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Trends in Well-Being and Opportunities to Support Caregivers of Individuals With Fetal Alcohol Spectrum Disorder Across the Lifespan

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ABSTRACT

Background: Caregivers of individuals with fetal alcohol spectrum disorder (FASD) experience unique challenges, stressors, and strengths, and there is growing understanding of the needs of these caregivers. However, less is known about how the broader caregiver context, including sociodemographic and ecological factors, may be associated with well-being.

Methods: Data for this study were collected between 2021 and 2025, gathered at baseline as part of an ongoing international longitudinal survey about caregiver experiences and perspectives of raising people with FASD ($N = 234$). Information on sociodemographic factors, family characteristics, and caregiver well-being was analyzed.

Results: Participants predominantly identified as women (95%) and had a mean age of 54 years (range 26–82); most (69%) were adoptive caregivers of children and adults with FASD and 67% were living in Canada. Family structure and composition varied across participants, and many caregivers reported financial challenges. Overall, caregivers reported high levels of stress and limited social support, along with strengths in their relationships with spouses/partners and relatives. Self-reported well-being was highest among parents who were retired, did not experience employment disruptions because of parenting responsibilities, cared for adults (as opposed to young children) with FASD, and had only one (as opposed to multiple) dependent(s) with FASD.

Conclusions: This study provides insight into broad contextual factors (i.e., employment status, life stage) that may influence well-being among caregivers of people with FASD. Understanding these factors can lead to more tailored and effective responses, interventions, and policies that support stability and thriving among caregivers, families, and communities of people with FASD.

1 | Introduction

Fetal alcohol spectrum disorder (FASD) is a lifelong neurodevelopmental disability characterized by differences in learning, behavior, physical and mental health, and social and adaptive functioning (Cook et al. 2016). People with FASD experience multifaceted and evolving needs such that integrated and long-term services are often required to support day-to-day functioning and to promote successful experiences across the lifespan (Flannigan, Edwards, Murphy, and Pei 2024). FASD is a uniquely complex disability associated with co-occurring health needs, environmental adversity, deep-rooted stigma, and sociocultural influences (Flannigan et al. 2021). Because of the complex and lifelong nature of this disability, parents and caregivers often play a significant role in navigating service systems and advocating for their family members with FASD.

Caring for a child with FASD is associated with higher levels of stress among parents and families compared to those with children who have other disabilities (Ilchena et al. 2023). Moreover, caregivers of people with FASD (including biological, foster, and adoptive parents, as well as other family members) report widespread barriers to intervention and support for their individuals and families (Coons et al. 2018; Pepper et al. 2018). Compounding these barriers to support, caregivers often report feeling misunderstood, shamed, and inadequately supported by systems and sectors from which they seek help (Coons et al. 2018). These added feelings of stress and isolation can have significant impacts on caregivers and families, such as disrupted day-to-day functioning, reduced sense of parenting competence, avoidance of social engagement, and relational breakdown within the family (Skorka et al. 2020). Despite these obstacles, caregivers of people with FASD are remarkably adaptable and hopeful, and find great joy and fulfillment in their caregiving roles (Clement et al. 2023; Coons et al. 2016; Kautz-Turnbull et al. 2022). Parents and caregivers are strong advocates in broader efforts to balance the narrative for individuals with FASD, highlighting the many strengths, values, and contributions that people with FASD bring to their families and communities (Kautz-Turnbull et al. 2022).

1.1 | Caregiver Stress and Well-Being

Caring for someone with any kind of illness or disability is associated with elevated levels of stress and burnout, decreased quality of life, and poorer health outcomes compared to caregivers of people without illness or disability (Biswas et al. 2015; Masefield et al. 2020). Importantly, all families of individuals with disabilities are unique, and stressors, strengths, and needs vary for caregivers across and within different disability groups (Biswas et al. 2015; Hammond et al. 2014). Developmental disabilities are frequently associated with increased levels of parenting stress compared to parents of children with physical disabilities or those without disabilities (Hayes and Watson 2013). Characteristics such as distractibility, demandingness, mood fluctuations, and limited adaptability can be more common among children with developmental disabilities and may contribute to distinct experiences of parenting stress (Scheibner et al. 2024).

The historical emphasis on the challenges and stresses of raising a child with a developmental disability has reinforced beliefs that caregiving families unquestionably present with pathology or dysfunction (e.g., Maul and Singer 2009). A more balanced focus to include positive family factors and caregiver well-being emphasizes how and why some families facing adversity manage to function well, while other families facing similar circumstances do not (Coons et al. 2016). This reframed approach on caregiver well-being can help parents focus less on the potentially negative aspects of their children's behaviors or their perceived limitations as parents (e.g., low empowerment, low participation in health-promoting activities), and can instead draw attention to the opportunities to promote healthy outcomes, positive parenting behaviors, increased service and support engagement, and overall family cohesion (Coons et al. 2016).

Efforts to understand caregiver coping, resilience, and support for families of people with developmental differences (e.g., Gibbs 2024; Scripps et al. 2025) has shed light on many important factors and characteristics that can influence well-being. One way of conceptualizing these factors is within a socioecological model of human health and development (Bronfenbrenner 1977), which has been applied in many contexts, including with caregiver populations (e.g., Talley and Crews 2007). These impacts are interactive and multidimensional, with many factors, including the characteristics of the individual with the disability, their caregiver(s), family, and broader community all playing a role (Raina et al. 2004). Relevant child, youth, and/or adult factors include age, severity of disability and related support needs, and behavioral challenges (Masefield et al. 2020). Demographic characteristics of the child or adult with a disability can also impact family quality of life (Ferrer et al. 2016) and the experience of parenting someone with a disability can change across ages and life stages (Seltzer et al. 2001).

At the caregiver level, characteristics such as gender, marital status, education, and income are all predictive of caregiver stress (Scheibner et al. 2024), well-being (Olsson and Hwang 2008), quality of life (Hsiao 2018), and resilience (Rajan et al. 2016). Parent resilience, self-efficacy, life purpose, and social support are all associated with physical and emotional well-being (Cejalvo et al. 2021). Quality of relationships also plays an important role with respect to caregiver life satisfaction and quality of life (Hammond et al. 2014; Huo and Kim 2023). Caregiver well-being is embedded in a broader sociocultural context (Bastawrous et al. 2015) with influence from socioeconomic and ecological factors (Oliver et al. 2024; Raina et al. 2004). Family coping resources and formal or informal supports vary based on the social and structural determinants of health, which may further impact caregiver and family well-being.

Despite what is known about caregiver well-being broadly, there are very few studies specifically aimed at investigating factors that impact well-being for caregivers of individuals with FASD. In 2019, researchers explored socioecological influences on the family and reported that country of residence, child gender and behavior, physical features of FASD, and caregiver mental health all influenced quality of life (Reid and Moritz 2019). In a similar study, Bobbitt et al. (2016) reported that age of dependent, parental relationship (e.g., biological compared to foster parent), and family income all impacted well-being among caregivers of individuals with FASD. Finally, in their study of caregiver distress, Biddle et al. (2020) reported significant differences in well-being among biological parents compared to non-biological parents of children with FASD, specifically that biological parents reported higher levels of guilt. Beyond these studies, most of what is known about the experiences and needs of caregivers of those with FASD comes from qualitative research or small quantitative studies with targeted research questions (Skorka et al. 2020, 2024).

The results of these previous studies provide vital and meaningful insight into specific elements of caring for someone with FASD, including the impacts of FASD for individuals and families across the lifespan and in various systems such as school and community (Skorka et al. 2020). However, the existing evidence remains limited in scope and generalizability because

of smaller sample sizes, restricted geographic representation, and limited data collection timeframes, hindering our understanding of the ways in which broad contextual factors such as sociodemographic characteristics and ecological factors (e.g., the social and structural determinants of health) may be related to caregiver experiences and well-being. Moreover, there is a growing call for more participatory FASD research guided by the values and priorities of those with living experience.

1.2 | Current Study

The goals of the current study were to (1) characterize sociodemographic and ecological factors of a large group of caregivers of individuals with FASD and (2) examine what factors may be associated with caregiver well-being. Understanding more about caregiver contexts is important for identifying potential protective factors and opportunities to bolster family systems. By focusing on this higher level of influence, we can determine where efforts, resources, and funding should be invested to strengthen family contexts and better support and equip caregivers to thrive, ultimately promoting healthy outcomes for individuals with FASD, their caregivers, and their communities.

2 | Materials and Methods

This study was part of an ongoing longitudinal research project developed to explore experiences of caring for someone with FASD across the lifespan (Flannigan, Edwards, Reid, et al. 2024). The broader project is a community-based collaboration between researchers and caregivers from diverse interdisciplinary backgrounds, intended to address gaps in our understanding of caregiver needs and priorities. Data for the current study were collected at baseline.

2.1 | Research Design

The larger study (Flannigan, Edwards, Reid, et al. 2024) involves a virtual survey managed and housed on the REDCap data collection platform (Harris et al. 2019), hosted at the University of Alberta. Baseline data collection was initiated in September 2021 and is ongoing (Flannigan, Edwards, Reid, et al. 2024). Participants are recruited from across the world, primarily using convenience and self-selection sampling. Inclusion criteria are age 18+, any gender, fluency in reading and writing in English, and self-identification as a caregiver of someone with FASD.

2.2 | Data Collection and Analysis

The larger baseline survey consists of three comprehensive sections capturing data on: (1) caregiver characteristics, family structure and composition, and caregiving role; (2) caregiver perspectives about their family members with FASD; and (3) advice that participants wish to offer other caregivers of individuals with FASD. For the current study, data were analyzed from the first section only and included caregiver sociodemographic and ecological factors and family factors (see Table 1), and caregiver self-reported well-being (see Appendix A for specific items). Of note, family factor data reflect dependents both with and without FASD; however, *all* participants included in the survey had at least one dependent with FASD. Caregivers were asked to report on the demographic characteristics of all their dependents, regardless of FASD diagnosis, to reflect the full caregiving scope, spectrum, and load of parents with children, youth, and adults with FASD.

Well-being was measured using Likert-scale questions (ranging from 0 to 5) rating one's physical health, emotional health, stress level, relationship with spouse, relationship with relatives, social support, and community belonging over the last 12 months as well as the last 10 years. Participants also reported on whether caring for someone with FASD impacted their well-being across each of these seven domains (yes/no) and the nature and degree of this impact (scale of 0 = significant stressor to 5 = significant strength).

Well-being questions were derived from the conceptual frameworks of the World Health Organization's (WHO 2012) *Quality of Life Scale*, Frisch's (2014) *Quality of Life Inventory*, and Sears et al.'s (2014) *Well-Being 5* instrument. These measures encompass broad domains of well-being, including physical health, emotional/psychological health, relationships and social support, and environment/community, all of which align with socioecological models of health and development. Items for the current survey were not taken verbatim from these sources but rather were synthesized into a short section of questions reflecting these broad domains and then vetted by caregiver research partners to ensure ecological validity. This survey development approach was used to balance the need to minimize caregiver burden with survey brevity while at the same time reflecting well-being domains recognized in the caregiver literature (e.g., Tebb et al. 2013).

Data were extracted for the current study in February 2025. The initial dataset included 253 records. Nineteen records were excluded because participants did not provide any information about their dependents. Descriptive statistics were used to characterize study participants. Comparison of 12-month and 10-year well-being scores was done using paired sample *t*-tests. Trends in caregiver well-being based on sociodemographic and ecological factors were examined using Pearson correlations for linear variables (caregiver age, number of dependents) and ANOVA (with post hoc Tukey's tests) for categorical variables (gender, marital status, region, multiple dependents with FASD, employment status, impacts of caregiving on employment [self and spouse], perceived income, age of dependent[s] with FASD, and type of caregiver relationship). Analyses were conducted for each of the seven domains of well-being assessed on the survey. To account for multiple comparisons, the Benjamini–Hochberg procedure (Benjamini and Hochberg 1995) was used with a false discovery rate of 0.20. Certain independent variables were prioritized in these analyses to reduce the number of tests conducted while balancing comprehensive analysis and meaningful interpretation (see Table 1).

TABLE 1 | Results from ANOVAs comparing mean scores across domains of well-being.

	n (%)	Emotional	Physical	Stress	Spouse	Relatives	Social	Community
Caregiver factors								
Age group ($n = 197$)		$p = 0.406$	$p = 0.171$	$p = 0.428$	$p = 0.606$	$p = 0.976$	$p = 0.858$	$p = 0.385$
< 50 years	75 (38.1)	2.15	2.16	1.53	3.05	2.70	2.03	2.08
50–64 years	89 (45.2)	2.40	2.55	1.78	3.29	2.66	2.06	2.17
65+ years	33 (16.8)	2.09	2.45	1.82	3.30	2.66	2.18	2.48
Gender ($n = 196$)		$p = 0.646$	$p = 0.393$	$p = 0.841$	$p = 0.626$	$p = 0.454$	$p = 0.383$	$p = 0.259$
Woman	184 (93.9)	2.26	2.41	1.69	3.21	2.69	2.04	2.16
Man	12 (6.1)	2.08	2.08	1.62	3	2.38	2.38	2.62
Marital status ($n = 195$)		$p = 0.474$	$p = 0.622$	$p = 0.762$	—	$p = 0.644$	$p = 0.215$	$p = 0.052$
Married/ common-law	137 (70.3)	2.30	2.38	1.68	—	2.66	2.16	2.34
Single/widowed	58 (29.7)	2.14	2.48	1.74	—	2.76	1.90	1.92
Region ($n = 196$)		$p = 0.649$	$p = 0.666$	$p = 0.731$	$p = 0.615$	$p = 0.291$	$p = 0.229$	$p = 0.869$
Urban	126 (64.3)	2.21	2.36	1.72	3.22	2.77	2.16	2.21
Rural/remote	70 (35.7)	2.31	2.45	1.65	3.01	2.54	1.91	2.17
Education level (self; $n = 197$)		$p = 0.081$	$p = 0.733$	$p = 0.722$	$p = 0.903$	$p = 0.091$	$p = 0.290$	$p = 0.525$
Up to high school	11 (5.6)	1.40	2.00	1.42	2.75	2.83	1.25	1.58
Certificate or diploma	20 (10.2)	1.96	2.30	1.45	3.00	2.60	2.10	2.10
Some college/ university	31 (15.7)	2.45	2.23	1.74	3.33	2.26	2.19	2.06
Completed college/university	87 (44.2)	2.46	2.44	1.81	3.17	2.57	2.15	2.31
Graduate/ professional degree	48 (24.4)	2.04	2.52	1.60	3.30	3.13	2.02	2.23
Education level (spouse; $n = 137$)		$p = 0.638$	$p = 0.665$	$p = 0.758$	$p = 0.015$	$p = 0.638$	$p = 0.348$	$p = 0.402$
Up to high school	22 (16.1)	2.55	2.68	1.86	2.91	2.62	2.64	2.45
Certificate or diploma	18 (13.1)	1.89	2.06	1.50	2.50	2.78	1.83	2.11
Some college/ university	16 (11.7)	2.25	2.50	1.38	3.67	2.25	2.13	2.75
Completed college/university	54 (39.4)	2.28	2.31	1.70	3.07	2.62	2.11	2.13
Graduate/ professional degree	27 (19.7)	2.44	2.41	1.78	3.78	2.93	2.11	2.56
Employment status (self; $n = 196$)		$p = 0.323$	$p = 0.346$	$p = 0.010$	$p = 0.036$	$p = 0.297$	$p = 0.030$	$p \leq 0.001$
Employed	121 (61.7)	2.23	2.36	1.68	2.93	2.75	2.17	2.28

(Continues)

TABLE 1 | (Continued)

	n (%)	Emotional	Physical	Stress	Spouse	Relatives	Social	Community
Homemaker	26 (13.2)	2.38	2.42	1.72	3.86	2.68	1.88	1.92
Unemployed/on leave	27 (13.8)	1.89	2.07	**1.15**	3.38	2.19	1.44	**1.37**
Retired	22 (11.2)	2.62	2.77	**2.43**	3.47	2.82	2.48	**2.96**
Employment status (spouse; $n=137$)		—	—	—	—	—	—	—
Employed	108 (78.8)	2.26	2.33	1.69	3.21	2.70	2.15	2.28
Homemaker	4 (2.9)	2.00	2.75	2.00	3.75	2.75	1.50	2.50
Unemployed/on leave	9 (6.6)	2.22	2.67	1.25	2.67	2.22	2.44	2.33
Retired	16 (11.7)	2.69	2.44	1.75	3.06	2.60	2.25	2.73
Impacts on employment (self; $n=160$)		$p=0.159$	$p=0.095$	$p=0.338$	$p=0.814$	$p=0.002$	$p=0.470$	$p=0.061$
Affected[a]	126 (78.8)	2.19	2.33	1.69	3.10	**2.50**	2.10	2.10
Not affected	34 (29.1)	2.57	2.77	1.94	3.18	**3.31**	2.29	2.62
Impacts on employment (spouse; $n=117$)		$p=0.302$	$p=0.130$	$p=0.109$	$p=0.448$	$p=0.377$	$p=0.949$	$p=0.240$
Affected[a]	58 (49.6)	2.16	2.21	1.53	3.11	2.58	2.10	2.07
Not affected	59 (50.4)	2.42	2.59	1.90	3.31	2.81	2.12	2.37
Annual income ($n=183$)		$p=0.730$	$p=0.751$	$p=0.894$	$p=0.240$	$p=0.025$	$p=0.425$	$p=0.139$
<$50,000	46 (25.1)	2.13	2.33	1.69	2.54	2.26	1.83	1.80
$50,0000–100,000	70 (38.3)	2.23	2.34	1.61	3.25	2.65	2.16	2.30
>$10,000	67 (36.6)	2.34	2.49	1.72	3.23	3.00	2.09	2.26
Perception of income ($n=190$)		$p=0.076$	$p=0.050$	$p=0.478$	$p=0.280$	$p=0.097$	$p=0.387$	$p=0.531$
Not/just enough	81 (42.6)	2.30	2.33	1.59	2.92	2.56	2.15	2.13
Enough	78 (41.1)	1.99	2.22	1.65	3.24	2.62	1.89	2.09
More than enough	31 (16.3)	2.65	2.90	1.94	3.48	3.19	2.19	2.42
Family factors								
Multiple dependents w/ FASD ($N=193$)		$p=0.040$	$p=0.672$	$p=0.026$	$p=0.911$	$p=0.620$	$p=0.203$	$p=0.139$
No	126 (65.3)	2.42	2.44	1.85	3.18	2.73	2.16	2.29
Yes	67 (34.7)	1.98	2.36	1.39	3.21	2.62	1.9	1.97
Age of dependent w/FASD ($N=144$)[b]		$p=0.13$	$p=0.044$	$p=0.003$	$p=0.509$	$p=0.104$	$p=0.192$	$p=0.020$ 1.74
0–12 years	57 (39.6)	2.02	2.11	**1.42**	3.00	2.42	1.88	2.45
13–17 years	41 (28.5)	2.29	2.41	1.59	3.12	2.80	2.44	2.56
18–25 years	27 (18.8)	2.78	2.89	**2.38**	3.53	2.52	2.33	2.53

(Continues)

TABLE 1 | (Continued)

	n (%)	Emotional	Physical	Stress	Spouse	Relatives	Social	Community
> 25 years	19 (13.2)	2.42	2.84	**2.47**	3.54	3.32	2.05	
Caregiver relationship ($n = 190$)		$p = 0.532$	$p = 0.802$	$p = 0.602$	$p = 0.021$	$p = 0.257$	$p = 0.724$	$p = 0.529$
Biological parent/ family or kinship	50 (26.3)	2.38	2.32	1.52	2.9	2.82	1.92	2.02
Foster parent (non-family)	18 (9.5)	2.5	2.33	1.72	2.2	2.17	2.17	2
Adoptive parent (non-family)	122 (64.2)	2.18	2.46	1.76	3.37	2.7	2.08	2.26

Note: Caregiver response dates spanned the years 2021–2025, though most data were collected in 2021 ($n = 83$, 35.5%), 2022 ($n = 73$, 31.2%), and 2023 ($n = 68$, 29.1%). Bolded values indicate significant differences.

[a]Includes stopped working entirely, reduced hours, or other impact(s).

[b]Analysis limited to caregivers with dependents in one single age group. Preschool (0–5) and school-aged (6–12) children were collapsed to ensure adequate cell counts in ANOVA.

3 | Results

3.1 | Participants

A total of 234 caregivers were included in this survey. The mean age of participants was 54 years (range 26–82). Most participants identified as women ($n = 219$, 94.6%), were married or in a common-law relationship ($n = 163$, 69.8%), from Canada ($n = 156$, 66.7%), and residing in urban ($n = 148$, 63.5%) or rural/remote ($n = 85$, 36.5%) locations. Most respondents completed at minimum a college or university degree ($n = 153$, 65.6%), and spouse education was generally lower (see Table 1). In terms of current occupation, over half ($n = 133$, 57.3%) were employed at the time of the survey, and 34 caregivers (15%) worked in the FASD field. A greater proportion of participant spouses ($n = 124$, 77%) were engaged in paid work. In terms of financial status, most caregivers ($n = 137$, 60.9%) reported earning less than $100,000 in annual household income. Only 36 caregivers (15.5%) reported that they earned "consistently more than enough" to meet the needs of their families, and 32 (13.7%) reported receiving income assistance at the time of the survey.

Of the 190 respondents who reported on the impacts of caregiving on their employment status, over half reported having to reduce their hours ($n = 45$, 23.7%) or stop working entirely ($n = 63$, 33.2%); almost one quarter ($n = 43$, 22.6%) reported that caregiving had *no* impact on their employment. For the 142 participants with spouses who reported on the impacts of caregiving roles and responsibilities on their partners' employment, 71 (50%) of respondents reported no impact, 29 (20.4%) reported that their spouse had to reduce their hours, and 13 (9.2%) reported that their spouse stopped working entirely.

3.2 | Caregiving Load

With respect to household size, most participants ($n = 176$, 75.9%) reported up to four people living in their home ($M = 3.7$, $SD = 1.81$). When asked how many children or dependent adults they actively care for, regardless of whether they live in the same home, most participants reported between one and three ($n = 200$, 85.8%). The maximum number of active dependents was 11. Almost all respondents ($n = 217$, 93.1%) noted that they are the primary caregiver in their home and most ($n = 146$, 65.8%) reported that they do *not* have support from outside the home to help them care for their family member(s) with FASD.

3.3 | Dependent Characteristics

Across the entire group of respondents, participants reported actively caring for 483 individuals, both with and without FASD, ranging in age from 3 months to 85 years. Most ($n = 386$, 79.9%) dependents were between ages 6 and 25 years, and 407 (85.1%) lived in the participant's home. There was an even number of dependents who, according to caregivers, identified as girls/women ($n = 233$, 48.8%) and boys/men ($n = 234$, 48.6%). All 11 (2.3%) dependents who identified as gender diverse (transgender or non-binary) had FASD. Most caregivers ($n = 145$, 65.3%) reported having only one child or adult with FASD, but the highest number of dependents with FASD was seven. Most caregivers (138; 63.6%) who completed this survey identified as non-family adoptive parents of their children or dependents adults with FASD. One quarter ($n = 51$, 23.5%) identified as family members or kinship caregivers, which included grandparents, siblings, and extended family members, as well as within-family foster and adoptive placements, 19 (8.8%) identified as non-family foster parents, and 9 (4.1%) identified as biological parents.

3.4 | Caregiver Well-Being

A total of 198 participants (84.6%) shared information about their well-being (see Table 1 and Figure 1). In general, caregivers reported their well-being to be worse in the last 12 months than

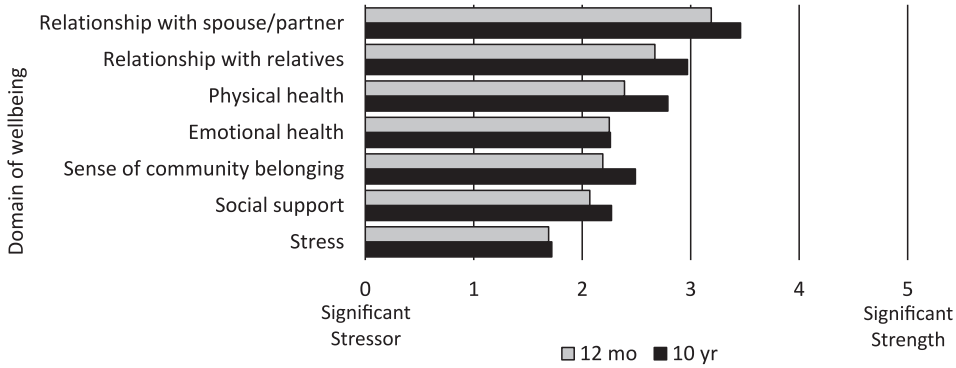

FIGURE 1 | Self-reported caregiver well-being across domains over the last 12 months and 10 years, rated on a scale of 0 (significant stressor) to 5 (significant strength).

TABLE 2 | Areas of well-being impacted by FASD caregiving.

	Impacted ("yes")	Degree of impact[a] (mean, SD)
Level of stress	180 (76.9%)	1.13 (1.34)
Emotional health	178 (76.1%)	1.33 (1.27)
Social support	138 (59.0%)	1.29 (1.23)
Community belonging	138 (59.0%)	1.23 (1.26)
Physical health	129 (55.1%)	1.77 (1.11)
Relationship with spouse[b]	83 (50.9%)	1.53 (1.36)
Relationship with relatives	113 (48.3%)	1.49 (1.12)

[a]Lower score indicates more significant stressor.
[b]Analysis of impacts of relationship with spouse was limited to participants who reported being married or in a common-law relationship ($n = 163$).

it had been over the last 10 years (all ps < 0.003). For both timeframes, relationships with spouse/partner and with relatives were rated as the greatest strengths and stress level was rated as the biggest challenge (see Figure 1).

When asked what area(s) of well-being were impacted by caring for someone with FASD, participants most often reported impacts on stress level and emotional health (see Table 2). Relationship with relatives and relationship with spouse were less often impacted by caregiving. With respect to the *nature* of these impacts, stress level, community belonging, and social support were impacted most negatively, whereas physical health and relationships with spouse and relatives were impacted less negatively.

3.4.1 | Trends in Past-Year Well-Being

No significant trends in caregiver well-being were identified based on caregiver age (continuous or grouped), gender identity, region, marital status, educational level (self or spouse), occupation in paid employment, spouse's employment, or perception of income. However, several trends were identified with respect to caregiver employment (see Table 1). There was a significant effect of caregiver employment status on stress level, $F(3, 191) = 3.92$, $p = 0.010$, $n^2 = 0.058$, and sense of community belonging, $F(3, 192) = 6.22$, $p < 0.001$, $n^2 = 0.089$. Specifically, caregivers who were retired had significantly lower stress levels ($p = 0.004$) and significantly higher sense of community belonging ($p < 0.001$) than caregivers who were unemployed/on leave. Relatedly, the *impacts of caregiving* on employment were significantly related to well-being, $F(1, 158) = 9.491$, $p = 0.002$, $n^2 = 0.057$, whereby participants whose employment status was *unaffected* by FASD caregiving responsibilities reported significantly higher quality of relationships with their relatives than those whose jobs were affected. Quality of relationships with relatives was also higher for caregivers who reported greater income, a finding that approached significance ($p = 0.025$). The association between spouse education level and caregiver well-being trended toward significance, whereby participants whose spouses attained a graduate or professional degree reported stronger spouse relationships than those whose spouses had a certificate or diploma ($p = 0.015$).

3.4.2 | Family Factors

Caregiver well-being varied significantly depending on the age of dependent(s) with FASD, $F(3, 139) = 4.894$, $p = 0.003$, $n^2 = 0.096$. That is, parents of children aged 0–12 years with FASD experienced significantly higher stress levels than caregivers of emerging adults 18–25 years ($p = 0.018$) and adults >25 years ($p = 0.022$) with FASD. Age-based trends approached significance with respect to sense of community belonging, again with caregivers of children reporting lower well-being in this area than caregivers of adults. No significant differences in well-being were identified based on the type of caregiver relationship to their family member(s) with FASD, though compared to foster parents, adoptive caregivers reported stronger relationships with their spouses at a level that trended toward significance ($p = 0.021$). Total number of dependents (with or without FASD) did not influence well-being when assessed as a continuous variable. However, when dependents were measured dichotomously ("one" vs. "more than one"), differences in stress levels trended toward significance for caregivers who had multiple dependents with FASD ($p = 0.026$).

4 | Discussion

There is growing evidence that caregivers of individuals with FASD report high rates of stress and unmet support needs along with significant strengths and coping strategies (Coons et al. 2016). However, very little is known about the contextual factors that may impact their well-being (Ilchena et al. 2023). In other disability populations, characteristics of the individual, the caregiver(s), and the broader family system all play a role in influencing caregiver well-being (Masefield et al. 2020). Caregiver well-being in general is embedded in a broader social system with influence from factors including demographics, socioeconomic status, and ecological contexts (Raina et al. 2004). For families of individuals with FASD, challenges associated with the disability can increase experiences of stress for caregivers (Ilchena et al. 2023), but there is a lack of research that explores how caregiver factors might influence their experiences or what factors may promote well-being. The goals of the current study were therefore to characterize the sociodemographic and ecological contexts of a large international sample of caregivers of people with FASD and to identify factors associated with caregiver well-being.

4.1 | Sociodemographic Trends

In the current study, participants were, on average, in their mid-50s and predominantly identified as women. Most were married, living in Canada, and identified themselves as the primary caregiver in their family. Caregivers most often supported one individual with FASD, though some families had up to seven dependents with FASD, and others were engaged in multigenerational caregiving. Notably, caregivers with multiple dependents with FASD had higher levels of stress than caregivers with only one child or adult with FASD, highlighting the impact of caregiving load for these parents and the importance of accessible FASD-informed family supports. Most participants were college- or university-educated and engaged in paid employment, with approximately one in four participants holding graduate or professional level degrees. More than 40% of caregivers reported that they did not have enough, or had *just* enough, income to make ends meet, and almost one quarter of the sample reported making less than $50,000 a year. There was a near-significant trend in well-being based on annual household income, whereby caregivers with income < $50,000 reported poorer quality of relationships with their relatives compared to caregivers with higher incomes. These findings add to the evidence that financial strain is a relevant factor for caregivers of those with FASD, which may contribute to stress and increase family-wide tensions (Bobbitt et al. 2016).

With poverty on the rise in Canada, alongside skyrocketing costs of living in Canada and internationally, it is important to recognize the additional challenges, including financial barriers, that may be experienced by families raising children, youth, and young adults with FASD. In Canada alone, it is estimated that one in six people with a disability live in poverty and one in three people with a disability living alone live in poverty (Disability Without Poverty and Campaign 2000 2024). Although the intersections of FASD and poverty have received limited attention in the academic literature, it has been suggested that many people with FASD may fall into the "poverty trap" (Thanh et al. 2013). In addition, given the uniqueness and complexity of FASD, comprehensive physical, neuropsychological, speech and language, educational, and occupational assessments are often required to assist caregivers in advocating for specialized interventions and services for their loved ones. Without publicly funded supports for these assessments, caregivers are faced with the dilemma of paying for private assessments or not having the tools to appropriately assist with some of the challenges associated with FASD, thus increasing the likelihood of adverse outcomes in social interaction, academic achievement, self-esteem, and family disruption. Given that poverty is a significant social and structural determinant of health, understanding how and why families may experience financial strains, alongside balancing other life stressors such as caregiving demands, their own employment, their spouse's employment, and other caregiving responsibilities (i.e., for their own parents or other extended family members) is crucial in informing supports and services for caregivers of individuals with FASD.

Notably, almost all (87%) participants in this study reported that caregiving impacted their employment, whereas only 50% reported that caregiving impacted their spouse's employment (analysis here was limited to caregivers who were married or in common-law relationships). Because almost all respondents identified as women (94.6%), this data reinforces the inequitable gendered parenting dynamic of women being responsible for many roles and hidden labor, including emotional and cognitive labor, domestic responsibilities, and childrearing (Schmidt et al. 2023). This imbalance is further enhanced for women caregivers of people with disabilities, particularly when it comes to unpaid labor (Sharma et al. 2016). Our findings also align with past evidence demonstrating that productivity loss is a significant demand with impacts on well-being for many caregivers and that caregiving for someone with a disability is linked to reduced employment opportunities (Cejalvo et al. 2021).

In our study, caregivers who were employed and did not have to stop working because of their caregiving role reported higher levels of well-being, perhaps because of their ability to uphold multiple identities and priorities that were important to them. This finding reflects other evidence where higher well-being is identified among parents who are employed compared to those who are not (Chou et al. 2010). It is possible that being employed provides opportunities for caregivers to spend time outside of the home, expanding their focus and energy beyond parenting-related issues to include interaction and connection with other adults with similar interests. Our finding that participants whose employment was unaffected by caregiving reported higher quality of relationships with their relatives, specifically, points again to the potential impacts of financial strain on whole-family well-being. Notably, retired caregivers had significantly lower stress levels and a greater sense of community belonging than other participants. This could relate to retirement being a time of increased opportunity for leisure activity, sense of agency, and quality of relationships (Kesavayuth et al. 2020). It could also be that once retired, participants experience a reduction in caregiver burden and more time for connection with

a broader community, which may in turn promote well-being (Kalenkoski and Oumtrakool 2017).

The predominantly woman representation in our participant group also highlights important identity considerations and lifespan shifts for working mothers of people with FASD. Given that roughly one in four participants in our sample had advanced educational degrees but were not currently employed, there seems to be a relationship between caregiving among professional women and a "motherhood penalty" of navigating caregiving responsibilities alongside professional demands (Halrynjo and Mangset 2025).

Furthermore, our finding that primary caregivers generally held higher levels of education than their spouses but reported greater impacts on their employment may speak to differences in career trajectory and disruption for these caregivers. Relatedly, trends in well-being based on spouse education levels neared significance, with caregivers reporting stronger relationships with partners who had higher education levels. This finding is consistent with previous research associating education with marital satisfaction and divorce rates (Ahn and Winters 2025), and may reflect differential impacts on career pathways where people with higher education may hold more advanced occupational goals which are disrupted by caregiving responsibilities. This idea is further supported by the finding that caregivers whose employment was unaffected by their caregiving responsibilities had higher levels of well-being than those who experienced employment disruption, specifically in terms of stronger relationships with relatives. In the broader literature, higher educational attainment has been linked to greater emotional well-being, especially for women (Lee and Yang 2022). Similarly, caregiver self-efficacy, life purpose, and diversity in social support systems are all associated with better physical health outcomes and lower levels of loneliness, depression, and other mental health needs (Cejalvo et al. 2021). Together, these findings emphasize the importance of ensuring fulfilling, enriching, and diverse experiences, career-related or otherwise, beyond the caregiving role for parents of people with FASD.

4.2 | Nature of the Caregiver Relationship

Most respondents in this study identified as non-family adoptive parents, and only 4% identified as biological parents of someone with FASD. These findings contrast trends in other neurodevelopmental disorder research, such as studies of ADHD and autism, which mainly include biological parents (Rennie et al. 2025). Even though participation in the current survey was entirely anonymous, it is possible that biological caregivers experienced concerns about stigma, judgment, and/or prejudice as they do in other contexts and systems such as healthcare, education, and child welfare (Corrigan et al. 2019; Wilson et al. 2024). Additionally, it may be that caregivers and families not reflected in our study are uniquely disconnected from services and supports and face distinct barriers to research participation, such as involvement with the child welfare system, challenges with mental health, and/or compromised social and structural determinants of health. This study provides further evidence of the need to promote equitable access to services for all families and to bring them into networks of support that address shared caregiving challenges rather than isolate and alienate. This emphasis is especially important for biological families who have been shown in past research to experience compounding impacts of shame and lower levels of self-compassion than non-biological caregivers (Biddle et al. 2020).

Interestingly, overall past-year well-being did not significantly differ based on caregiver type after controlling for multiple comparisons (though adoptive parents reported near-significant stronger spousal relationships). Existing literature in this area is mixed, with some researchers reporting no differences in well-being based on caregiver type and others reporting distinct and unique experiences across types (Biddle et al. 2020; Bobbitt et al. 2016; Ilchena et al. 2023). Exploring both the unique and shared experiences of caregivers can reveal important insights into areas for support and can provide opportunities for common understandings of the strengths and challenges associated with FASD no matter the family structure or type. At the same time, unique impacts on families must be taken into consideration, such as the experiences of shame and stigma among biological mothers (e.g., Bell et al. 2016; Corrigan et al. 2019; Wilson et al. 2024), or the distinct needs and challenges of kinship families (e.g., Clement et al. 2023). Considering these diverse perspectives will help to ensure adequate representation in both quantitative and qualitative research as well as inclusion in policy and service delivery decisions. Finally, regardless of caregiver type, most participants in this study reported that they had *no support* from outside the home to help care for their family members with FASD, underscoring again the need for more formalized support structures and accessible FASD-informed services for all families (Bobbitt et al. 2016; Petrenko et al. 2014).

4.3 | Age and Life Stage

The experience of parenting someone with a disability can change across ages and life stages. In the current study, we found that caregivers of children (up to 12 years) with FASD reported significantly higher levels of stress than those caring for adults (> 18 years). This trend is surprising, given the relatively well-established literature that caregivers of individuals with FASD often express significant fear and concern for the future of their children with FASD, particularly when they are no longer around to care for them (Clement et al. 2023). This finding also contrasts with other studies indicating that parents of adolescents with FASD experience the highest levels of stress compared to other age groups (Bobbitt et al. 2016) and that adolescence may be a particularly turbulent time for families (Watson et al. 2013). It is possible that caregivers of younger children with FASD in this study experience increased worry about the future and stressors to come, especially if they have been exposed to deficit-based and stigmatizing narratives about adverse outcomes and difficult life trajectories of people with FASD (Bell et al. 2016). In contrast, it may be that older dependents with FASD represented in the current study have achieved greater stability and interdependence and that caregivers experience a sense of relief, even if they still hold concerns for their future. This idea aligns with emerging evidence indicating that older

adults with FASD experience less challenges with certain areas of cognitive functioning and fewer difficulties with housing and independent living than younger people with FASD (Temple et al. 2025). Moreover, caregivers with older dependents may experience increased familiarity with FASD, having already navigated many challenges and strengths across the lifespan.

Age-related trends in this study may also relate to our findings regarding retirement, possibly explained by caregivers in later life stages experiencing reduced burden alongside increased leisure time and quality of relationships with their families and friends. Our finding that stress levels were higher among caregivers with younger dependents than those with adult dependents may reflect increased opportunities for bonding as their child progresses into adulthood, promoting family togetherness and connection (Kautz-Turnbull et al. 2022). Indeed, finding reward and purpose, feeling love toward their child, celebrating small accomplishments, accessing learning opportunities, accepting their children for who they are, and experiencing family togetherness are all perceived by caregivers to be protective factors and to build resilience (Clement et al. 2023; Coons et al. 2016). The quality of the relationship between a caregiver and the person receiving care plays an important role with respect to caregiver life satisfaction and quality of life (Hammond et al. 2014; Huo and Kim 2023).

4.4 | Emerging Patterns

In terms of specific domains of well-being, participants most often reported impacts (and the most *negative* impacts) of caregiving on their stress levels and emotional health, adding evidence to trends in the existing literature that emotional well-being is an important correlate of caregiver stress (Bobbitt et al. 2016). Caregivers in this study also expressed relatively low levels of social support and community belonging. Other researchers have similarly reported that caregivers of individuals with FASD experience high levels of social strain, and pointed to social connection and peer support, particularly emotional support, as an important area of need (Blake et al. 2025; Bobbitt et al. 2016). One unique consideration in this study is that data collection was initiated shortly after the onset of the COVID-19 pandemic. Coupled with relatively low levels of reported social connection, our finding that participants generally reported poorer well-being in the last 12 months compared to the last 10 years may reflect temporal trends related to the global impacts of the pandemic and family well-being. It is well established that the pandemic had disproportionately negative impacts on people with disabilities and their families (e.g., Goyal et al. 2023), but research specific to FASD is scarce (e.g., Champagne et al. 2023).

Contrarily, caregiver relationships with their spouses were less often (and less negatively) impacted in this study, and participants consistently rated their relationships with spouses as their strongest area of well-being. This finding reflects other recent research findings, highlighting partner support as a significant protective factor for mental health among caregivers of children with FASD (La Fico et al. 2025) and speaks to the importance of these close relationships. Although spousal relationships may be relatively insulated from stress for some caregivers, wider support networks and systems of care and community are lacking for caregivers of people with FASD. This finding points to the need for targeted supports for mental health and coping for caregivers and families, and supportive relationships as a clear area of strength. Interventions that help caregivers maintain strong relationships with their spouses and improved relationships with peers and their broader communities may be key in promoting whole-family well-being.

One unique contribution of this study is the collection of information pertaining to gender identity among individuals with FASD. Although reported by caregivers on behalf of their children and adults with FASD, this study is one of the first, to our knowledge, to report descriptive information of this nature. This data contributes to emerging evidence of the potentially higher rates of gender diversity among people with FASD compared to the general population (Dwomoh and Harding 2023) as has been suggested among other disability populations. Given the increased awareness of and attention to gender and sexual diversity among people with disabilities, understanding how people with FASD experience sexuality and gender, as well as the intersectional complexities and adversities potentially faced by members of multiple equity-seeking communities, is critical in informing best practices in service and care for individuals with FASD and their supporters.

4.5 | Implications for Practice and Policy

Existing interventions developed to support caregivers of people with FASD show promising results. Commonly reported outcomes from these interventions include increased sense of parent self-efficacy, reduced parent stress, better caregiver self-care, reduced child behavior challenges, increased child regulation and self-esteem, improved parent–child relationships, greater family needs being met, and increased caregiver FASD knowledge and advocacy (Olson et al. 2023). There is also emerging evidence for the success of interventions that specifically focused on parent well-being, such as those targeting caregiver self-compassion (Biddle et al. 2020) and social connection (Blake et al. 2025). Results from the current study complement this literature and highlight the need for expanding the scope of these efforts, along with policies to strengthen and sustain large-scale family-based care systems. Specific areas for advancement include financial support, gender-informed care, FASD-informed respite opportunities, early interventions, supports that persist/evolve across life stages, increased access to FASD services for families in rural and remote locations, and targeted efforts to strengthen caregivers' sense of community.

4.6 | Limitations and Considerations for Future Research

Findings from this study reflect important trends in the experiences of well-being in a large international sample of caregivers of individuals with FASD rooted in a socioecological context. However, participants were a relatively homogenous group of middle-aged, educated, adoptive parents who identify as women, which limits the generalizability of results to other groups. The demographic characteristics of participants in this study align with trends identified in past FASD caregiver research and

indicate that more intentional investigation into underrepresented caregiver groups (e.g., non-adoptive parents, caregivers who identify as men, 2SLGBTQIA+ caregivers, BIPOC caregivers, those with a lower socioeconomic status, those residing in rural and remote communities, and those living outside of North America) will be crucial in future work (Rennie et al. 2025). These factors and their intersections are relevant and must be understood in the context of social and structural determinants of health as they undoubtedly influence experiences of health and well-being (Lopez and Gadsden 2017).

Another limitation of this study was that data were cross-sectional, and therefore, longitudinal changes could not be explored. As well, all participants in this study had at least one dependent with FASD, and without a comparison group, it is not possible to examine how well-being differs between caregivers of children, youth, and adults with and without FASD. Moreover, we lack specific data on ethnicity for both caregivers and their dependents. Although questions about ethnicity were included in the survey, these items were open-ended and difficult to code consistently, resulting in large amounts of missing data in this area. Relatedly, this study did not involve examination of the "outer layers" of socioecological frameworks, such as policies or government investment related to FASD, cultural norms, impacts of media, or environmental influences, and how they may affect caregiver well-being. Expanded exploration of these factors will provide important insight into other potential areas of vulnerability and opportunities for support. Finally, continued and long-term investigation into the experiences of caregivers with diverse backgrounds and experiences will provide insight into how trends in well-being may differ for certain groups, evolve over time, and how supports may influence family health and well-being trajectories.

5 | Conclusion

Well-being among caregivers of individuals with disabilities is complex, dynamic, and situated within the broader context of social and structural determinants of health. For caregivers of people with FASD, many challenges and barriers resemble those faced by other caregiver populations, yet their experiences of stress are unique and often more severe. Findings from the current study add to the growing literature on stress, coping, and overall well-being among caregivers of children and adults with FASD. Understanding the ways in which sociodemographic and ecological factors may relate to caregiver well-being provides insight into possible areas for intervention and priorities for policies that promote stability, leverage strengths, and foster healthy outcomes in families of people with FASD across the lifespan.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Appendix A: Well-Being Items

Over the last 12 months, how would you rate...	0 (significant stressor)	1	2	3	4	5 (significant strength)
Your physical health?	O	O	O	O	O	O
Your emotional health (e.g., sadness, anger, frustration, hopelessness)?	O	O	O	O	O	O
Your level of stress?	O	O	O	O	O	O
The quality of relationship with your spouse/partner?	O	O	O	O	O	O
The quality of relationship with your relatives?	O	O	O	O	O	O
The quality of your social support?	O	O	O	O	O	O
Your sense of belonging in your community?	O	O	O	O	O	O

Which of the following areas of well-being have been impacted by your role as a caregiver of someone with FASD? Select all that apply.

- Physical health
- Emotional health (e.g., sadness, anger, frustration, hopelessness)
- Level of stress
- Quality of relationship with your spouse/partner, if applicable
- Quality of relationship with your relatives
- Quality of social support
- Sense of belonging in your community

To what degree has caring for someone with FASD impacted your...	0 (significant stressor)	1	2	3	4	5 (significant strength)
Physical health?	O	O	O	O	O	O
Emotional health (e.g., sadness, anger, frustration, hopelessness)?	O	O	O	O	O	O
Level of stress?	O	O	O	O	O	O
Quality of relationship with your spouse/partner?	O	O	O	O	O	O
Quality of relationship with your relatives?	O	O	O	O	O	O
Quality of social support?	O	O	O	O	O	O
Sense of belonging in your community?	O	O	O	O	O	O