and for other families	

(Continues)

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TABLE 5 (Continued)

Comparing disability-related supports between groups	Code 10: Support from services is important and valued	Code 5: Services and supports are valued and help FQOL	Both groups reported that services and supports helped their FQOL. However, parents of school-aged children missed the ECIS support, the coordinated care of services, and the funding. They also said that inclusion of their child into mainstream schools was difficult and they missed the inclusive settings from the early days.
	Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL	5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours	
	Code 9: **Support from partner**, family, and friends varies but is valued; **however, reluctant to ask for support**	5.2: Respite care is valuable because it provides parents with time away from caregiving and the CWD enjoys the time in respite too	Families in ECIS were more focused on child-specific outcomes and funding for services, particularly therapy needs, was important to them rather than family outcomes or their own needs. They did not seek respite care or support groups.
		5.3: Help is available from family and some others, and is valued, but **parents reluctant to ask for help** due to increasing caregiving needs as the CWD gets older. **Partners and spouses are the main support.**	Parents of school-aged children mentioned the importance of self-care and parent well-being in early years and that they were child-focused because it was difficult for them to see the future.
		5.4: Support groups are valued because they provide information, research, and friendships	
		Code 6: Families miss the ECIS family-centered support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD	Both groups said that they were reluctant to ask for support from extended families and friends. Both groups reported that their main support was from their spouse.
		6.1: Parents miss the ECIS services and family interaction	Both groups valued respectful and trusting workers and preferred consistency in the workers (therapist, keyworkers, or respite care workers) who were involved in caregiving for their CWD.

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TABLE 5 (Continued)

		6.2: Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful	Families of school-aged children found the supports from special school, respite care, and parent groups helpful.
		6.3: Inclusion of CWD into mainstream schools is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support	
	Future caregiving worries	Future caregiving worries	Future caregiving worries
	Code 11: Support after exiting ECIS is scarce	3.5: Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving and fear that siblings will resent or reject the CWD in the future	Parents in ECIS were worried about transition to school and concerned that there would be lack of funding and resources for their CWD. Most parents were expecting their child to attend mainstream school with a few exceptions being families who had previous experience of having a CWD in a mainstream school. Lack of support and funding at mainstream school limited their choice and they wanted to choose special schools over mainstream schools due to better supports and services.
			Families of school-aged CWD confirmed that lack of support at mainstream schools was the main reason they chose special schools. Many parents had unpleasant experiences of mainstream schools and the lack of resources to manage their child's needs.
			The main worry for parents of school-aged children was related to future supports and residential care for their child. They were also worried about siblings having to bear the burden of care and this led to a fear of resentment by siblings.

Note: Parent perspectives of FQOL = Orange; Support to FQOL = Green; Parent occupations = Red; Challenges to FQOL = Purple; Consequences of having a CWD = Brown.

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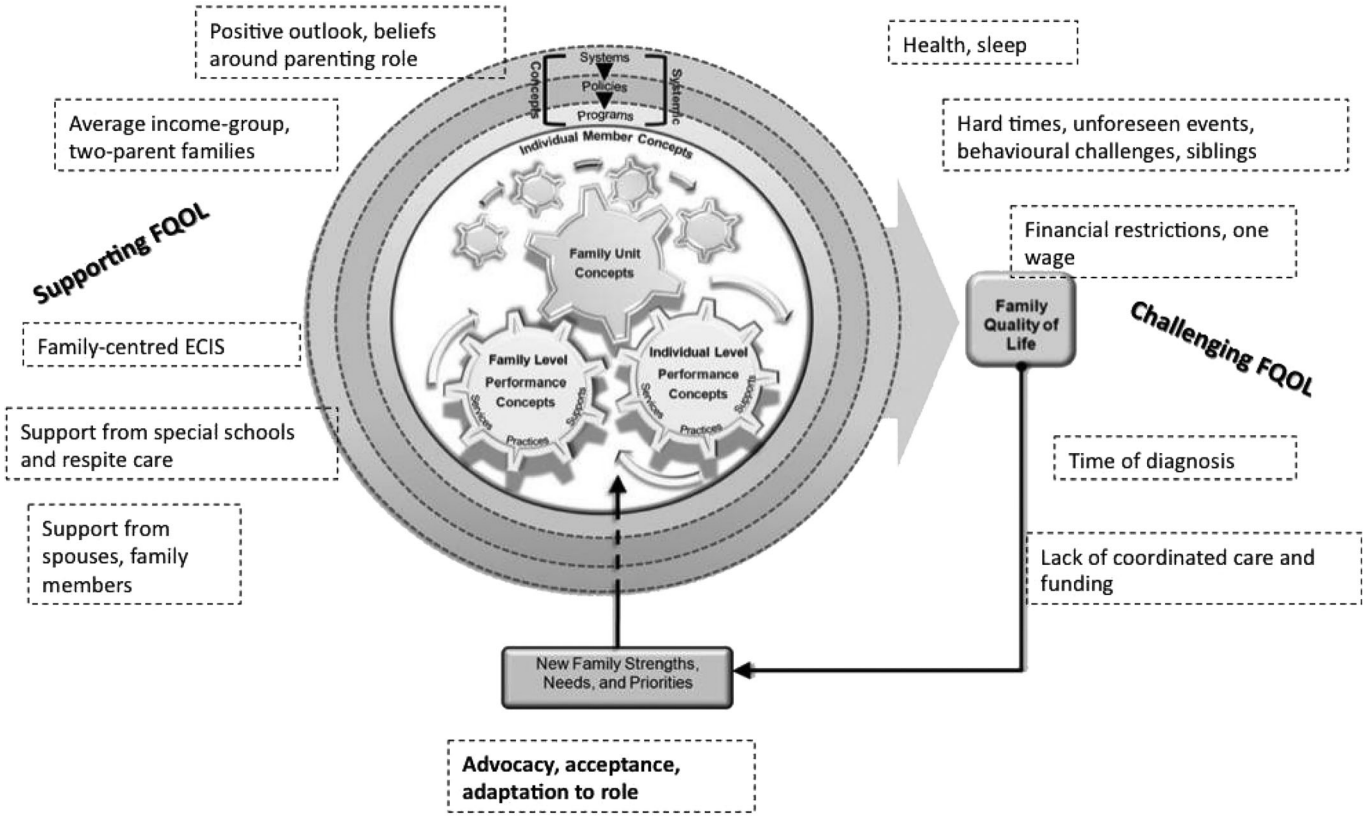

FIGURE 3 Unified theory of family quality of life (FQOL)—application to this study. *Source*: Zuna et al. (2010), p. 268

groups. This is consistent with past studies, where interrupted sleep and lack of time for self-care due to high day- and night-time care responsibilities led to poor maternal health (Bourke-Taylor et al., 2013).

In terms of disability-related support, the results indicated that parents of children in ECIS felt more satisfied with their service providers and felt better supported as compared to the school-aged group with transitions to school recognized as the most difficult period. Crotty's report on transitions from childhood to adulthood for people with intellectual disabilities also concluded that the transition period for family carers is fraught with isolation, confusion, disruption, and stress in terms of their aspirations, needs, supports, and services (Crotty, 2016).

To conclude the discussion, the findings from both studies link with the unified theory of FQOL (Zuna et al., 2010). Consistent with this theory, findings in both the completed studies, highlighted that supports and services were important mediating and moderating factors that impacted the FQOL of both groups. In Study 1, parents felt supported by their ECIS, their partners, and their extended families, and in Study 2, parents felt supported by their partners, special schools, friends, and respite care services, and this had a positive impact on their FQOL (Table 5).

According to Zuna et al. (2010) systems, policies, and programs indirectly impact individual- and family-level supports, services, and practices, while individual demographics, characteristics, and beliefs, and family-unit dynamics, are direct predictors of FQOL. In terms of individual demographics, the majority of families in both studies were from an average income group, married, and English speaking, and these demographics were important determinants of FQOL. Characteristics and beliefs included feeling positive about having a child with disability, and most mothers believed that parenting their child was their main role. This belief helped them to accept the caregiving role and had a positive influence on their FQOL.

The unified theory also suggests that program quality predicts implementation of best practice, which in turn impacts individual factors and in turn FQOL. In terms of program quality having an influence on FQOL, most participants in Study 1 experienced high-quality family-centered ECIS programs that are considered best practice, and this could have influenced the high scores on their FQOL. In terms of participants in Study 2, the majority were well-supported in special schools and had access to some respite care, so this could have influenced the high scores on their FQOL in concurrence with the theory of FQOL.

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The theory of FQOL also states that if one of the system factors changes, it disrupts the smooth running of the cogs leading to changes in FQOL until adaptation or homeostasis occurs within the individual or family (Zuna et al., 2010). The findings from the qualitative studies showed that many families went through hard times such as transitions or marriage separation, and these were a setback for them. However, they bounced back and used positive adaptation to continue with their everyday lives and experienced fluctuating FQOL.

Lastly, the unified theory of FQOL emphasizes that singly or combined, the predictors result in a FQOL outcome that produces new family strengths, needs, and priorities that re-enter the model as new input, resulting in a continuous feedback loop throughout the life course (Zuna et al., 2010). These new strengths were seen in both groups of families in the qualitative studies. Parents of preschool children reported how they were adapting to the parent role, and parents of school-aged children reported on how they had adapted their occupations to become advocates and researchers, and these new strengths helped their FQOL. The relationships of the findings from this research to the unified theory model of FQOL are depicted in Figure 3, where the dotted text boxes contain findings from this research.

Limitations

Due to uneven numbers between Study 1 ($N = 72$) and Study 2 ($N = 50$), the total participants from the two studies ($N = 122$) were divided into four groups to allow for matched comparisons. Bootstrapping was also conducted to allow for estimation of the sampling distribution and to ascertain that the sample distribution was a good approximation to the population distribution (Ong, 2014). This still allowed us to answer our question about comparing preschool and school-aged groups. Another limitation was the BC-FQOLS does not reflect parent occupations so we had to incorporate this via interviews and qualitative data. Future studies may consider using the international FQOL scale (Brown et al., 2006) because it comprises life participation domains like careers, leisure, and community participation, that reflect these important occupations.

RECOMMENDATIONS FOR PRACTICE, POLICY, AND RESEARCH

Practice

Measuring family outcomes such as FQOL on a regular basis is strongly recommended, as FQOL changes based on circumstances and events. Practitioners and service providers need to take responsibility for providing information around the caregiver's health and well-being, rather than just provide home-based programs that are targeted toward child-focused outcomes. Service providers need to help parents in advocating for better supports and resources at mainstream schools to enable better inclusion and participation, thereby working toward a just and equitable society for people with disability. Access to respite care needs to be urgently reviewed and parents/caregivers need to be able to access respite care for a better FQOL. Sufficient public and private funding for such services is recommended.

Policy

Policy makers responsible for service evaluation need to consider family-focused outcomes such as FQOL, caregiver health, and caregiver capacity building, alongside child-focused goals. Within Australia, the National Disability Insurance Scheme (NDIS) was established to provide services and supports to people with disability nationwide (NDIS, 2013, 2016). The results from this research strongly recommend that the NDIS promote service providers to consider goals for not only the client with disability but also their family members to ensure better FQOL outcomes.

Research

Conducting more comparative and longitudinal studies would extend this research further and add to the understanding of positive coping and how families continue to stay positive despite having a child with disability. Studies into the relationships of respite care, interim residential care, and FQOL are few and conducting larger studies in this area will guide future service provision for families.

CONCLUSIONS

This research adds new knowledge to FQOL studies and presents consequences of having a child with disability on parent occupations and its relationship with FQOL. It concludes that the loss of previous parent occupations has an impact on financial stability and caregiver health, and this impact increases as the child gets older. There is a strong relationship between supports and FQOL with the provision of quality supports having a positive influence on FQOL. In the ECIS group, supports such as family-centered care, supports provided within a variety of natural environments for the child (in ECIS), and

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access to funding for therapy contributed to a better FQOL. In the school-aged group, provision of respite care, support from special school, and parent support groups was related to a good sense of FQOL. Beliefs, hopes, and values contributed to positive coping in both groups and these attributes helped their overall FQOL. This research concludes that even though families feel satisfaction with their FQOL, the hardships and challenges of caregiving increase as the child gets older.

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ETHICS STATEMENT

Ethics committee(s) approval was sought for the proceeding study from Monash University Human Research and Ethics Committee and the Ethics Committee of the Department of Education and Early Childhood Education.

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