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Caregiver and family quality of life for children with fetal alcohol spectrum disorder

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ABSTRACT

Background: Fetal alcohol spectrum disorder (FASD) is a common neurodevelopmental condition. Given that individuals with FASD can experience lifelong challenges, one field of research that could be applicable is the paediatric chronic health literature.
Aims: The aim of the current study was to investigate the utility of the Pediatric Quality of Life Inventory (PedsQL) Family Impact Module, designed to measure the impact of paediatric chronic health conditions on caregivers and families.
Methods and procedures: 109 caregivers of children with FASD completed an online survey that assessed a range of areas including, caregiver and family quality of life, caregiver mental health and child behaviour.
Outcomes and results: Overall, caregivers reported the areas most impacted on the PedsQL module were Family Daily Activities and Worry. Caregiver's country of residence, mental health, child gender, and level of child behaviour problems were found to be predictors of caregiver and family quality of life.
Conclusions and implications: The results demonstrate that there are multidimensional challenges for caregivers and families. These findings have important implications for policy and practice regarding the provision of supports and services for children with FASD and their families.

What this paper adds

The current study provides increased understanding regarding caregiver and family quality of life, in families with children with fetal alcohol spectrum disorder (FASD). This information was gathered using the Pediatric Quality of Life Inventory (PedsQL) Family Impact Module, which has been previously used to assess the impact of a range of childhood chronic conditions. The results from the current study demonstrate the potential applicability of a paediatric chronic health approach to considering the impact of FASD on caregiver and family functioning. Furthermore, the current study identified the need for interventions to address caregiver mental health in order to optimise child outcomes.

1. Introduction

Fetal alcohol spectrum disorder (FASD) is a neurodevelopmental condition associated with prenatal alcohol exposure. Individuals

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with FASD can experience a range of neurocognitive impacts, including, but not limited to impairments in executive function, learning and memory, general cognitive abilities, speech and language and adaptive and social skills (Lange, Rovet, Rehm, & Popova, 2017). There is growing literature regarding the experiences of caregivers and families in supporting individuals with FASD. Domeij et al. (2018) recently conducted a systematic review and synthesis of all the qualitative studies that explored experiences of individuals living with FASD or those caring for a child with FASD. They identified 18 studies, most of which reported on caregivers' experiences of looking after a child with FASD. From the studies identified, it was evident that individuals and families faced many challenges, for which they were requiring support, including feeling isolated and burdened.

Previous research (e.g., Bobbitt et al., 2016; Olson, Oti, Gelo, & Beck, 2009; Paley, O'Connor, Frankel, & Marquardt, 2006) has documented that caregivers of children with FASD experience increased levels of stress. This also includes a study conducted by Watson, Coons, and Hayes (2013) that compared parents of children with autism spectrum disorder (ASD) to parents of children with FASD. ASD is known to be a stressful disability for parents (e.g., Estes et al., 2009). Watson et al. (2013) found that parents of children with FASD reported significantly more overall stress compared to parents of children with ASD. Other studies (e.g., Bobbitt et al., 2016; Morrissette, 2001) have focused on documenting the needs of caregivers of children with FASD. The magnitude of the challenges and unmet needs reported by caregivers suggests that caregiver and family quality of life may be impacted.

Numerous studies to date have documented the importance of the family environment for improving outcomes for children with FASD. A seminal study conducted by Streissguth et al. (2004) found that the amount of time spent in a stable home environment was the most influential protective factor to reducing secondary disabilities (e.g., involvement with the criminal justice system, mental health problems or alcohol and drug dependence) for children with FASD. Additionally, Jacobson, Jacobson, Sokol, Chiodo, and Corobana (2004) found that a more positive home environment was associated with less severe cognitive outcomes in a large longitudinal study of 7.5-year-olds exposed prenatally to alcohol. Therefore, factors related to positive family adaptation are key to developing effective family-based interventions for children and young people with FASD.

Given that individuals with FASD can experience lifelong challenges, one field of research that could be applicable is the paediatric chronic health literature. In paediatric chronic health, the impact of the disease and the treatment on caregiver and family functioning is a significant consideration, given the essential role of the family in child adaptation to the health condition (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). A risk and resistance model proposed by Wallander and Varni (1998) conceptualises chronic health conditions as "an ongoing strain" for both children and caregivers. Chronic strains are defined as "persistent objective conditions that require continual readjustment, repeatedly interfering with the adequate performance of ordinary role-related activities" (p. 31). An important part of the model is that risk and resistance factors are modifiable and can be identified and utilised to inform the development of interventions for children with chronic conditions. For example, previously identified risk factors include: diagnosis type, impairment severity, daily living abilities and psychosocial stressors. Resistance factors in the model include: intrapersonal factors (e.g. temperament, competence); social ecological factors (e.g. family environment, social support, family adaptation); and stress processing factors (e.g. coping strategies) (Wallander & Varni, 1998). This approach may be pertinent for caregivers and families of children with FASD. Therefore, the aim of the current study was to investigate social-ecological factors utilising the Inventory PedsQL Family Impact Module (Varni et al., 2004).

2. Method

2.1. Participants and procedure

Participants consisted of 109 caregivers of children with FASD. The majority of the participants were adoptive (56%) or foster parents (26%) and the remainder were grandparents (7%); biological parents (7%); aunt/uncles (4%); or stepparents (1%). Participants completed the survey from Australia (33%); U.S (31%); New Zealand (16%); Canada (13%); U.K (3%); and South Africa (2%). See Table 1 for additional participant demographics. Caregivers were recruited online through FASD-related organisations. The organisations were contacted via email and provided with a flyer regarding the research study, which was distributed on their websites, via social media, and/or their newsletters. Caregivers were invited to participate if they had a child who had received an FASD diagnosis. Study data were collected from May 2018 until September 2018 and managed using REDCap electronic data capture tools hosted at The University of Queensland (Harris et al., 2009). The study was approved by the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee.

2.2. Measures

2.2.1. Demographic

Demographic data included caregiver and child age and gender, country of residence, comorbid conditions, caregiver status, number of care placements and number of traumatic events the child had experienced. Caregivers were asked to provide their child's FASD diagnosis, multiple choice options were provided that covered each of the diagnostic criteria that are available worldwide. An "unsure" option was also provided. Caregivers were also asked to provide the clinic and the doctor's name who diagnosed their child.

2.2.2. Pediatric quality of life (PedsQL) family impact module (Varni et al., 2004)

The PedsQL Family Impact Module is a 36-item measure that includes six scales measuring caregiver reported functioning: Physical Functioning, Emotional Functioning, Social Functioning, Cognitive Functioning, Communication and Worry and two scales measuring caregiver reported family functioning: Daily Activities and Family Relationships. A 5-point scale is used (0 = never a problem

Table 1
Participant demographics.

Variable	*N*	
Child age (yrs), Median, (Range)	109	11 (0 -18)
Birth to 5 years (%)		7 (6%)
6-12 years (%)		55 (50%)
13-18 years (%)		47 (43%)
Child gender (%)	109	
Male		65(60%)
Female		44(40%)
Child age at FASD diagnosis, Median (Range)	108	7 (0 – 17)
Birth to 5 years (%)		39 (36%)
6-12 years (%)		55 (51%)
13-17 years (%)		14 (13%)
FASD diagnosis*	109	
FASD with physical features		62 (57%)
FASD without physical features		47 (43%)
Number of comorbid conditions, Median (Range)	108	3, (0-9)
Number of care placements, Median (Range)	100	1 (0-12)
Number of traumatic events, Median (Range)	109	2 (0-8)
Strengths and Difficulties Questionnaire, Mean (*SD*), Range	102	23.93 (6), 8 – 39
Primary caregiver age, Median (Range)	105	50 (26-71)
Primary caregiver gender, Frequency (%)	108	
Male		5 (5%)
Female		102 (94%)
Non-binary		1 (1%)
Primary caregiver schooling, Frequency (%)	107	
Did not complete high school		31 (26%)
Completed high school		76 (71%)
Primary caregiver highest qualification, Frequency (%)	106	
Post-school skills or technical training		56 (53%)
University		50 (47%)
Primary caregiver currently in paid work, Frequency (%)	109	
Yes		57(52%)
No		52(48%)
Primary caregiver marital status, Frequency (%)	109	
Married/de facto		73 (67%)
Single/divorced		36 (33%)
Number of people in the household, Median (Range)	106	4 (2-11)
Depression Anxiety Stress Scale Total Score, Median (Range)	100	25 (0 – 106)

Note. FASD = fetal alcohol spectrum disorder; SD = standard deviation. *FASD with the physical features included children diagnosed with: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) or FASD with the 3 sentinel facial features. FASD without the physical features included children diagnosed with: Neurobehavioral Disorder, Static Encephalopathy or FASD without the 3 sentinel facial features.

to 4 = always a problem). Items are reverse scored and linearly transformed to a 0–100 scale (i.e. 0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0), so that higher scores indicate better functioning. The PedsQL Total Score is the sum of all 36 items divided by the number of items answered. The Parent Health Related Quality of Life (HRQOL) Summary Score (20 items) is the sum of the items divided by number of the items answered in the Physical, Emotional, Social and Cognitive Functioning Scales. The Family Functioning Summary Score (8 items) is the sum of the items divided by the number of items answered in the Daily Activities and Family Relationships Scales. Note, for the current study, based on feedback from a pilot study of 13 participants, the wording of the questions was changed (e.g. original wording "In the past ONE month, as a result of your child's health, how much of a problem have you had with…" current study wording "In the past ONE month, as a result of your child's FASD, how much of a problem have you had with…" The internal consistencies for the current sample were high, α = .96, 0.94, .93 for the PedsQL Total Score, Parent HRQOL Summary Score, and the Family Functioning Summary Score respectively.

2.2.3. The depression, anxiety and stress scale – short form (DASS-21 Lovibond & Lovibond, 1995)

The DASS-21 is a 21 item self-report measure where participants rate the extent to which each question applied to them over the past week on a 4-point scale ranging from 0 (did not apply to me at all) to 3 (applied to me very much or most of the time). The DASS-21 Total score is provided in the current study, which is the sum of each of the seven item scales (i.e. Depression, Anxiety and Stress). The internal consistency for the current sample was high, α = .94.

2.2.4. The strengths and difficulties questionnaire (SDQ; Goodman & Goodman, 2009)

The SDQ; is a 25-item questionnaire used to screen for internalising and externalising problems in children and young people. The parent report SDQ is a widely used measure that has good predictive validity and convergence with DSM-IV criteria. For each question, caregivers report whether the listed behaviour was "not true", "somewhat true" or "certainly true" of their child. The SDQ

provides three subscales (peer problems, conduct problems and emotional problems) that are summed to provide a total score. Higher scores reflect more behavioural difficulties. The SDQ Total score was reported for the current study. The internal consistency for the current sample was acceptable, $\alpha = .73$.

2.3. Data analysis

Descriptive statistics were reported as means and standard deviations (*SD*) for normally distributed continuous data or medians and ranges for non-normally distributed data. Normality was assessed using a Shapiro-Wilk test. Categorical variables were presented as frequencies and percentages. Six caregivers reported they were unsure about their child's diagnosis and one caregiver did not respond to this question. These participants were removed, which resulted in a final sample of 109 caregivers for the current study. Differences between diagnostic groups were also explored, by first recoding the FASD diagnosis variable into two groups: FASD with the physical features (i.e., FAS, pFAS, FASD with the 3 sentinel facial features) and FASD without the physical features (i.e., Neurobehavioural Disorder, Static Encephalopathy and FASD without the 3 sentinel facial features). Given the majority of the PedsQL scales were non-normally distributed, group differences were tested using a Mann-Whitney *U* test

A multiple linear regression analysis was performed to explore the relationship between caregiver and family quality of life (PedsQL Total score) and several caregiver and child characteristics. All potential predictors that reached significance in the univariate model and $p < 0.2$ in the multivariate model were included in the final model. All variables listed in Table 1; country of residence (the four largest groups were considered i.e. Australia, New Zealand, U.S, and Canada); caregiver mental health (DASS-21 Total score); and child behaviour (SDQ Total score) were considered as potential predictors. All assumptions were tested and validated. Pearson correlation coefficients were calculated to assess the association between child, caregiver and quality of life outcomes. All analyses were performed using SPSS version 22 and *p*-values were two-tailed, with $p < 0.05$ considered statistically significant.

3. Results

Overall, caregivers reported the areas most impacted on the PedsQL Family Impact module were family Daily Activities (Median = 25; e.g., "family activities taking more time and effort"); and Worry (Median = 27.5; e.g., "I worry about my child's future"). Caregivers reported areas of relative strength in Cognitive Functioning (Median = 45; e.g. "It's hard for me to think quickly") and Physical Functioning (Median = 41.67; e.g. "I feel tired when I wake up in the morning"). See Fig. 1 for a summary of the PedsQL total and scale scores between the diagnostic groups. There were a number of significant differences between the two diagnostic groups, with caregivers of children with the physical features of FASD reporting better overall quality of life (PedsQl Total), Parent Health Related Quality of Life, Emotional Functioning, Cognitive Functioning, Communication, Worry, Overall Family Functioning and Family Relationships.

3.1. Multiple regression and correlation analysis

Table 2 provides the results of the multiple regression. The model significantly predicted caregiver and family quality of life $F(5,76) = 29.19$, $p = < .001$, adjusted $R^2 = .64$. Caregiver mental health (lower DASS-21 scores), caregivers not residing in the U.S, children being male, and child behaviour (lower SDQ scores), were found to be independent predictors of overall caregiver and

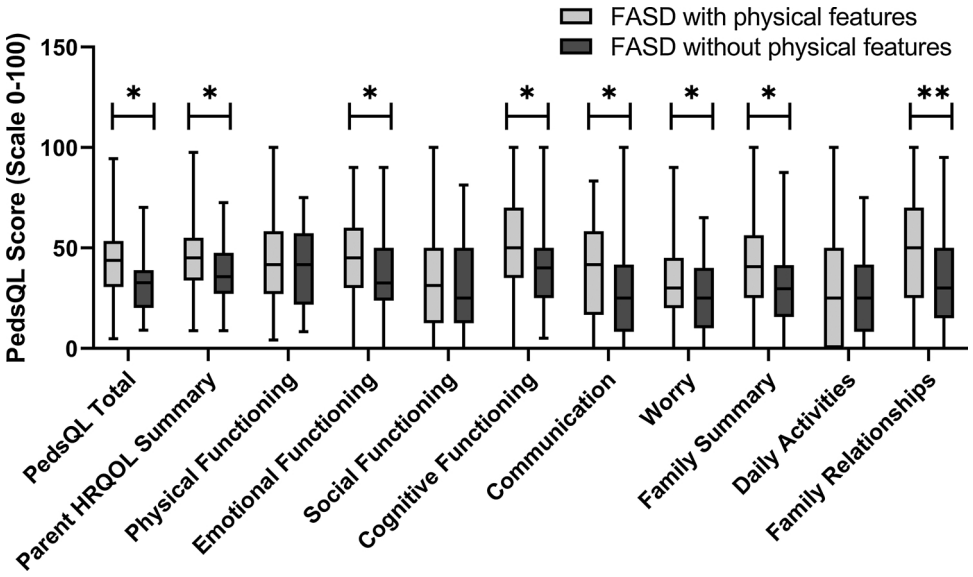

Fig. 1. Comparisons of caregiver and family quality of life between the two diagnostic groups.

Table 2
Standard errors, standardised coefficients, t-values, p values of the multiple regression model predicting caregiver and family quality of life.

	PedsQL Total Score			
	SE	β	*t*	*p*
Residing in the U.S	2.79	−.18	−2.60	0.01
DASS-21 Total	.06	−.63	−8.62	0.00
Child gender	2.55	−.15	−2.18	0.03
Number of comorbid conditions	.74	−.13	−1.58	.12
SDQ Total	.24	−.21	−2.68	0.01

family quality of life (PedsQL Total scores). Correlational analysis are displayed in Table 3. Notably, positive associations were found between caregiver mental health and child behaviour, number of comorbid conditions a child had been diagnosed with and the child's age at diagnosis.

4. Discussion

The aim of the current study was to investigate the utility of the PedsQL Family Impact Module for caregivers of children with FASD. The current study demonstrated that overall caregivers reported a range of areas of challenge and relative strengths for themselves and their families. Differences were found between the diagnostic groups, such that caregivers of children with the physical features of FASD reported better quality of life. Furthermore, the current study identified a number of predictors of caregiver and family quality of life, which included what country caregivers resided in, caregiver mental health, child gender and behaviour. Overall, the results from the current study demonstrate the potential applicability of a paediatric chronic health approach to considering the impact of FASD on caregiver and family functioning.

The PedsQL Family Impact Module has been used to assess the impact of a wide range of childhood chronic conditions (e.g., ASD, cerebral palsy, seizure disorder, down syndrome; Caicedo, 2014). Compared to a number of previous studies, including a non-clinical community sample (Medrano, Berlin, & Davies, 2013), children with attention deficit hyperactivity disorder (Limbers, Ripperger-Suhler, Boutton, Ransom, & Varni, 2011) and children with ASD (Nuske, Hedley, Tseng, Begeer, & Dissanayake, 2018) caregivers of children with FASD in the current study reported reduced levels of caregiver and family functioning (See Supplemental Data File 1 for detailed comparisons with previous studies). This is in line with a previous study undertaken by Watson et al. (2013), which found that parents of children with FASD reported increased levels of stress compared to parents of children with ASD. Additional pressure may be placed on caregivers of children with FASD due to a lack of societal knowledge regarding FASD, which requires caregivers to be their child's advocate across multiple settings (Olson et al., 2009). The results of the current study are also consistent with previous research that has documented high levels of stress, multiple areas of concern and needs for caregivers of children with FASD (e.g., Bobbitt et al., 2016; Chamberlain, Reid, Warner, Shelton, & Dawe, 2017; Domeij et al., 2018; Paley et al., 2006). Until families are provided with appropriate supports, successful adaptation to raising a child with FASD will be a challenging task for caregivers and families.

The current study found that caregivers of children with the physical features of FASD reported better quality of life. This may be due to children with the physical features being able to obtain access to additional supports, compared to children without the physical features of FASD. This is consistent with a previous study by Streissguth et al. (2004) who found that children with "fetal alcohol effects" had higher rates of adverse outcomes compared to those with FAS. The authors suggested that these differences may be due to individuals with FAS having increased access to developmental disability services. This finding highlights the importance of access to supports for all children, not just those with the physical features of FASD.

Of note the current study identified a number of factors that influenced caregiver and family quality of life. Interestingly, residing in the U.S was found to negatively influence quality of life. One possible explanatory factor is the differing health systems between

Table 3
Pearson correlations for all continuous variables.

	1	2	3	4	5	6	7	8	9	10
1 PedsQL Total		−.45**	−.15	−.05	−.31**	−.04	.06	−.01	.06	−.70**
2 SDQ Total			.10	.06	.28**	.14	−.08	−.01	.24*	.29**
3 Child age				.48**	.25*	−.01	−.01	−.06	.06	.08
4 Child age at diagnosis					.13	.11	.22*	−.10	.09	.20*
5 Number of comorbid conditions						.01	.22*	.19	−.06	.26*
6 Number of care placements							.32**	−.12	.12	.03
7 Number of traumatic events								.00	.11	.03
8 Number of people in the household									.01	−.04
9 Primary caregiver age										−.16
10 DASS-21 Total										

Note. ** Correlations significant at the 0.01 level *correlations significant at the 0.05 level.

the countries included in the current study. For example, Australia has the Medicare system, which provides free or reduced cost health care services, including mental health services for children and families. Additionally, child behaviour and caregiver mental health were identified as important contributors to caregiver and family wellbeing. Numerous previous interventions have focused on improving child behavioural outcomes for children with FASD (Reid et al., 2015), however limited research has focused on supporting and improving caregiver mental wellbeing. Previous research with other neurodevelopmental disabilities has documented that increased parental distress was related to reduced emotional availability in the parent-child relationship (Barfoot, Meredith, Ziviani, & Whittingham, 2017). This impacts on child development, as it is well documented that positive caregiver-child interactions contribute to optimal child development (e.g., Eshel, Daelmans, Mello, & Martines, 2006). Consequently, based on the findings from the current study, interventions that can support caregiver mental wellbeing are an important area of future research in the FASD field.

4.1. Limitations

Some limitations of the current study need to be taken into consideration. The sample was collected via an online survey that was circulated by FASD-related groups and participants self-selected to participate. Therefore, this may limit the generalisability of the results. Caregivers were required to self-report their child's FASD diagnosis, although there were questions in place to provide verification, this could impact the validity of the comparison between diagnostic groups. Lastly, only a small number of male and biological caregivers participated. Previous research has found differences between the experiences of foster or adoptive parents compared to biological parents. For example, Paley et al. (2006) found that biological parents reported higher levels of parent stress, which the authors suggested could be related to unresolved guilt or experiences of stigma. Future research, using a larger more diverse sample could address these limitations, including specifically investigating any potential differences that may be experienced between caregivers of different genders and biological compared non-biological caregivers to inform the development of future interventions.

4.2. Conclusions

Overall, to the author's knowledge this is the first study to apply the PedsQL Family Impact Module for children with FASD. The results demonstrate that there are multidimensional impacts on caregiver and family functioning. These findings have important implications for policy and practice regarding the provision of supports and services for caregivers and families. The health and wellbeing of caregivers and families are clinically important factors to ensure positive outcomes for children with FASD. Given the importance of the family environment to outcomes for children with FASD, having additional assessment tools that can provide understanding of caregiver and family experiences is beneficial and consequently clinical relevant. Future research is needed to investigate if the PedsQL Family Impact Module could be responsive to change following a family-level intervention. Overall, increased understanding of caregiver and family functioning will inform the development and implementation of effective family-level interventions.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.ridd.2019.103478.

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