# Qualitative Content Analysis of Type I Diabetes Caregiver Blogs and Correlations With Caregiver Challenges and Successes

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## Abstract

Social media increasingly reflects patient experience, especially for self-managed conditions. We examined family experience with type I diabetes (TID) through qualitative analysis of blogs written by caregivers of children with TID, survey derived from that analysis, and survey administration among TID caregivers. Analysis of 140 blog posts and 663 associated comments identified 77 topics, which were categorized into self-management, emotional, challenges, and successes. By subcategory analysis, self-management challenges were strongly correlated between blog content and survey responses (R = .838, P = .005), and emotional challenges were moderately correlated (R = .415, P = .02). Emotional successes were not significantly correlated (R = .161, P = .511), and self-management successes were too few to analyze. The range of topics and the correlations between blog expressions and survey responses highlight the potential of blog analysis to gain insight into the challenges facing families living with TID.

## **Keywords**

blogs, type I diabetes, qualitative research, qualitative content analysis, social media, mixed methods research, survey development

# Introduction

Various forms of social media are used increasingly by individuals to seek health-related information, including by people with diabetes and their caregivers (1-7). This is especially the case when people want information quickly or feel that they cannot or do not get particular types of information from their health care providers, as they turn increasingly to self-help in order to improve their experience (3). Blogs represent a form of social media which allows personal reflection by the author and responsive discussion among visitors to the blog website, asynchronously, from the convenience of users' Internet-connected devices. They represent a relatively underinvestigated source of peer support, tips, and advice. This study focused on blogs written by caregivers of children with type 1 diabetes (T1D) aiming to (1) conduct a qualitative content analysis of such blogs and comments and (2) to determine whether the topics and their relative priorities as discussed on blogs might be associated with the priorities expressed among a cross-section of caregivers.

# Method

All procedures were approved by the Penn State College of Medicine Institutional Review Board prior to commencing any study activities.

# **Blog Analysis**

Full details of blog selection and criteria are described in a prior publication (8). Briefly, blogs were selected by Google search for "parent diabetes blogs" and cross-referenced with a list of top blogs for parents of children with diabetes (9). Included for analysis was the qualitative content of blogs

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#### Table I. Characteristics of Included Blogs.

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Blog/blogger characteristic		
Caregiver role (n) Family characteristic (n) Genders of children with TID (n) Blog posts during study period (associated comments)	Mother (2) 2-Parent family (2) Female (3) I40 (663)	Father (I) Single-parent family (I) Male (3)

Abbreviation: TID, type I diabetes.

written by caregivers of their children with T1D, where the focus of the blogs was mostly or exclusively on T1D. Content not relating to diabetes was excluded. Written consent from all blog owners was obtained. Characteristics of the included blogs are presented in Table 1. The 2:1 ratio of mothers to fathers is roughly representative of the population of caregiver diabetes bloggers, estimated at 55% to 92%(7,10–13). It is also roughly representative of primary caregiving responsibility in the broader population of parent caregivers, where the majority of primary caregivers to children with T1D tend to be mothers (14,15). Additionally, the included sample of bloggers represents a 2:1 ratio of 2-parent to single-parent families (12,16,17) and a 2:1 ratio of families with multiple children with T1D compared to families with 1 child with T1D. Conventional qualitative content analysis (18) began with importing blog content into qualitative analysis software (NVivo, QSR International), conducted in July 2018. A codebook was developed through joint coding by the entire research team in order to capture the meanings of the blog content; distinct topics discussed on the blogs were each assigned a code to represent this issue. Initial codebook development was followed by further codebook refinement, independent coding of 10% of the data set to establish intercoder reliability (initial  $\kappa = .920$ ), and then independent coding of the remainder of the data set ( $\kappa = .934$ ). Discrepancies were few and addressed at weekly research team meetings. After coding 140 blog posts and 663 associated comments, saturation was achieved and coding ceased. Most codes belonged to one of 4 categories which emerged during analysis (see Results section).

## Survey Development and Administration

From the blog analysis, each code with its associated definition was used to create a statement and Likert-type responses to represent the code in a survey. For example, for the code "lost sleep" and its definition of caregivers losing sleep in the management of their child's T1D, the corresponding survey item became "I lose sleep in caring for my child with T1D" with 5 responses ranging from "never" to "very frequently." Survey items were reviewed for clarity and meaning by 2 caregivers to children with T1D, with adjustments made until clear, in order to arrive at the final wording for each item. Most items required no adjustment, while about one-third required minimal adjustment and 4 required substantial adjustment and rereview. The 4 items that required the most substantial revision had explanation or illustrative examples added to them, which ultimately made them adequately clear to the field testers who felt or demonstrated that they were insufficiently clear at first. For example, from the blog code "T1D is an invisible disease" came the item "I find it challenging that T1D is a mostly invisible disease," which was revised by appending "e.g., my child looks healthy to others from the outside" to the original item. Similarly, the blog code "Normalcy" gave rise to the item "My child does normal childhood things," which was appended with "(the same things that a child without T1D can do)." Finally, 1 item asked about caregiver resilience while another asked about resilience of the child(ren) with T1D; a parenthetical explanation was added to achieve the final survey items "I experience resilience (adapting, bouncing back, handling things) specific to T1D in caring for my child" and "My child with T1D is resilient (can bounce back, handle things)."

Participants were recruited through online announcement on a public forum for caregivers of children with T1D (Chil drenWithDiabetes.com) and by flyers at a conference for such caregivers (Friends for Life International Conference, Orlando, Florida), representing a convenience sample for this cross-sectional survey. Participants provided implied consent and completed the online survey by following a link to REDCap, a secure online platform of electronic data capture tools, hosted at Penn State College of Medicine (19).

## Comparative Analysis

It was unknown whether the frequency with which a code was represented in the blog data set might be related to the magnitude of the corresponding issue in caregivers' experiences. To explore this, codes from the blog analysis were ranked by frequency of their application in the blog data set (eg, the code that was used most frequently was ranked highest, and the code used least frequently was ranked lowest); and survey items were ranked by the value of the mean response for each item (the item with the highest mean score was ranked highest, and the item with the lowest mean score was ranked lowest). Spearman's rank correlation coefficient (R) was calculated to compare the rankings for the blog codes to the survey items, for both the overall set of topics, and also by categories described below in Results section.

## Results

The codebook broadly emerged into 2 sets of classifications, which generated 4 categories; only a few codes did not fit into one of these categories. Of the 77 codes from the final codebook, 62 (81%) could be classified as being related either to emotion (50) or to self-management (12), and 74 (96%) represented either a challenge (47) or a success (27). Only 4 codes (5%) fit none of these categories. As such, the 4 categories were self-management challenges, selfmanagement successes, emotional challenges, and emotional successes. Survey respondents were predominantly female (28/34, 82%), and their children had been treated for T1D between 1 and 5 years (mean 4.2 years) at the time of survey administration. The codebook categories, code and rank within category (by frequency), and corresponding survey item and rank within category (by mean score) are presented in Table 2.

For the overall set of 77 topics, a weak correlation was observed between blog code rank and survey score rank (R = .265, P = .02). When examining by category, a moderate correlation was observed for challenges (R = .478, P < .001) but not for successes (R = .095, P = .636). When examining still further by subcategory, a strong correlation was observed for self-management challenges (R = .838, P = .005) and a moderate correlation for emotional challenges (R = .415, P = .02). Emotional successes were not significantly correlated (R = .161, P = .511). Selfmanagement successes were too few to analyze.

## Discussion

This study accomplished 2 broad goals. First, qualitative content analysis demonstrated the breadth of topics represented and the frequency with which they appear in the included sample of T1D caregiver blogs. Second, it allowed survey development and administration among a different sample of T1D caregivers, which further allowed assessment of whether the relative frequency of appearance in blog content was correlated with the frequency with which caregivers identify the issues occurring in their experience. The blogs analyzed here demonstrated a remarkable breadth of topics discussed, as there were 77 unique codes comprising the final codebook. Among these, emotion-related topics outnumbered self-management-related topics by more than 4:1 (50 and 12, respectively). Challenges outnumbered successes nearly 2:1 (47 and 27, respectively). We found that challenges were correlated between the blogs and surveys but not successes. Self-management challenges were especially correlated, and emotional challenges somewhat less so, but still significantly correlated as well. The weighting of blog content toward emotions and challenges likely reflects the tendency toward more sharing of emotions and challenges online and seeking advice about these, especially as emotions are more likely to be shared among peers or behind the perceived safety of a computer screen, and as challenges are more likely to be vented than successes touted; this has been seen in studies about online sharing in T1D (7) and in other chronic conditions (10,16,20).

The "Blogging Practices" conceptual framework posits that blogging communities are comprised largely of "groups of people who share certain routines and expectations about the use of blogs as a tool for information, identity, and relationship management" (21). The findings presented here and in another report related to this work (8) align especially well with the information and relationship management factors of the Blogging Practices framework, as the most frequently coded segments related to emotions (and often to relationship management as quite frequently such segments involved the provision and/or receipt of emotional support among peers, as has been found by others) (7,10,16,20). Less frequently than emotion-related content, but still prominently, self-management topics were discussed, especially relating to information sharing, another of the 3 major factors comprised by the Blogging Practices framework. Identity was not as clearly represented but could be seen as contributing to the overall existence of and motivation to grow the blogs themselves, as all are rooted in the experiences of (and identifying as) a caregiver to a child with T1D.

Accordingly, coding frequency here was hypothesized to reflect relative priorities within such a blogging community. The findings of correlations between blog data and survey respondent data may serve as support for the hypothesis that code frequencies on blogs reflect relative priorities within the blogging community; or it may support the hypothesis that code frequencies on blogs (at least around challenges in general and self-management challenges in particular) partially reflect the priorities of a similar group of caregivers unrelated to blogs and perhaps to the more general population; or it could be that neither hypothesis is correct, but future research could help explore this further.

This complements other work we have done investigating blog content of caregivers to children with T1D (8). That study reported on thematic analysis of the blog content but part of it also included a comparison of blog content to the content of interviews of caregivers. It found roughly 70% overlap of codes/topics between blog and interview data sets, with the remaining 30% of codes/topics found only in 1 data set or the other evenly split, with about 15% uniquely contributed from blogs and about 15% uniquely contributed from interviews. While that study found significant overlap between the 2 data sets and therefore from the 2 different samples that generated those data sets, this study attempted to provide some quantitative evaluation of strength of correlation.

This study adds to the growing literature on how blogs can be incorporated in research and contribute to the ongoing quest for new knowledge (5,8,13–17,22-26). It reinforces that blogs can be used as a qualitative data source. The process of discovering what experiences are of particular importance to a patient population through analyzing blogs can also be a relatively rapid and inexpensive method of

Category code	Blog data set rank (code frequency)	Survey data set rank (mean Likert score)	Survey item
Self-management challenges			
Heavy workload of TID	4 (218)	6 (4.33)	Diabetes management is a lot of work
Unpredictability of TID	5 (198)	38 (3.53)	My child's TID is unpredictable
General challenges of self- management	6 (166)	26 (3.73)	TID self-management is a challenge
Transition of TID care to child	12 (102)	52 (3.22)	I think about transitioning TID care from myself to my child
Lows/hypoglycemia	20 (60)	21 (3.82)	l have stories I can tell about a low blood sugar
Highs/hyperglycemia	21 (59)	34 (3.63)	l have stories I can tell about a high blood sugar
Financial and insurance	37 (38)	40 (3.51)́	I experience financial and/or insurance challenges related to
challenges	41 (2.4)	70 (0 50)	my child having TID
Change in clinical guidelines/ treatment goals	41 (34)	72 (2.52)	I feel challenged by changes in clinical guidelines/treatment goals, eg, new lower AIc goals for children
Difficulty of travel	52 (22)	75 (2.34)	I find it difficult to travel specific to caring for my child with TID
Emotional challenges			
Emotional burden of TID	9 (137)	42 (3.49)	Living with TID is an emotional burden
TID is a family disease	13 (87)	11 (4.08)	My child's TID affects the whole family
Lost sleep	I4 (70)	12 (4.00)	l lose sleep in caring for my child with TID
New normal/TID changes everything	16 (68)	3 (4.37)	TID causes a "new normal," TID changes everything
	17 (64)	(2 (2 94)	Leve eniones function and/on oncen in living with TLD
Frustration and anger	17 (64)	62 (2.94)	I experience frustration and/or anger in living with TID
TID is 24/7/365	19 (60)	I (4.60)	TID is always there, 24/7/365
False hope—waiting/hoping for a cure	24 (56)	48 (3.38)	I find it emotionally challenging to wait/hope for a cure for TID
Reluctance to accept help/ lack of help	25 (55)	57 (3.08)	I am reluctant to ask for/accept help, or I do not have truster caregivers
Everyone's diabetes is different	27 (48)	9 (4.14)	I feel that everyone's TID is different
Needles	29 (47)	53 (3.22)	I think about the needles, finger sticks, sharp objects involved in caring for my child with TID
General fear	32 (44)	44 (3.46)	I experience fear specific to TID in caring for my child
Sadness	34 (43)	63 (2.92)	I experience sadness as a result of caring for a child with TIE or in thinking about my child's TID
Others judge/don't	36 (39)	13 (4.00)	I feel that others judge/don't understand my situation specifie
understand your situation	20 (27)		to what it is like to have a child with TID
Guilt and blame	38 (37)	66 (2.75)	I experience guilt and/or blame related to my child having TIE or caring for my child with TID
Negative emotions	39 (36)	59 (3.08)	I experience negative emotions specific to TID in caring for my child
Unsolicited advice/incorrect advice/myths	42 (32)	20 (3.82)	It is challenging to receive unsolicited or incorrect advice, or hear myths regarding TID
Fear of lows	45 (31)	25 (3.79)	I am fearful of low blood sugars in my child
Pre-TID memories	47 (29)	74 (2.45)	I think about life before my child was diagnosed with TID
Sacrificing caregiver needs for child's health	48 (29)	16 (3.96)	I sacrifice my needs for my child's health
Feeling defeated	49 (27)	61 (3.00)	Caring for TID can make me feel defeated
Stress	50 (22)	31 (3.67)	I feel or experience stress specific to TID in caring for my child
Intrusion of TID into	53 (21)	55 (3.17)	TID intrudes into the relationship I have with my partner
relationships of partners Fear of what the future holds	56 (18)	45 (3.45)	I experience fear of what the future holds for my child with TID
Exhaustion	58 (16)	35 (3.60)	I feel or experience exhaustion specific to TID in caring for m child

**Table 2.** Joint Display of Qualitative Content Analysis Blog Codes' Ranks and Frequencies and Corresponding Survey Items' Ranks and Mean Scores, by Category.

(continued)

## Table 2. (continued)

Category code	Blog data set rank (code frequency)	Survey data set rank (mean Likert score)	
Information overload	63 (10)	65(2.77)	I experience information overload in caring for my child with TID
TID takes and steals	64 (10)	56 (3.10)	I feel TID "takes and steals"
Invisible disease	66 (8)	29 (3.67)	I find it challenging that TID is a mostly invisible disease, eg, my child looks healthy to others from the outside
Lost spontaneity/too much planning/need for set schedule	67 (6)	50 (3.28)	l feel there is lost spontaneity, excessive planning, or need for a set schedule specific to diabetes in caring for my child
Fear of complications	70 (4)	41 (3.49)	I experience fear of long-term TID complications for my child
Child feels different	73 (3)	54 (3.22)	My child feels different as a result of having TID
Need to care for children without TID	75 (2)	69 (2.62)	I find it challenging to care for my child(ren) without TID as well as my child(ren) with TID
Self-management successes			
General self-management successes	43 (32)	22 (3.81)	I experience success in managing my child's TID
Positive aspects of food/diet/ eating habits	72 (4)	39 (3.53)	I experience positive aspects of food/diet/eating habits specific to TID in caring for my child
Positive aspects of exercise	76 (1)	58 (3.08)	I experience positive aspects of exercise specific to TID in caring for my child
Emotional successes			
Advocacy and awareness	I (503)	19 (3.87)	I feel it is important to make others aware of what it is like living with TID
Peer support—caregiver to caregiver	2 (465)	5 (4.35)	I find support when I interact with other parents of children who have TID
Affirmation	3 (399)	49 (3.37)	When I share about my experiences with TID, I feel people appreciate it
Reasons to blog/write	10 (114)	46 (3.41)	I am motivated to share my experiences with TID in writing, eg, blog, post, comment, online journal, etc.
Child normalcy	( 02)	2 (4.53)	My child does normal childhood things; the same thing as a child without TID can do
Positive emotion—general	15 (69)	51 (3.98)	l experience positive emotions related to living with TID
Caregivers are resilient	22 (58)	27 (3.71)́	I experience resilience (adapting, bouncing back, handling things) specific to TID in caring for my child
Humor and sarcasm	23 (57)	24 (3.79)	I use humor and/or sarcasm and living with TID
Having trusted caregivers	28 (48)	70 (2.58)	I have competent and trusted caregivers who can give me a break when it comes to TID care
Parent normalcy	30 (46)	17 (3.92)	I do similar things other parents do who are not caring for a child with TID
Children are resilient	33 (44)	4 (4.35)	My child with TID is resilient, e.g. can bounce back, handle things
Норе	40 (34)	43 (3.49)	I experience hope in caring for my child with TID
Religion/belief in a higher power	51 (22)	64 (2.82)	I use my believe in a higher power, my religion, or spirituality to cope with caring for my child with TID
School support	54 (21)	36 (3.59)	I feel my child's school provides support regarding my child's TID
Peer support—children to children	57 (18)	37 (3.58)	My child finds support in interacting with other children with TID
Pride	61 (14)	32 (3.65)	I experience pride specific to TID in caring for my child
Inspiring stories from adults with TID/role models	62 (11)	15 (3.96)	It is helpful for myself or my child to have role models with TID, e.g. to hear inspiring stories from adults with TID
General resilience	65 (10)	33 (3.63)	I think about/observe resilience, [adapting, bouncing back, handling things] related to life with TID
Diaversary	71 (4)	23 (3.80)	My family or myself celebrates or marks the anniversary of my child's diagnosis or "Diaversary"

#### Table 2. (continued)

Category code	•	Survey data set rank (mean Likert score)	Survey item
Uncategorized			
Alc	35 (43)	28 (3.68)	I think about my child's
			Hemoglobin AIc as I care for my
			child with TID (eg, the meaning
			or impact of the AIc result)
Helpfulness of device alarms	77 (0)	8 (4.23)	l feel device alarms are helpful.
Diagnosis story	7 (146)	67 (2.75)	I find myself thinking back to the
- •			time when my child was diagnosed.
Peer support—giving advice	18 (64)	47 (3.4)	I offer advice to others about life with TID.

Abbreviation: TID, type I diabetes.

inquiry, without need for often costly transcription services or interviewee stipends that are required with more traditional interview studies. This work also introduces the idea that blogs can be used for survey development and thereby to seek insight about the experiences of broader populations. With this analysis showing that the blog frequency ranks are not associated with survey item response ranks for successes, it appears that the use of blog analysis for survey development may be limited to content around challenges. With the especially strong correlation for self-management challenges, this appears to be the most useful area for focus. Aside from survey development, it is noteworthy in its own regard to observe that the more frequently a specific selfmanagement challenge was mentioned on a blog, the more frequently it was identified as a challenge by survey respondents as well. As such, directly examining public blog content written by a population of interest (in this case, caregivers to children with T1D) could be considered in the development or revision of survey instruments in order to ensure that they reflect recent areas of importance to that population of interest, especially as topical issues change over time. While blog analysis may be a useful tool to consider incorporating into survey development, especially if able to help with identifying topical issues and providing a relatively rapid and less expensive process that may, on some level, streamline the process, it should not be considered a replacement, and it remains important to maintain fidelity to the important fundamentals and principles of survey development.

## Limitations

It remains unclear whether and/or how frequencies of topics being discussed on blogs are actually related to level of priority for the affected populations; this is an area for future investigation, as this study did not address that. It is important to note that the 34 survey respondents represent a rather small sample, which should certainly limit any temptation to apply these findings to a broader population. However, future research could explore this further and should include a larger sample size. Additionally, these findings are limited to a focused caregiver population and 1 clinical condition, and applicability to other populations and conditions cannot be established from this study. As such, future research may include extending this approach to type 2 diabetes and to adults with T1D, to conditions other than diabetes, and to extend the approach to other forms of social media, beyond blogs.

### Authors' Note

The authors completed this research at Penn State College of Medicine, before beginning their current positions at the University of Colorado School of Medicine.

#### **Declaration of Conflicting Interests**

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