



# Caregivers of Children with Fetal Alcohol Spectrum Disorder: Psychosocial Factors and Evidence for Self-compassion as a Potential Intervention Target

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## Abstract

**Objectives** Fetal alcohol spectrum disorder (FASD) is a common neurodevelopmental condition involving lifelong challenges for both children and their families. The aim of the current study was to explore experiences of caregivers of children, adolescents and young adults diagnosed with FASD. More specifically, we examined the relationship between shame, guilt, pride, self-compassion and caregiver psychological distress. It was hypothesised that shame, guilt, pride and self-compassion would be uniquely associated with caregiver psychological distress. We also examined differences between biological and non-biological caregivers on these variables. It was hypothesised that relative to non-biological caregivers, biological parents would (i) report significantly higher levels of psychological distress, guilt and shame and (ii) report significantly lower self-compassion scores.

**Methods** The current study included 175 caregivers of children and young people diagnosed with FASD. Caregivers completed an online survey that included a range of standardised self-report measures that assessed psychological distress, shame, guilt, pride and self-compassion.

**Results** Caregiver self-compassion was negatively correlated with psychological distress, shame and guilt, and positively correlated with pride. Hierarchical multiple regression controlling for significant caregiver demographics revealed that shame, pride, guilt and self-compassion accounted for 68.1% of the variance in caregiver psychological distress. Shame and self-compassion were both unique significant factors in the final model. Some preliminary differences between caregiver groups were also found; specifically, biological parents reported higher levels of guilt compared with non-biological caregivers.

**Conclusions** The current findings revealed shame, pride, guilt and self-compassion were associated with caregiver psychological distress. Self-compassion and shame were identified as unique contributors to caregiver psychological distress. Future longitudinal research is required to establish if these associations may be casual, which will provide a useful starting point for further investigation into the efficacy of interventions that target self-compassion for promoting better psychological outcomes in this population.

**Keywords** Fetal alcohol spectrum disorder · Parents · Caregivers · Psychological distress · Self-compassion · Shame · Guilt · Pride

Fetal alcohol spectrum disorder (FASD) is a term describing the range of developmental deviations that can result from prenatal alcohol exposure (Chudley et al. 2005). FASD is a

significant public health concern, which is poorly diagnosed, chronic and costly (Shelton et al. 2018). Recent estimates suggest that the global prevalence of FASD among children and youth in the general population is 7.7 per 1000 population (Lange et al. 2017). The extent of developmental deviation can be profound for affected individuals, and impairments can be experienced in a wide range of areas, including social, behavioural and cognitive functioning (Reid et al. 2015). Given the challenges faced by families with a child who has FASD, psychosocial and quality of life impacts have been reported for caregivers (Reid and Moritz 2019). Domeij et al. (2018) conducted a systematic review and synthesis of qualitative data, which explored experiences of individuals

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living with FASD or those living with a child diagnosed with FASD. From the studies identified, most individuals and families reported facing many challenges such as feeling isolated, burdened and different from others. Previous research has also documented elevated levels of stress and psychological distress in caregivers of children with FASD (Bobbitt et al. 2016; Mukherjee et al. 2013; Olson et al. 2009; Paley et al. 2006).

Furthermore, Watson et al. (2013) compared parents of children with autism spectrum disorder (ASD) with parents of children with FASD, as ASD is known to be a stressful disability for parents to manage (e.g. Estes et al. 2009). Watson et al. noted caregivers of children with FASD reported significantly more overall stress compared with caregivers of children with ASD. Past research has also found differences between the experiences of foster or adoptive parents and biological parents of a child with FASD. Specifically, Paley et al. (2006) reported foster and adoptive parents of children with FASD experienced higher levels of child-related parent stress (e.g. externalising and internalising behaviours or executive functioning impairment), compared with biological parents who reported higher levels of parent-related stress (e.g. family resources, parental status). The authors suggested that this may be due to foster parents being unprepared to cope with the extent of their child's difficulties, while biological parents' difficulties may be related to experiencing guilt related to their child's condition. Taken together, these studies demonstrate caregivers of children with FASD are at increased risk of experiencing psychosocial distress.

Although FASD is a prevalent developmental condition, it is still highly stigmatised. Concern has been raised about the negative effects faced by women when discussing the consumption of alcohol during pregnancy, particularly shame, blame and guilt (Bell et al. 2015). Shame and guilt are distinct, but overlapping "moral" emotions. Where shame involves negative judgements of the self and is commonly associated with destructive behaviours, guilt involves negative evaluations of one's behaviour. Thus, while guilt may be limited to a specific act or event, which violates one's moral standards, shame can be a more pervasive perception that the individual themselves is bad or wrong (Tangney et al. 2007). Of specific interest in the current study is the theme of personal responsibility and blame towards caregivers. Research shows that blame and shame negatively impact the self-perceptions of pregnant women using alcohol or other drugs (Bell et al. 2015; Poole 2008), suggesting that biological mothers' shame and guilt about causing their children's FASD are prevalent, persistent and continuous (Zabotka et al. 2017).

Previous research (Paley et al. 2006; Salmon 2008) has documented biological parents raising children with FASD report feelings of shame, guilt and blame, and mothers can be viewed with greater disdain and greater blame than mothers with a mental illness or substance use disorder (Corrigan et al. 2017). Additionally, the burden of shame may extend to non-

biological mothers, who report they have to explain that their child was adopted in order to avoid negative reactions of others (Bell et al. 2015; Whitehurst 2012). Parental shame, guilt and blame are major contributors to parental wellbeing, depression and anxiety (Mak and Kwok 2010; Neff and Faso 2015) and managing these self-conscious emotions is important for promoting psychosocial wellbeing in this group. One potential coping strategy to help lessen feelings of shame is self-compassion (Neff et al. 2005; Wong et al. 2016). Self-compassion can be broadly described as the recognition and desire to alleviate one's suffering with self-kindness and non-judgement, and has been shown to be associated with several positive outcomes (e.g. greater psychological health, reduced isolation, and improved wellbeing) (Neff 2003; Neff et al. 2008). A number of studies have suggested that self-compassion provides an internal coping resource for caregivers, lessening feelings of shame and self-criticism (Neff et al. 2005; Robinson et al. 2018; Wong et al. 2016). Research examining self-compassion and psychological distress in parents of children diagnosed with intellectual and developmental disabilities found greater self-compassion was associated with lower parental stress and mental health symptomatology (e.g. depression), and improved wellbeing (Neff and Faso 2015; Robinson et al. 2018).

Self-compassion may also support improved family functioning, which in turn can provide a more advantageous home environment for children with FASD. Psychogiou et al. (2016) explored self-compassion and parenting stress in caregivers diagnosed with depression. Findings highlighted that higher self-compassion was associated with lower child-directed criticism and distressed caregiver reactions, and greater compassionate responding to child behaviour (Psychogiou et al. 2016). Psychogiou et al. posited that parents with greater self-compassion might explain their children's behaviour as responses to external factors, rather than to innate character traits of their child. A recent study explored parental self-compassion in the context of parenting a child with ASD. Findings indicated that self-compassion predicted psychological wellbeing, lower distress and lower parenting stress (Torbet et al. 2019).

There is an increasing recognition of the importance of exploring positive perceptions and experiences of families of children with developmental disabilities (Hastings and Taunt 2002). Broadly speaking, positive outcomes include satisfaction in providing care, personal growth and development, achievement, pride and joy. Such experiences may contribute to wellbeing and resilience in caregivers by building enduring inter- and intrapersonal resources (Fredrickson 2001; Hastings and Taunt 2002). More specifically, positive experiences for caregivers can include pride in child development and achievements, purpose and fulfilment, and caregivers feeling capable or useful (Marschall et al. 1994; Rapanaro et al. 2008). For example, research exploring perceived benefits

experienced by caregivers of young adults with an intellectual disability found caregivers reported experiencing pride related to their child's efforts and achievements, independence, increased maturity and standing up for their child's rights (Broberg 2011; Rapanaro et al. 2008). Similarly, an Australian study exploring the experiences of grandparents of children with a disability reported positive outcomes such as pride in their family's ability to adjust and cope with the challenges of raising their child and overcoming societal stigma (Woodbridge et al. 2009). Additionally, Kayfitz et al. (2010) reported parents of children with ASD experienced more positive experiences when they reported lower levels of parenting stress. Current literature highlights that caregivers can experience a powerful and positive emotional journey when raising children with disabilities and these experiences may buffer against potential negative impacts to wellbeing (Kayfitz et al. 2010).

The aim of the current study was to explore experiences of caregivers of children, adolescents and young adults diagnosed with FASD. More specifically, we examined the relationship between shame, guilt, pride, self-compassion and caregiver psychological distress. It was hypothesised that after controlling for key demographic variables, shame, guilt, pride and self-compassion would be uniquely associated with caregiver psychological distress. We also examined differences between biological and non-biological caregivers on these variables. It was hypothesised that relative to non-biological caregivers, biological parents would (i) report significantly higher levels of psychological distress, guilt and shame and (ii) report significantly lower self-compassion scores.

## Method

### Participants

Participants were 175 caregivers of children, adolescents and young adults diagnosed with FASD, aged from 0 to 25 years ( $M = 12.03$ ;  $SD = 4.64$ ). The highest proportion of children were aged from 6 to 12 years ( $n = 83$ ; 48.3%), followed by 13–17 years ( $n = 54$ ; 31.4%); 18–25 years ( $n = 22$ ; 12.8%) and 0–5 years ( $n = 12$ ; 7%). Caregivers within the current study were defined as anyone who provided care for a child, adolescent or young adult with FASD. Caregivers were adoptive ( $n = 97$ ; 55.4%) and foster parents ( $n = 46$ ; 26.3%), grandparents ( $n = 14$ ; 8%), biological parents ( $n = 10$ ; 5.7%), aunts/uncles ( $n = 6$ ; 3.4%) and step-parents ( $n = 2$ ; 1.2%). Caregivers completed the survey from Australia ( $n = 62$ ; 38.5%), the USA ( $n = 52$ ; 32.3%), New Zealand ( $n = 22$ ; 13.7%), Canada ( $n = 20$ ; 12.4%), the UK ( $n = 3$ ; 1.9%) and South Africa ( $n = 2$ ; 1.2%) (see Table 1 for further participant demographics).

## Procedure

Caregivers were recruited online through FASD-related organisations. Each organisation was contacted via email or the organisation's social media account and provided with a flyer regarding the research study. The flyer was shared on the organisation's website, social media account, and/or their newsletter. Caregivers accessed a link to the study and online questionnaire. Data were collected from May 2018 until March 2019. Study data were managed using REDCap (Harris et al. 2009), an electronic data capture tool.

## Measures

*Demographic questions* included caregiver age and gender, country of residence, caregiver status (e.g. biological parent, foster or adoptive parent, or family member), education (e.g. technical training to postgraduate degree), marital status and ethnicity. Caregivers were requested to provide their child's FASD diagnosis, which consisted of multiple-choice options of available worldwide diagnostic criteria (e.g. fetal alcohol spectrum disorder with the facial features, fetal alcohol spectrum disorder without the facial features, fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, static encephalopathy, and neurobehavioural disorder).

*The Depression Anxiety Stress Scale (DASS-21*; Lovibond and Lovibond 1995) is a 21-item self-report measure designed to assess depression ("I felt down-hearted and blue"), anxiety ("I felt scared without any good reason") and stress ("I found it hard to wind down"). Participants rated 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 degree to which each statement applied to them over the past week. The DASS-21 total score is provided in the current study, which is the sum of each of the seven-item scales, multiplied by two. Total scores range from 0 to 126, and higher scores indicate greater psychological distress. The internal consistency for the current sample was high ( $\alpha = .94$ ).

*The Self-Compassion Scale Short Form (SCS-SF*; Raes et al. 2011) was used to measure parental self-compassion. The SCS-SF consists of 12 items assessing positive and negative aspects of the three main components of self-compassion: self-kindness ("When I'm going through a very hard time, I give myself the caring and tenderness I need") versus self-judgement ("I'm disapproving and judgemental about my own flaws and inadequacies"); common humanity ("When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people") versus isolation ("When I fail at something that's important to me, I tend to feel alone in my failure"); and mindfulness ("When something upsets me I try to keep my emotions in balance") versus over-identification ("When I'm feeling down I tend to obsess

**Table 1** Participant demographics

Variables	<i>n</i>	
Primary caregiver age, median (IQR)	160	50.06 (43.80–54.88)
Caregiver gender, frequency (%)	173	
Female		166 (96%)
Male		6 (3.5%)
Non-binary		1 (0.6%)
Primary caregiver schooling, frequency (%)	172	
Did not complete high school		43 (25%)
Completed high school		129 (75%)
Primary caregiver highest qualification, frequency (%)	168	
Post-school skills or technical training		51 (30.4%)
Advanced diploma or diploma		33 (19.6%)
Bachelor degree		50 (29.8%)
Graduate degree		15 (8.9%)
Postgraduate degree		19 (11.3%)
Primary caregiver currently in paid work, frequency (%)	175	
Yes		86 (49.1%)
No		72 (41.1%)
Permanently unable to work		17 (9.7%)
Primary caregiver marital status, frequency (%)	175	
Married		108 (61.7%)
Divorced		20 (11.4%)
Single		39 (22.2%)
De facto		8 (4.6%)
Number of people in the household, median (IQR)	170	4 (3–5)

*IQR*, interquartile range

and fixate on everything that's wrong"). Responses were provided on a 5-point scale ranging from (1) *almost never* to (5) *almost always*. All negative aspects were reverse-scored and a total self-compassion score was calculated by taking a mean of all items. Higher scores indicate higher levels of self-compassion. The internal consistency for the current sample was high ( $\alpha = .85$ ).

*The State Shame and Guilt Scale* (SSGS; Marschall et al. 1994) is a 15-item self-report scale that was used to measure in-the-moment feelings of shame ("I want to sink to the floor and disappear"), guilt ("I feel remorse, regret") and pride ("I feel worthwhile, valuable"). Participants were asked to indicate how they are feeling in the moment on a 5-point scale ranging from (1) *not feeling this way at all* to (5) *feeling this way very strongly*. High scores across each of the three variables indicate high levels of shame, guilt and pride. The internal consistency for the current sample was high for each variable (shame,  $\alpha = .86$ ; guilt,  $\alpha = .88$ ; and pride,  $\alpha = .87$ ).

## Data Analyses

Descriptive statistics were reported as means and standard deviations (*SD*) for normally distributed data, or medians

(*Mds*) and interquartile ranges (*IQRs*) for non-normally distributed data. The Shapiro-Wilk test was used to test normality. Frequencies and percentages are presented for categorical variables. Missing data were random and infrequent (Little MCAR test  $\chi^2(27) = 21.17, p = .779$ ) and, therefore, were managed by listwise deletion. Cronbach's coefficient alpha was used to indicate internal consistency of instruments. Spearman's rank coefficients were calculated to assess the association between key outcomes of interest.

Univariate linear regression was performed, examining the relationships between caregiver mental health (DASS-21 Total Score) and several key caregiver and child characteristics. This included the following: caregiver and child age and gender, caregiver marital status, work and education and shame, guilt, pride and self-compassion. All variables that reached significance were then included in a hierarchical multiple linear regression model. Control or covariates were entered at the first step; shame, guilt and pride at the second step; and self-compassion at the third step. All assumptions for the model were tested and validated. There was independence of residuals, assessed by a Durbin-Watson statistic of 1.96 and there was no evidence of multicollinearity, as assessed by the tolerance values (.56, .31, .38, .47) and variance inflated

factors (1.83, 3.19, 2.67, 2.12) for pride, shame, guilt and self-compassion, respectively.

Between-group differences on the non-normally distributed variables (i.e. shame and guilt) were explored using Mann-Whitney *U* tests. A Welch *t* test was run for the normally distributed variable of self-compassion, due to the assumption of homogeneity of variances being violated, as assessed by Levene’s test for equality of variances ( $p = .023$ ). Analyses were two-tailed *p* values and were considered statistically significant at  $p < .05$ . Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS, Version 26.0.0.1).

## Results

### Descriptive Statistics and Correlations

Table 2 presents the descriptive statistics and correlations of the study variables. Caregiver psychological distress (DASS-21) was negatively correlated with self-compassion and pride, and positively correlated with shame and guilt. That is, caregivers with higher psychological distress had lower levels of self-compassion and pride, and higher levels of shame and guilt. All results were found to be significant, moderate to strong associations.

### Factors Associated with Caregiver Psychological Distress

Table 3 provides the results of the univariate regression analyses. At the univariate level, two caregiver demographic factors (completing high school and residing in New Zealand) along with shame, guilt, pride and self-compassion were factors significantly associated with caregiver psychological distress. Table 4 provides the results of the hierarchical multiple regression. At step 1, the control variables of high school completion and location did contribute significantly to the model ( $F_{2,126} = 4.32, p = .015$ ), accounting for 6.4% of the variance in caregiver psychological distress. The introduction of shame, guilt and pride at step 2 accounted for an additional

**Table 3** Univariate regression caregiver psychological distress ( $n = 128$ )

	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i> value
Caregiver age	-.02	.21	-.01	.92
Caregiver gender (male)	-9.40	10.38	-.07	.36
Child age	.40	.40	.08	.33
Child gender (male)	-4.43	4.28	-.09	.30
Completed high school	9.12	4.56	.16	.047
Currently in paid work	-2.37	3.96	-.05	.55
Currently married/defacto	-3.85	5.60	-.06	.49
Caregiver status (non-biological)	-14.45	8.03	-.14	.07
Location				
Australia	-2.13	4.27	-.04	.62
USA	-3.18	4.39	-.06	.47
New Zealand	11.88	5.61	.18	.036
Canada	1.82	6.19	.03	.77
UK	-10.41	14.31	-.06	.47
Shame	4.10	.29	.75	< .001
Guilt	3.39	.36	.61	< .001
Pride	-3.37	.40	-.56	< .001
Self-compassion	-25.09	2.19	-.69	< .001

58.8% of variance in caregiver psychological distress and this change in  $R^2$  was significant ( $F_{3,123} = 46.08, p \leq .001$ ). Shame and pride were the only significant variables. At step 3, the addition of self-compassion explained an added 2.9% of the variance in caregiver psychological distress, which was significant ( $F_{1,122} = 43.39, p \leq .001$ ). Shame remained as a significant contributing factor, alongside self-compassion. The final model accounted for 68.1% of the variance in caregiver psychological distress.

### Exploration of Biological and Non-biological Group Differences

Distributions of psychological distress scores, self-compassion scores and guilt scores for biological parents compared with those for non-biological (i.e. foster or adoptive)

**Table 2** Descriptive statistics and Spearman rank correlations among variables

	1	2	3	4	5	<i>M</i> ( <i>SD</i> )	<i>Mdn</i> ( <i>IQR</i> )
1. DASS-21	-	-.66**	.74**	.64**	-.49**	-	26 (14–50)
2. Self-compassion		-	-.62**	-.54**	.53**	3.15 (.67)	-
3. Shame			-	.75**	-.55**	-	8 (5–12)
4. Guilt				-	-.40**	-	7 (6–11)
5. Pride					-	-	17 (14–19)

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ . *M*, mean; *SD*, standard deviation; *Mdn*, median; *IQR*, interquartile range. DASS-21  $n = 157$ ; Self-compassion  $n = 165$ ; Pride  $n = 172$ ; Shame  $n = 174$ ; Guilt  $n = 170$



**Table 4** Hierarchical multiple variable regression analysis caregiver psychological distress ( $n = 128$ )

	Step 1				Step 2				Step 3			
	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>B</i>	<i>SE</i>	$\beta$	<i>p</i>
Constant	21.81	6.43		.001	8.80	9.64		.36	35.78	12.32		.004
Completed high school	7.93	4.97	.14	.11	5.73	3.10	.10	.07	4.11	3.01	.07	0.18
Located in New Zealand	12.50	6.01	.18	.04	.63	3.91	.01	.87	3.54	3.88	.05	0.36
Shame					3.00	.51	.54	<.001	2.60	.51	.47	<.001
Guilt					0.91	.51	.15	0.07	.61	.49	.11	.21
Pride					-1.08	.38	-.19	.005	-.54	.40	-.10	.17
Self-compassion									-8.92	2.68	-.25	.001
$R^2$	.064				.652				.681			
$F$	4.32		.005		46.08				43.39			
$\Delta R^2$					.588				.029			
$\Delta F$					69.24			<.001	11.07			.001

caregivers were not similar, as assessed by visual inspection. Guilt scores were significantly higher for biological parents ( $Mdn = 13$ , IQR [8.50–19]) than for non-biological caregivers ( $Mdn = 7$ , IQR [6–10.25]),  $U = 286.00$ ,  $z = -3.44$ ,  $p = .001$ . There was a non-significant trend for self-compassion to be higher for non-biological caregivers ( $M = 3.16$ ,  $SD = .69$ ) compared with biological caregivers ( $M = 2.95$ ,  $SD = .26$ ) ( $M = .21$ , 95%CI [- .01 to .42],  $t(15.75) = 2.04$ ,  $p = .059$ ). There were no significant differences between psychological distress scores for biological parents ( $Mdn = 64$ , IQR [20–70]) and non-biological caregivers ( $Mdn = 26$ , IQR [14–48]) ( $U = 491.50$ ,  $z = -1.75$ ,  $p = .080$ ) or shame scores for biological parents and non-biological caregivers ( $Mdn = 9$ , IQR [7.50–14.50] and  $Mdn = 8$ , IQR [5–12]) ( $U = 576.00$ ,  $z = -1.60$ ,  $p = .110$ , respectively).

## Discussion

In an international sample of caregivers of children with FASD, the current study examined the relationships between shame, guilt, pride, self-compassion and caregiver psychological distress. The hierarchical multiple regression revealed that shame, pride, guilt and self-compassion accounted for a significant proportion of the variance in caregiver psychological distress. Furthermore, shame and self-compassion were both uniquely associated with caregiver psychological distress, after controlling for other variables in the model. The results provide partial support for the hypotheses. That is, self-compassion and shame accounted for unique variance in psychological distress and pride and guilt did not. The findings suggest that self-compassion may represent a protective resource for caregivers, whereas shame may contribute to risk of distress. Alternatively, it may be that those with less distress

are more kind and understanding towards themselves and feel less shame. It is likely that these relationships are bidirectional. The results also provided partial support for the hypothesis that biological caregivers would report higher levels of psychological distress, guilt and shame and lower levels of self-compassion. While biological caregivers reported higher guilt and a trend for lower self-compassion than non-biological caregivers, the two groups reported similar levels of shame, and psychological distress.

Findings of the current study are consistent with previous research exploring self-compassion in caregivers of typically developing children, and children diagnosed with other neurodevelopmental conditions (e.g. Gouveia et al. 2016; Moreira et al. 2015; Neff and Faso 2015; Robinson et al. 2018). The results of the current study demonstrated a negative association between self-compassion, guilt and shame, suggesting that caregivers with higher levels of self-compassion reported less internal shame and guilt. This finding is consistent with previous research, again supporting the notion of self-compassion as a protective resource or internal coping strategy for caregivers, subsequently lessening feelings of shame (Neff et al. 2005; Robinson et al. 2018; Wong et al. 2016). By being more self-compassionate, caregivers may be less likely to feel alone in their struggles, less likely to over-identify with difficult thoughts and feelings, and thereby less affected by challenging experiences (Neff 2003; Neff and Faso 2015).

The current results also indicated that shame and guilt, but particularly shame, were associated with higher levels of caregiver psychological distress. These findings are consistent with previous research that found depression among parents of children with ASD was often exacerbated by feelings of shame, self-blame and grief (Cappe et al. 2011; Johnson and O'Brien 2013; Mak and Kwok 2010). Additionally, in a

general sample of parents, Kirby et al. (2019) recently reported that shame was a significant predictor in both psychologically controlling and dysfunctional parenting styles, after controlling for psychological inflexibility, parental mental health and fears of compassion. Gilbert (2011) suggested that compassion can be a “powerful antidote to the alienating experience of shame” (p. 339). This may be particularly pertinent for caregivers of children with FASD, who commonly experience both internal shame (e.g. in the case of biological parents, this could be related to self-criticism regarding the occurrence of the prenatal alcohol exposure) and external shame (e.g. feeling judged by their family and friends due to their child’s misbehaviour) (Corrigan et al. 2017). Consequently, compassion-focused interventions, and more specifically compassion-focused therapy (CFT; Gilbert 2010), developed specifically for people with high levels of shame and self-criticism, may be an important avenue to explore for caregivers of children with FASD.

Previous research has shown that caregivers of children with and without developmental disabilities have benefited from mindfulness-based interventions (Bazzano et al. 2015; Benn et al. 2012; Gouveia et al. 2016; Moreira et al. 2015; Reid et al. 2017). Mindfulness-based training has also been shown to reduce stress, anxiety and depression, and increase self-compassion, acceptance, mindfulness and wellbeing in caregivers of children diagnosed with developmental disabilities (Bazzano et al. 2015; Benn et al. 2012; Jones et al. 2014; Neece 2014). One study to date has incorporated mindfulness-based approaches for caregivers of children with FASD (Reid et al. 2017). Given the conceptual overlap between self-compassion, mindfulness and acceptance, the current study suggests mindfulness and acceptance may be important psychological processes to be explored in future research involving caregivers of children with FASD and may further contribute to the development of family-focused interventions for this population.

Furthermore, an intervention approach such as acceptance and commitment therapy (ACT) may also prove useful in supporting positive parenting experiences and improving psychological wellbeing (Weiss et al. 2012; Whittingham 2014) for this population. Research has demonstrated the completion of ACT-based interventions has improved quality of life and decreased parental psychological symptoms of caregivers of children diagnosed with a disability (Weiss et al. 2012; Whittingham 2014; Whittingham et al. 2015), which may, in turn, improve parental fulfilment and satisfaction, foster acceptance and intentional awareness, and support parenting experiences (Da Paz and Wallander 2017; Weiss et al. 2012; Whittingham et al. 2015). Interestingly, Luoma and Platt (2015) suggested the core ACT processes (i.e., defusion, acceptance, mindfulness, values, committed action and self-as-context)—while being inherently self-compassionate—may be enhanced for people experiencing high levels of shame by explicitly targeting self-compassion.

Findings from the current study indicated that there may be important differences in the experiences of caregivers. Biological caregivers in the current sample reported higher levels of guilt compared with non-biological caregivers (e.g. foster/adoptive). However, the current results emphasised that the burden of shame was experienced regardless of caregiver status, which is a consistent finding in the literature exploring caregivers of children diagnosed with ASD and FASD (Bell et al. 2015; Paley et al. 2006; Salmon 2008; Whitehurst 2012). These findings suggest that when examining caregiver psychological distress, devising interventions to reduce shame and guilt is an important goal. There have been numerous interventions that have promoted self-compassion as an outcome (Ferrari et al. 2019) and future research could consider the application of compassion-focused approaches for caregivers of children with FASD as a potential approach to help alleviate feelings of shame and guilt. Based on the findings from the current study, self-compassion-focused interventions may be particularly relevant for supporting biological caregivers, who reported higher levels of guilt and potentially lower levels of self-compassion. However, these are preliminary results given the small and uneven sample sizes. It is suggested that future research could explore these potential group differences in more detail, which could include the consideration of possible differential treatment effects.

## Limitations and Future Research Directions

The current study provided an exploration of the relationship between self-compassion, pride, shame, guilt and psychological distress among caregivers of children with FASD. Investigating positive parenting factors such as self-compassion and pride offers a new avenue to better understand caregiver experiences and factors that might protect against distress and enhance quality of life. Another strength of the current study was the consideration of group differences for biological and non-biological caregiver experiences. However, the current study has several limitations that must be noted. The sample was collected via an online survey, which was circulated by FASD-related groups, and participants self-selected to participate. Although the study aimed to include all types of caregivers, most participants were female and adoptive caregivers. Future research using a larger, more diverse sample could address these limitations. Such work is important to inform the development of future interventions for biological and non-biological caregivers, and to explore possible gender differences within these groups. Additionally, caregivers were asked to self-report their child’s FASD diagnosis, which may have impacted on response validity, although additional questions were included to verify the diagnosis (e.g. clinic and doctor that provided the diagnosis) and caregivers who selected “unsure” were removed from the analysis. Future research directly assessing children and caregivers in clinical settings would provide further explication of the current findings.

Furthermore, the current study had large heterogeneity in terms of child age and included one caregiver who was not currently residing with their child, and this may have influenced caregiver psychosocial wellbeing. Additionally, although some information was available regarding caregiver and family variables, future research would benefit from a more detailed examination of sociodemographic factors that could be related to psychosocial wellbeing for caregivers. Lastly, the current study utilised the short form scales of the SCS-SF and DASS-21, so associations between the three dimensions of self-compassion (self-kindness versus self-judgement, common humanity versus isolation, and mindfulness versus over-identification) were not explored. Using the full scale for each measure may permit future research to explore the scales in greater detail, which may assist in the development of tailored and targeted interventions. Overall, the current study has identified self-compassion as a potential target of intervention with caregivers of children with FASD, and therefore, these findings provide a useful starting point for further investigation into the efficacy of self-compassion-based interventions for this population.

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**Author Contributions** NR established the online survey initiated participant recruitment. ZB assisted with participant recruitment. NR undertook the data analysis with assistance from ZB. ZB undertook the literature review and led the first draft of the manuscript. All authors contributed to the study design and writing of the manuscript and approved the final version before submission.

## Compliance with Ethical Standards

**Ethical Approval** The study received ethical approval from Children's Health Queensland Ethics Committee (HREC/17/QRCH/272) and Griffith University's Human Research Ethics Committee (2019/494) and was conducted in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Conflict of Interest** AFJ is a trained facilitator of several compassion-based training programs and is paid to deliver these programs. Other authors declare no conflicts of interest.

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