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Mixed-Method Study of the Experiences and Routines of Caregivers of Children with Type 1 Diabetes

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Mixed-Method Study of the Experiences and Routines of Caregivers of Children with Type 1 Diabetes

Abstract

Background: Type 1 diabetes is one of the most prevalent chronic childhood conditions that affects family roles, routines, and the ability to participate in meaningful occupations after a child's diagnosis. Because of the complex health management routines required to ensure the safety and well-being of a child with type 1 diabetes, caregivers may experience decreased overall health and well-being.

Method: This sequential mixed-method study used a cross-sectional survey (n = 37) and phenomenological interviews (n = 6) to explore burden (the Burden Scale for Family Caregivers), quality of life (the WHO Quality of Life-BREF), and role engagement (a questionnaire) for caregivers of children living with type 1 diabetes.

Results: The findings suggest that as caregiver burden increased, quality of life decreased ($r = -.73$, $p < 0.05$). The caregivers described how caring for their children affected relationship maintenance with spouses, family, and friends; impacted their productive occupations involving work, home responsibilities, self-care, and finances; and revealed a pressing need for education and advocacy.

Conclusions: The findings highlight the importance of supporting caregivers in their roles in providing diabetes management care to children with type 1 diabetes. Future research is needed to develop and test novel occupational therapy interventions aimed to simultaneously improve family-centered participation goals that support the medical management of diabetes care and the caregiver's psychosocial well-being.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

type 1 diabetes, quality of life, caregiving, chronic conditions

Credentials Display

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Approximately 187,000 adolescents and children under 20 years of age are living with type 1 diabetes (T1D), making T1D one of the most prevalent chronic childhood conditions (Centers for Disease Control and Prevention [CDC], 2020). More alarming are the increasing incidence rates in the United States and globally, with predictions of diagnoses to increase to nearly 600,000 by 2050 (CDC, 2020; Imperatore et al., 2012; Mobasserri et al., 2020). T1D is an autoimmune disease with no known cause or cure, typically developing during childhood (American Diabetes Association [ADA], 2021). The condition frequently presents with little warning, with one-third of children developing life-threatening diabetic ketoacidosis by the time of diagnosis (ADA, 2021). There are no known modifiable risk factors for prevention. Diabetes health management becomes imperative to prevent secondary health complications, such as cardiovascular disease, neuropathies, blindness, neurocognitive decline, stroke, tissue and organ damage, and even death (CDC, 2020). Because of the complexity of the child's health management activities, caregiver involvement is essential. The hypervigilance required to ensure targeted blood glucose levels can place large amounts of stress on caregivers (Commissariat et al., 2019).

After a child's T1D diagnosis, significant demands may be placed on the family, and changes in daily routines frequently occur (Jönsson et al., 2012). Families are thrust into a new routine focused on daily health management activities. Some of these routines include continuous monitoring of their child's blood glucose levels, nutritional needs, activity and sleep patterns, stress and emotional responses, and medication administration, to name a few. In addition, the caregivers become inundated with time and financial strain for travel for new medical appointments, management of health care insurance policies, and medical bills, causing some caregivers to cease employment or locate a job that allows for increased flexibility (Herbet et al., 2017).

Diabetes health management includes unpredictable activity patterns, routines, and diet patterns while the child is developing physiologically, cognitively, behaviorally, and socio-emotionally (Gallegos et al., 2022; Streisand & Monaghan, 2014). Families may have difficulty with the day-to-day tasks associated with T1D, such as administering medication, interacting with medical personnel, and gaining access to the care they need (Pennafort et al., 2016). The increased demand and responsibility of caring for a child with T1D can cause elevated stress levels and add pressure on the caregiver in addition to typical child caretaking responsibilities (Streisand & Monaghan, 2014). Caregiver burden may compromise the family's quality of life and the caregiver's ability to participate in meaningful everyday activities.

Diabetes management affects a child's daily routine, including playtime, mealtime, interactions with peers and family, and social experiences in school or extracurricular activities (Fornasini et al., 2020). Children with T1D are more likely to have difficulties at mealtime, such as taking longer to eat, picky eating, and disruptive behaviors (Streisand & Monaghan, 2014). Caregivers may have difficulty finding daycare and school settings that will care for their child, which in turn affects their employment choices (Herbert et al., 2017). The financial burden is increased because of the cost of medical care, which also impacts employment decisions (da Costa Silveira Martins et al., 2013; Herbert et al., 2017). Differences in family routines and structure affect a caregiver's ability to care for their child and maintain a stress-free home.

Caregivers of children with T1D experience increased stress, depression, and anxiety (Smith et al., 2018). Caregivers who used coping strategies, such as acceptance, relied on social relationships, used supportive communication, experienced less depression, and had more collaboration and adherence to diabetes management from their child (Goethals et al., 2019; Jaser et al., 2014; Pennafort et al., 2016). Others who used disengagement and controlling communication experienced more stress, defiance, and less internalization of diabetes management (Goethals et al., 2019; Jaser et al., 2014;

Pennafort et al., 2016). Attitude, coping strategies, and communication style may affect stress levels and disease management.

Quality of life may be affected by stress and perceived burden. Research supports that higher levels of perceived burden lead to poorer physical and psychosocial well-being for caregivers (Capistrant et al., 2017; Gallegos et al., 2022). Quality of life measures (e.g., family cohesion, physical, social, cognitive, and emotional function) and acceptance and understanding are negatively correlated with stress from caring for children with T1D (Jönsson et al., 2014; Moreira et al., 2013; Saoji et al., 2018). When caregivers feel high stress and burden, their quality of life declines, which can affect glycemic control (CDC, 2020).

Roles are a set of behaviors created by society and culture that can provide structure for occupations and activities (American Occupational Therapy Association, 2020). Caregivers of children with T1D reported high stress levels because of changes in family routines and added responsibilities while managing a child's health management routines (Gallegos et al., 2022; Whittemore et al., 2012). While it is known that caring for a child with a chronic condition affects a caregiver's quality of life, there is a paucity of information about how caregiver burden and quality of life impact the caregiver's occupational roles. Therefore, the purpose of this study was to examine how caring for a child with T1D affects the caregiver's roles, routines, quality of life, and perceived caregiver burden. Occupational therapists may use this information to provide family-centered care to improve the caregiver's performance and competence in providing their child's T1D health management routines.

1. What correlations exist between caregiver burden and quality of life for caregivers of children living with T1D?
2. How do caregivers experience role changes when raising a child living with T1D?

Method

Research Design

The research study used a sequential mixed method study design to explore both the potential relationships and the lived experience of individuals caring for children with T1D on quality of life, caregiver burden, and everyday roles. Using quantitative surveys followed by in-depth interviews allowed the researchers to enrich the findings on caregiver burden, quality of life, and role engagement and increase the depth and breadth of knowledge by collecting, analyzing, and interpreting both qualitative and quantitative data in a single study. The quantitative approach used a descriptive correlation design, while the qualitative approach used a phenomenological approach (Moustakas, 1994; Portney, 2020). This inductive process allowed for the discovery and elaboration of themes and concepts during the interview process. The Creighton University Institutional Review Board (IRB) approved the study, and all caregivers provided consent.

Participants

Caregivers were recruited from across the United States using a nonprobability convenience sampling method, allowing the researchers to contact caregivers who were readily available in multiple settings and geographic locations (Brown, 2016). Inclusion criteria included unpaid primary caregivers of a child aged 19 years or younger with T1D. Exclusion criteria included caregivers who did not live with the child with T1D, as that context would have a different impact on the caregiver. Six caregivers provided their contact information at the end of the online survey to participate in the semi-structured interviews to gather in-depth information.

Instruments

The quantitative component of the study included an online survey with demographic questions, the Burden Scale for Family Caregivers (BSFC), and the World Health Organization Quality of Life - BREF Assessment (WHOQOL-100/WHOQOL-BREF). The qualitative component of the study included a semi-structured interview to explore further how caregiver burden, quality of life, and occupational roles were impacted by raising a child with T1D.

The BSFC. The BSFC determined the level of burden caregivers feel when caring for a child with T1D. The BSFC uses a 4-point Likert scale to assess attitudes and beliefs on the amount of burden the caregiver experiences. This scale's internal consistency was tested using split-half reliability, which obtained values higher than .80 (Elmar et al., 2003). Test-retest reliability was found to be .94 (Elmar et al., 2003). Construct validity was examined based on the idea that perceived burden and perceived stress are correlated, as the burden is a type of stress. Pearson's correlation coefficient was .56 ($p < .001$) (Elmar et al., 2003).

The WHOQOL-100/WHOQOL-BREF. The WHOQOL-BREF examined the quality of life caregivers experienced when caring for a child with T1D (World Health Organization [WHO], 1996). The WHOQOL-BREF is a 26-question short form of the WHO Quality of Life-100 and addresses four domain-level profiles, which are physical health, psychological, social relationships, and environment (WHO, 1996). The assessment demonstrates good internal consistency with a Cronbach alpha value ranging from .71 to .86 in the domain scores (WHO, 1998). More test-retest reliability data needs to be collected, but overall, the Pearson's correlation coefficient was .78 (WHO, 1998). Findings showed that the assessment produces comparable scores and results over an extended period if no interventions or life-changing events occur.

Questionnaire. The questionnaire included five demographic questions and six open-ended questions with additional probing questions garnering in-depth responses from the caregivers (see Table 1). The researchers developed the semi-structured questionnaire, using literature to create questions to gather caregivers' lived experiences related to role participation, completion of daily tasks, relationships, and self-care routines. An expert panel ($n = 4$) of experienced health care qualitative researchers reviewed the questionnaire for content validity before completing caregiver interviews, with no modifications suggested by the panel.

Procedures

Participant recruitment for the survey portion of the study occurred through social media posts, professional networks, Facebook support groups for caregivers of children with T1D, and a regional Juvenile Diabetes Research Foundation (JDRF) chapter that distributed an email with study information. After survey completion, the caregivers could participate in an individual interview by checking "yes" in the survey and providing contact information. The first and second authors then followed up with all interested caregivers via e-mail to schedule an interview. The interviews were conducted via a phone conversation and were semi-structured, with the authors having a template of questions and asking follow-up questions as needed for clarification. The researchers digitally recorded and transcribed all individual interviews verbatim.

Data Analysis

For the quantitative portion, descriptive statistics were used to report the demographics of caregivers and cared children. Twenty-eight Likert scale questions of BSFC were summed up as a total score. Based on the cutoff of the total score, the burden was categorized as none to mild, moderate, and severe to very severe groups. A total score of QOL was calculated based on 26 Likert scale questions. Four domain scores were calculated and then converted to QOL 100 scale. The correlation between the total score of BSFC and QOL was analyzed using the Pearson correlation coefficient.

Each of the four domain scores was compared between three levels of burden using one-way ANOVAs. All statistical analyses were performed in IBM SPSS Statistics for Windows, Version 26.0 (IBM Corporation, 2019). A p-value less than 0.05 was considered statistically significant.

Table 1
Interview Questionnaire

Main Question	Follow-up Questions
1. Demographics	a. How many children do you have? b. How many have type 1 diabetes? c. How long since their diagnosis? d. Do they have other diagnoses? e. How much care do you give (% of your time)?
2. How does caring for a child with type 1 diabetes affect your ability to get things done, such as:	a. Working? b. Doing household chores, including running errands? c. Making food? d. Other daily tasks and responsibilities?
3. For activities that cause stress or are difficult because of the challenges of caring for a child with T1D, do you have a backup plan to complete those activities or a way to ease those stressors?	
4. How does caring for a child with type 1 diabetes affect your relationship roles:	a. As a spouse? b. As a friend? c. As a parent to other children?
5. How does being a caregiver for a child with type 1 diabetes affect your health?	a. Are you able to manage your appointments? b. Do you have time for your mental health and well-being activities (exercising, eating right, meditation, yoga)?
6. Reflecting on your daily routine, are there other hobbies or activities that you would like to participate in? How is your participation in these tasks affected by caring for a child with type 1 diabetes?	
7. What support do you have?	

The qualitative data were analyzed using a phenomenological analysis method (Moustakas, 1994). Each interview was recorded and transcribed by a researcher who did not conduct the interview. The researchers shared the transcripts and separately completed the phases of analysis of familiarizing themselves with the data, considering the significance of the caregivers' lived experiences, clustering statements into meaning units of experience, and synthesizing units of experience into themes (Moustakas, 1994). The researchers initially completed data analysis separately to ensure research triangulation and then met together to consensually define and name the themes (Curtin & Fossey, 2007).

To establish trustworthiness, the researchers recruited caregivers from multiple geographic locations to obtain a breadth of information to ensure space triangulation (Curtin & Fossey, 2007). The authors kept an audit trail and debriefed with the fourth author, an experienced qualitative researcher. After training by the fourth author, the first two authors coded interviews independently, compared notes to determine themes to maintain consistency, and identified and minimized bias for research triangulation (Curtin & Fossey, 2007). The mixed-method study design ensured method triangulation (Curtin & Fossey, 2007). For reflexivity, the researchers kept notes while coding the qualitative data to reflect on the influence of their perspectives on coding and to note how these perspectives may have changed over time (Curtin & Fossey, 2007).

Results

Demographic Information

Forty-three caregivers completed the demographic section of the survey, and 37 completed the entire survey (see Table 2). Most caregivers were female (95%; $n = 41$), and more than three-fourths of the caregivers worked outside the home, either on a full-time or part-time basis (81%; $n = 35$).

Table 2
Survey Caregivers' Demographics

Characteristics	Count (n=43)	%
Caregiver gender		
Male	1	5
Female	41	95
Geographic location		
West	16	37
Midwest	12	28
Northeast	7	16
South	5	12
Unknown	3	7
Work outside of the home		
Yes, 32+ hrs. a week	26	60
Yes, part-time	9	21
No	7	16
Unknown	1	2
Experience caring for a child with T1D		
Less than one year	11	26
1–2 years	9	21
3–5 years	16	37
6–10 years	5	12
11+ years	2	5
Extent of care caregivers provide individually for the child(ren)		
0–24% of the care	4	9
25%–49% of the care	8	19
50%–74% of the care	10	23
75%–100% of the care	21	49
Have more than one child with T1D		
No	42	98
Yes, 2 children with T1D	1	2
Current age of the oldest child with T1D		
Birth to 3 years	0	0
4–6 years	7	16
7–10 years	15	35
11–14 years	10	23
15–18 years	11	25
Children with T1D have other medical conditions diagnosed by a medical provider?		
Yes	11	26
No	31	72
Other, seeking diagnosis of celiac	1	2
Diagnosis		
Abdominal migraines	1	2
Anxiety disorder	1	2
Asthma	3	6
Autism spectrum disorder	1	2
Celiac	3	6
Grave's disease	1	2
Hashimoto's Disease	2	4
Allergies	1	2
Growth Hormone Deficiency	1	2
Depression	1	2
Accessible and helpful support		
Family	25	58
Friends who have children with T1D	13	30
Friends who do not have children with T1D	14	32
Local support groups	3	6
Online support groups	23	53
Other		
ADA staff	1	2
Barbara Davis Center	1	2
My husband who is T1D	1	2
School nurse	1	2
Number of children under the age of 19 living in the home with the child(ren) with T1D?		
1–2	29	67
3 or more	5	12
None	9	21
Adults over the age of 19 living in the home with the child with T1D		
None	19	44
1	18	42
2 or more	6	14

Note. ADA = American Diabetes Association; T1D = type 1 diabetes.

The caregivers resided in various geographic locations, with most of the caregivers reporting throughout the United States. The caregivers' experience caring for a child with T1D ranged from less than 1 year (26%; n = 11) to 11 or more years (5%; n = 2), with most of the caregivers providing 50%

or greater of the care (72%; $n = 32$). Only one participant had more than one child with T1D (2%). The children with T1D ranged in age from 4–6 years (16%; $n = 7$) to 15–18 years (25%; $n = 11$). Most of the children had no other medical diagnosis other than T1D (72%; $n = 31$). The caregivers reported family as their most helpful and accessible support (58%; $n = 25$), followed by online support groups (53%; $n = 23$), friends without children with T1D (32%; $n = 14$), friends with children with T1D (30%; $n = 13$), and local support groups (6%; $n = 3$).

Six people participated in the phone interviews. There were five females and one male interviewed. Most of the caregivers reported providing 50% or greater of the care for their children with T1D (67%; $n = 4$). All interviewed caregivers had one child with T1D (100%; $n = 6$). Most of the caregivers' children only had the T1D diagnosis, except for one participant's child who also had asthma and Grave's disease (17%; $n = 1$). The ages of the caregivers' children at diagnosis ranged from 2 to 14 years of age. During the interview, the caregivers reported 2 to 4 years since their child's diagnosis of T1D. See Table 3 for interview participants' demographics.

Table 3
Interview Caregivers' Demographics

Name	Anne	Beth	Holly	John	Mary	Sarah
Number of Children	3	3	3 living, 1 deceased	2	1	1
Age of Children (years)	8,5,3	12,8,6	23,16,13	5,2	6	13
Age of Child with T1D (years)	8	6	16	5	6	13
Number of Children with T1D	1	1	1	1	1	1
Child Age at Diagnosis (years)	6	2	14	2.5	4	10
Years Since the Diagnosis	2	4	2	2	2	3
Other Diagnoses	no	no	Asthma, Grave's Disease	no	no	no
Percentage caregivers provide care	50%	85%	95%–100%	25%–50%	95%	30%
Adults in home	M+F	M+F	M+F	M+F	M+F	^b

Note: T1D = type 1 diabetes; M+F = mother and father. ^a = Pseudonyms were used for the confidentiality of caregivers. ^b = Only mother, at father's house 50% of the time.

Survey Results

Of the 35 caregivers who completed the BSFC, 21 (60.0%) reported none to mild caregiver burden, 11 (31.4%) reported moderate caregiver burden, and three (8.6%) reported severe to very severe caregiver burden (see Table 4) when caring for their children with T1D.

The caregivers rated their physical health subdomain for quality of life as the most impacted by providing care to their child (65.24 ± 15.55), followed by the environment subdomain (65.13 ± 17.94), social relationships subdomain (57.71 ± 18.64), and psychological subdomain (56.95 ± 19.50). To analyze the WHOQOL-BREF scores, the researchers completed an ANOVA analysis to determine how the mean quality of life scores differed between each level of burden and if the mean scores increased when the levels of burden increased or decreased. There were significant differences in mean quality of life scores between the three levels of burden across all four domains (see Table 4). Significant linear trends were also noted in all four domains, indicating as a participant's level of burden increased, the quality of life decreased (see Table 4).

Table 4
Comparisons of Mean Domain Scores of the WHOQOL-BREF among Three Levels of BSFC

Domain	Level of BSFC (mean \pm SD)			p for ANOVA	p for trend
	None to Mild (n = 21)	Moderate (n = 11)	Severe to Very Severe (n = 3)		
Physical Health	71.48 \pm 14.51	59.27 \pm 15.64	52.00 \pm 6.93	0.027	0.037
Psychological Health	63.43 \pm 17.37	52.36 \pm 18.95	29.00 \pm 3.46	0.007	0.003
Social Relationships	62.19 \pm 16.99	59.64 \pm 18.73	27.00 \pm 3.46	0.008	0.002
Environment	73.43 \pm 13.82	60.91 \pm 13.07	39.67 \pm 13.05	0.001	<0.001

Note. SD = standard deviation; WHOQOL-BREF = World Health Organization Quality of Life-BREF; BSFC = Burden Scale for Family Caregivers.

Pearson's correlation coefficient was used to compare the relationship between participant scores on the WHOQOL-BREF and the BSFC. Pearson's Correlation coefficient between the two scores ranged from -0.525 for the domain of physical health to -0.661 for the domain of environment, with all p values equal to or less than 0.001, as shown in Table 5.

Table 5
Correlation Between BSFC and WHOQOL-BREF Domains

Correlation with Burden	r	P
Physical Health	-0.525	0.001
Psychological Health	-0.630	<0.001
Social Relationships	-0.561	<0.001
Environment	-0.661	<0.001

Note. r = Pearson correlation coefficient; BSFC = Burden Scale for Family Caregivers; WHOQOL-BREF = World Health Organization Quality of Life- BREF.

Interview Results

The researchers conducted phone interviews with six caregivers to examine their perceptions of how raising a child with T1D impacted their ability to engage in everyday roles. The results showed that caretaking responsibilities impacted stress and anxiety and affected the caregiver's ability to engage in everyday roles. New roles and routines were established to incorporate the needs of their child, which in turn caused other roles and routines to deteriorate. Three themes emerged from the in-depth interviews: (a) relationship maintenance, (b) the impact on productive occupations, and (c) the need for education and advocacy.

Relationship Maintenance

The time and energy demands of caring for a child with T1D altered relationships with spouses, friends, and family members. The caregivers expressed loneliness and a lack of support from friends and family. Subthemes included preserving the spousal relationship, difficulty managing connections with friends, and difficulty taking care of nuclear and extended family members.

Preserving the Spousal Relationship. The caregivers had mixed thoughts about how caring for a child with T1D affected their role as a spouse. Some caregivers believed caring for a child with T1D brought a deeper connection to their spouses to form co-parenting teams. Sarah stated that she "share[s] the same stress" with her spouse, and Mary relayed that the diagnosis "banded them together" and "made our relationship stronger." Other caregivers believed caring for a child with T1D led to arguments and increased marital tension. Some of the caregivers reported that their marriage became a lower priority. Beth said, "We kind of were not there for each other." The perceived lack of understanding and support with the diabetes management tasks led to a lack of trust. Holly stated about her husband: "He pretty much doesn't really understand or do much with the diabetes management."

Difficulty Managing Connections with Friends. The caregivers had difficulty maintaining friendships after their child's diagnosis of T1D. Mary stated, "We lost a lot of our friends after the diagnosis, um, they just stopped calling." A few caregivers reported that friends were supportive, empathetic, and compassionate but had difficulty understanding the burden of care. One common dilemma was finding care for their child so the caregiver could spend time alone with a spouse or friends. Often, babysitters or grandparents were unable or unwilling to learn how to care for the child. John explained, "We have to plan things pretty far in advance and then subject to having to cancel." Friendships became hard to sustain after their children's diagnosis.

Difficulty Taking Care of Nuclear and Extended Family Members. The participants' responses about the effects on family relationships were consistent; all felt the strain. The needs of a child with T1D must be met before the needs of the siblings, at times. One mother, Anne, felt her sibling child acted sick to get her attention. "When something's wrong, that's how you get mommy's

full attention,” she stated. Conversely, several of the caregivers reported that the siblings were often patient, understanding, and flexible with the needs of the child with T1D.

Relationships with extended family were problematic. For some, it affected their ability to visit family who lived in other cities. Holly was unable to perform expected roles, such as caring for her aging parents. She explained, “She [her sister] had gotten very angry with me because I wasn’t able to come up there and help out.” Some families were supportive, including grandparents who tried to be helpful; however, the caregivers did not feel the extended family members understood or were fully trained to care for their child by themselves. Relationships with family members ranged from those who were trying to be supportive to those who were critical and angry.

Impact on Productive Occupations

Caring for a child with T1D affected the caregivers’ ability to complete occupations at work and home. The caregivers spoke of difficulty maintaining their health and self-care routines. The financial responsibility, even after health care insurance, was a burden. Subthemes included the impact on participation in work obligations, home responsibilities, the ability to maintain self-care routines, and the burden of financial responsibilities.

Impact on Participation in Work Obligations. The caregivers noted increased stress on their roles as employees. The caregivers described choosing specific jobs to have the flexibility to care for their child with T1D, which included working late evenings or weekends. Holly reported her changes in employment came with a “significant cut in pay.” Most of the caregivers stated that their employers were not flexible. Sarah stated, “My work isn’t as forgiving as you would think.” Holly said, “I could risk losing my job because of it” (i.e., in relationship to stepping away from work to manage the child’s blood sugar or insulin needs). The caregivers reported having fewer choices in employment because of limited childcare options. Beth stated she felt “restricted to stay at this job because I can’t find help after school for my kiddo with type 1.” The caregivers experienced restrictions in their work because of the burden of caring for their child with T1D.

Home Responsibilities Impacted. Activities, such as meal preparation and house cleaning, were affected by the needs of the child with T1D. Caring for a child with specific dietary needs was challenging, affecting how the caregivers shopped for and prepared food. Some found it hard to find something the whole family could eat. The caregivers found it stressful to manage inconsistent eating patterns, keep track of what was eaten, and correct it. This was particularly true if eating at someone else’s house, especially during holidays. John shared, “If she decides she’s not hungry anymore after we’ve already dosed her for it, that adds a whole level of challenge.” In addition, T1D takes priority over all other household chores, such as house cleaning and laundry. Mary said, “The house we kind of just accepted that it’s not going to be perfectly clean all the time.” Home responsibilities and routines are affected by the needs of a child with T1D.

Inability to Maintain Self-care Routines. The caregivers reported difficulty with self-care because of a lack of sleep, stress, and anxiety that causes physical and mental challenges. Beth reported, “there hasn’t been a time since this whole thing started that I’ve been able to really take care of myself.” The caregivers experienced health problems, such as depression, high blood pressure, and weight gain. Even when the caregivers were sick, they still had to care for their children. Anne stated, “If I’ve got the flu, I’m still calculating shots and giving shots and taking blood sugar.” The caregivers reported stopping or pausing their hobbies and health care to focus on their children. Holly stated, “in the past, we were involved in a church bible study and a small group [and] going out with friends that’s all just kind of been put on hold.” Many of the caregivers reported a need to prioritize their child’s health over their self-care activities.

Burden of Financial Responsibilities. Many of the caregivers discussed the increased medical expenses required to care for a child with T1D. The biggest expenses were the cost of healthy food and medication. The caregivers frequently acquired out-of-pocket expenses because of limited health insurance coverage. Anne said:

When she uses too many test strips because she's been really high for a particular week and it's not covered by insurance [or] we are on a road trip, and we can't find her bag somewhere that we're going to be out hundreds and hundreds of dollars just to get her supply so she can maintain her quality of living because insurance isn't going to cover for it because they've already paid for it and it got lost.

The caregivers must prioritize medical expenses over other expenses, forcing them to allocate family funds differently than they would have otherwise.

Need for Education and Advocacy

The caregivers expressed frustration with the lack of diabetes education they received at initial diagnosis. They were disappointed with misunderstandings between health care practitioners and the general community. These misunderstandings forced the caregivers to become advocates for their children and to educate community members. Subthemes include a lack of education from and in the medical community and misunderstandings in the community leading to a need for advocacy.

Lack of Education from and in the Medical Community. Some of the caregivers felt the medical community did not provide enough educational and emotional support regarding care for their child with T1D. When their child was first diagnosed, they were not given adequate diabetes instruction, making their parenting role more challenging. Mary stated, "There's nothing for parents here, so you are left to sink or swim, good luck." The caregivers reported feeling a significant amount of responsibility for their child's future health based on the decisions they were making. John reported not knowing what decisions to make and how these daily choices would affect his child's entire life. John said:

The biggest thing that weighs on me is, if she is spending too much time high, too much time low, and what that does to her, how that affects her short-term and long-term health. The person who has it obviously has the lion's share of the burden, but those who care for that person, especially for a child, we arguably have a worse burden. If it was me myself, I can take care of whatever things happen to me. To be inflicting that on somebody else is a lot harder. At this point, she has to live with our decisions.

Some of the caregivers did not trust primary care and emergency room physicians and nurses to care for their children adequately. In 1987, one participant took her 21-month-old daughter to the pediatrician with symptoms of polydipsia and enuresis. The physician refused to test her blood sugar levels and diagnosed her with the flu. Over the weekend, the child continued to feel sick, and the participant was told to return to the office on Monday. Upon arrival on Monday, she was in severe ketoacidosis and was admitted to the pediatric floor of the hospital. She received excessive IV fluid, which led to severe cerebral edema and, ultimately, death. Holly stated, "the brain damage was irreversible, and they couldn't bring her back." This participant now has another child with T1D and is extremely cautious about her care. Other caregivers had to tell the physicians how to care for their children. Beth stated:

We have had a couple of really bad experiences at the emergency room, and it was absolutely due to lack of knowledge which is so disappointing to go to an emergency room and have your ER doc or nurses not have a clue what to do.

The caregivers had strong feelings of inadequate knowledge and care from some physicians and nurses.

Misunderstandings in the Community Leading to Need for Advocacy. The caregivers agreed that there was a lack of education in the community regarding T1D and the differences with type 2 diabetes. Many wished that the two diseases had different names. Anne felt frustrated with the judgments from others when she discussed calorie intake or insulin amounts with her children in front of others. She stated, “You have to educate every single person that’s around you [about T1D].” Many of the caregivers frequently provided formal and informal education to physicians, nurses, school teachers, and athletic coaches on how to manage the disease and increase opportunities for their children with T1D. The caregivers agreed that they would like more empathy, awareness, and education for the community.

Overall, stress and anxiety were evident throughout the interviews. Many daily roles were affected by the stress of caring for a child with T1D, including maintaining relationships and completing work and home tasks. Education was a frequent topic in interviews. This included caregiver education at diagnosis as well as education of the people their children encountered every day, such as teachers, coaches, and other community members. Though it is hard to deal with, the caregivers developed routines that fit their family dynamics. Anne stated, “It becomes your whole life, and you don’t see your life around it . . . it just becomes your fabric, and it’s not a simple fabric.”

The results from the survey showed a correlation between caregiver burden and quality of life for the caregivers of children with T1D. In addition, the results showed that quality of life characteristics, such as physical health, interaction with the environment, social relationships, and psychological well-being, were affected. As caregiver burden increased, quality of life decreased. The caregiver interviews indicated the presence of stress and anxiety and a need for greater support from friends, family, employers, medical practitioners, and the community. This mixed-method study revealed the connections between burden, quality of life, and the caregiver’s ability to engage in everyday roles when caring for their child with T1D as well as themselves and their family.

Discussion

Overall findings from this study indicated an inverse relationship between caregiver burden and quality of life. Furthermore, the caregivers reported an initial impact on their productive occupations and nuclear and extended relationship maintenance. They also expressed a strong need for advocacy and education related to their children’s diabetes and health management needs. The relationship between the burden experienced when caring for a child with complex medical needs and a caregiver’s quality of life was an expected finding and is consistent with previous findings that showed stress impacted specific quality of life measures, such as physical, social, and emotional functioning (Gallegos et al., 2022; Jönsson et al., 2014; Saoji et al., 2018).

In addition, we investigated caregivers’ perceptions of how raising a child with T1D impacted their ability to engage in everyday roles. The findings suggested that caring for a child with T1D either strengthened or strained intimate partner relationships. The increased marital and intimate partner relationship strain was an expected finding, as previous research indicates a two-fold higher divorce rate for parents of children with other chronic conditions, such as autism spectrum disorder (Hartley et al., 2010). In addition, previous research supports that caregivers reported decreased marital satisfaction and increased strain because of the added stress of co-parenting a child with complex medical needs (Saini et al., 2015). However, it was an unexpected finding that approximately half of

the caregivers reported that after their children's diagnosis, they became a stronger co-parenting unit. At times, the caregivers felt their friends and family members were not supportive or fully understood the complexity of caring for a child with T1D. All of the caregivers reported changes in the relationships with their children with T1D and their siblings, which was expected as previous studies found that siblings reported changes in their family routines by assisting with health management tasks and expressing concern for their siblings (Wennick & Huus, 2012). Furthermore, although siblings of children with T1D are generally well-adjusted, certain factors have been found to impact family dynamics, such as higher levels of caregiver distress (Jackson et al., 2008).

In this study, the caregivers described the impact of T1D on productive occupations, such as the kinds of employment they chose, the amount of time they worked, the need for a flexible work environment, and the impact of sparse childcare options on their employment options. These findings were expected, as previous studies found that mothers' paid employment significantly declined after their children's T1D diagnosis ($p < 0.001$) (Dehn-Hindenberg et al., 2021). Furthermore, two qualitative studies found that parents of children with T1D frequently seek employment that has a flexible work schedule so they could attend to their children's medical needs (Herbert et al., 2017; Jewell et al., 2022). Not surprising was how the decreased employment opportunities frequently led to increased financial strain (Dehn-Hindenberg et al., 2021; Herbert et al., 2017).

The caregivers expressed the need for education and advocacy in the community. The caregivers felt they were not adequately educated about T1D and, therefore, were not prepared to take care of their child's medical needs, which caused them stress. The caregivers also felt the medical community did not have the knowledge to care for their child with T1D, potentially causing more harm. This is consistent with the findings that found parent frustrations with delayed diagnosis and dismissed concerns when seeking care from physicians and emergency departments (Jewell et al., 2022; Smith-Jackson et al., 2018; Valenzuela et al., 2014). This is concerning, as one caregiver in our study reported the death of her child because of a misdiagnosis and lack of awareness of the severity of T1D. Furthermore, families that experience barriers to accessing health care services are known to have poorer glycemic control ($p = 0.004$) (Valenzuela et al., 2014). Comparable to other studies, the caregivers felt compelled to educate and advocate for their children in medical situations, including when they were at school, participating on athletic teams or in extracurricular activities, and in childcare situations (Jewell et al., 2022).

Many of the caregivers prioritized their children's health management over home responsibilities and self-care routines, further impacting the caregivers' sleep participation and overall stress with their expected roles and routines. This is consistent with previous studies that showed caring for a child with T1D disrupts typical routines and responsibilities (Moreira et al., 2013; Streisand & Monaghan, 2014). The findings from this study outline the need for a holistic approach to re-establishing caregiver routines to ensure all necessary responsibilities are addressed, while simultaneously providing sufficient care for caregivers to manage their children's diabetes. Compared to other studies that focused more on the quality of life of children with T1D and the psychological changes that the management of T1D had on children, this study provided specific information related to the caregiver's quality of life and changes that were made in their daily routines because of the child's diagnosis (Diabetes Research in Children Network Study Group, 2006; Marchante et al., 2014). The benefit of this study is the identification of the breadth of the impact these changes in routine had on the caregivers' health, participation, and well-being. The caregivers may require more comprehensive diabetes management than outlined in the ADA's Standards of Care for youth (ADA, 2021). For example, sleep participation or health care insurance and financial management are two occupations that were highlighted as urgent needs by the caregivers in this study that are currently not

addressed in standards of care (ADA, 2021). This study highlighted the need to help caregivers manage or minimize the burden, prioritize and organize daily tasks and routines, and educate and advocate in the community.

Limitations

This study has several limitations. Using limited modes of response via the electronic survey may have led to a low response rate (Dillman et al., 2014). Although the research attempted to reach a large, heterogenous geographical area and sample, the findings may not represent all caregivers of children with T1D. The small sample size may limit the generalizability of the findings. In addition, convenience sampling may present a higher potential for sampling error or introducing bias (Brown, 2016). Convenience sampling may also impact the response rate, as the researchers were unable to follow-up with the caregivers (Dillman et al., 2014). Inaccurate responses were possible with the electronic survey because it is impossible to know if those who filled out the survey met the inclusion criteria, understood the questions accurately, or answered truthfully (Dillman et al., 2014). Interview limitations included the biased wording of questions, potentially prompting the interviewees to respond in a particular way. Furthermore, the caregivers may have answered sensitive questions inaccurately because of fear of judgment.

Further Research and Implications for Practice

Future research conducted with a larger sample size representing various demographics and populations would be beneficial to increase knowledge on the impact of caregivers raising a child with T1D, especially with fathers. Examining the relationships between demographic variables, quality of life, and caregiver burden would be helpful to examine in the future. Including the child with T1D or other family members in future studies may be useful to increase the perspectives in the research findings. The development of an occupational therapy assessment to measure the constructs of caregiver-specific diabetes distress and the performance of health management routines may assist therapists with measuring outcomes and developing family-centered goals. Finally, the development and testing of family-centered interventions to address the complex medical and psychosocial needs of caregivers and children living with T1D are necessary to determine the efficacy and effectiveness of occupational therapy as an integral part of the interprofessional endocrinology team.

The findings of this study suggest that caregivers struggle with maintaining current relationships, making meaningful and supportive connections with others, managing their time and daily tasks, and educating the community. A consultative or coaching intervention approach might assist caregivers in first identifying which activities and goals are meaningful to the caregiver and family. Therapists could collaborate with caregivers to set family-centered goals and assist caregivers to manage their time and ensure they make time for their self-care, relationship maintenance, diabetes advocacy, and management of their child's complex health management routines. Occupational therapists are experts in lifestyle adaptations needed to meet their goals. Equally important is looking to the child's future needs as they grow and change.

The caregivers resided in various geographic locations, with most of the caregivers reporting throughout the United States. The caregivers' experience caring for a child with T1D ranged from less than 1 year (26%; n = 11) to 11 or more years (5%; n = 2), with most of the caregivers providing 50% or greater of the care (72%; n = 32). Only one participant had more than one child with T1D (2%). The children with T1D ranged in age from 4–6 years (16%; n = 7) to 15–18 years (25%; n = 11). Most of the children had no other medical diagnosis other than T1D (72%; n = 31). The caregivers reported family as their most helpful and accessible support (58%; n = 25), followed by online support groups (53%; n = 23), friends without children with T1D (32%; n = 14), friends with children with T1D (30%; n = 13), and local support groups (6%; n = 3).

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