

Stages of the Diabetes 'Roller Coaster': A Textual Analysis of Tudiabetes.org®

"It is the emotion which drives the intelligence forward in spite of obstacles."

- Henri Bergson, "Moral Obligation," *The Two Sources of Morality and Religion*, 1932,
Translated by R. A. Audra & C. Brereton, 1935.

Interactive dialogue distinguishes virtual communities and online social networks. In fact, numerous studies show socialization is a primary purpose of these communities (Nyland, 2007; Raacke & Bonds-Raacke, 2008; Stern & Taylor, 2007; Subrahmanyam et al., 2008; Urista et al., 2009). Online virtual health communities have recently emerged to engage people with common medical conditions and experiences. Demiris (2006) describes a virtual health community as a social unit connected by communication technologies and having a common interest, experience, or involvement with a health condition. An example of such a community is the Scandinavian Breast Cancer List, where women used the internet to share information and combat feelings of isolation (Høybye, Johansen & Tjønhøj-Thomsen, 2005). These communities provide interactive support beyond traditional face-to-face support groups or clinical settings.

Influenced by significant technological advancements, virtual health communities are quickly growing. This rapid diffusion demonstrates their potential to support patients, caregivers, families, and health care providers. Tudiabetes.org® represents a dynamic, peer-to-peer virtual health community created for people with diabetes, their families, and caregivers. It was chosen for examination in this study because it exemplifies a vibrant, online virtual health community. Members are free to share and express their own ideas in a safe and non-moderated space. Exploring how people talk within this community advances understanding of the communication attributes of members within a vital, online virtual health community.

Type 1 diabetes represents a prevalent chronic health condition that often develops in children, adolescents, or young adults. Commonly known as juvenile diabetes (Juvenile Diabetes

Research Foundation, 2011), this serious disease develops when the body's immune system attacks the cells that make the hormone insulin, which is needed to regulate blood glucose. People with type 1 diabetes must take insulin by injection or pump to survive (Centers for Disease Control and Prevention, 2011). The experience of being diagnosed with type 1 diabetes is challenging and stressful for individuals and their families. They must learn to cope with significant changes in their everyday lives including regular blood glucose testing, insulin infusions, and carbohydrate counting. Daily life is never the same, and thus support becomes vital in the initial days following a diagnosis and remains necessary for long-term wellness (McKay et al., 2002).

According to its website, tudiabetes.org® (2011) is a virtual community that supports "people touched by diabetes" and is run by a non-profit organization called the Diabetes Hands Foundation. It is an online community where "the members help each other out, educate ourselves and share the steps we take every day to stay healthy while living with this very serious condition" (tudiabetes.org®, About Us tab, 2011). The members embrace values such as community support, health and wellness, communication and information, diversity and respect, creative expression, and transparency. Since its creation in 2008, tudiabetes.org® has over 19,290 members comprised of people with diabetes or family members of people with this chronic condition. Members can create their own pages, invite friends, and join member groups. Nearly 500 groups currently exist, with up to 1,094 members. There are groups based on geographic location (Canada Diabetes, Pennsylvania Diabetics), treatment method (OmniPod Users, Minimed Paradigm Insulin Pump Users), roles and experiences (Parents of Pumpers, Grandparents Loving Diabetic Grandchildren, Hypoglycemic Experiences), and common interests (Cycling Diabetics, Twitterbetics).

The “parents of kids with Type 1” is a group of 833 members in the tudiabetes.org® community. Created for parents of children with diabetes, participants engage in asynchronous communication through online discussion forums or message boards. Membership is open, but individuals must register with tudiabetes.org® to contribute to discussions. This research specifically explored dialogue within the “New to the life of diabetes! (LONG)” discussion thread. The full discussion included 73 posts occurring over nearly two months, beginning on November 2, 2010, and concluding on December 29, 2010. A similar discussion thread (“Newbie to Type 1”) was started on January 28, 2010. While the content of this discussion closely resembled the dialogue of “New to the life of diabetes! (LONG),” it was not the focus of this study. Nevertheless, the similarity highlights the significance of this topic for parents and situates the present study within the broader context of the “parents of kids with Type 1” group forum. In this exploratory study, the “New to the life of diabetes!” discussion was analyzed to understand how parents of children with type 1 diabetes engage in online dialogue within the context of a virtual health community.

It is important to consider the discourse of parents of newly diagnosed children with type 1 diabetes because a diagnosis experience provokes anxiety and affects the entire family (e.g. Dantzer, Swendsen, Maurice-Tison and Salamon, 2003; Lloyd, Dyer, and Barnett, 2000; Wysocki et al., 2006). Parents assume a significant role in a child’s diabetes self-management; therefore, emotional support is imperative for caretakers. Tudiabetes.org® offers a unique forum for understanding the collective discourse of parents in the early days of a child’s experience with type 1 diabetes.

Literature review

According to a study conducted by van Uden-Krann et al. (2008), people actively seek out and join virtual health communities when they find themselves in stressful situations, such as having a family member diagnosed with a chronic illness. Various studies have identified the specific benefits of virtual health communities when compared to their face-to-face communication counterparts, including the absence of geographical boundaries, unlimited availability, cost-efficiency, and anonymity (Finfgeld, 2000; Finn, 1999; Salem, Bogat, & Reid, 1997; Winzelberg, 1997).

Virtual health communities

Virtual health communities offer support to people with chronic or acute health conditions through mutual support, expression of feelings, and information exchange (Demiris, 2006; Zrebiec & Jacobson, 2000). Members of these communities share a common experience with a particular health condition, and thus comprise a collective health community. Participants often include a combination of patients, caregivers, family members, and health-care providers or educators. "Virtual communities involving only patients function as self-help groups for individuals diagnosed with the same medical condition or undergoing the same treatment" (Demiris, 2006, p. 179). As such, peer-to-peer virtual communities commonly operate without professional moderation. This means discussion posts are not filtered, and members depend on their internal values to guide acceptable discourse and behavior.

Social networks and language

Various technologies are possible for facilitating discussion in virtual health communities. Online message boards and mailing lists allow for asynchronous communication, while videoconferencing and Internet chat rooms provide options for synchronous discourse. Social network sites (SNSs) offer an emerging platform for virtual health communities and are

defined as web-based services that "allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system" (boyd & Ellison, 2008, p. 211). SNSs therefore afford a unique opportunity to share and receive support in the face of a new medical diagnosis or chronic health care.

Tudiabetes.org® represents one example of a virtual health community created within a social network environment.

As SNSs have boomed in popularity, numerous studies have explored who is using them, how they are using them, and the motivations behind using them (Madge et al., 2009; Marwick & boyd, 2010; Yardi & boyd, 2010). However, little is known about the nature of discourse within peer-to-peer virtual health communities and how individuals engage in conversation about their experiences with chronic health conditions. Exploring their language would shed light on how these people understand their experiences with chronic health conditions. With this in mind, the research question guiding this study asks: how do people talk about the initial experience of becoming a parent of a child with type 1 diabetes?

Method

This study analyzed the communication of parents within a peer-to-peer virtual health community. A qualitative research approach was considered most appropriate for this exploratory research. This perspective recognizes the existence of multiple realities and their social constructions (Guba, 1990). The present study assumed people construct meaning for their experiences through language. Thus, the interactive dialogue of parents within the tudiabetes.org® community revealed co-constructed meaning influenced by context and individual interpretation. Qualitative inquiry offers rich contextual and informational insight that

increases the validity of health communication research. The “New to the life of diabetes! (LONG)” thread was examined through a qualitative textual analysis that probed below the surface of a text to expose richer meanings.

Contributors

People contributing to this online discussion were members of the “parents of kids with Type 1” group within the t1diabetes.org® community. Many contributors were parents of children with type 1 diabetes, while a few members identified themselves as people with type 1 diabetes. These people shared their personal experiences and related their interpretations of their parents’ experiences surrounding the diagnosis experience. Several parents participating in this discussion had recently become parents of children with type 1 diabetes (one year or less), while others were experiencing their child’s multiple-year anniversary since the diagnosis incident. Fathers and mothers alike talked about the experience of one or more of their children being diagnosed with type 1 diabetes. Careful consideration was made to individually identify each participant separately.

Textual analysis

In qualitative research, understanding is accomplished through inductive analysis and interpretation (Lindlof & Taylor, 2011). Analysis of the t1diabetes.org® discussion thread “New to the life of diabetes! (LONG)” was accomplished by reading and rereading the original dataset of 73 posts, which equated to 35 printed Word pages. Individual posts and conversations were broken down to identify recurring themes and categories. Three researchers independently completed this process and met on several occasions to compare, modify, and refine initial findings. Consensus of themes was achieved through an iterative process that resulted in an intersubjective interpretation of the data. Four dominant themes emerged to describe parents’

interactive dialogue: catastrophic, support-seeking, cathartic release, and “new normal.” These themes emerged from the data through inductive analysis as described by Patton (1990).

Analysis

The discussion thread analyzed in this study originated with a mother of a newly diagnosed 12-year-old boy. She likened her experience of becoming a parent of a child with type 1 diabetes to a vivid “roller coaster ride.” This metaphor captured the overall essence of the parents’ dialogue surrounding their children’s diagnosis experiences, and furthermore the emic phrase provided an overall thematic structure for the conversation of parents. In fact, parents commonly employed metaphors to share their stories (400 pound man, cosmic joke, roller coaster ride):

Fast forward to almost a month into this new life we have. While I feel somewhat less overwhelmed, I still wake up feeling *like a 400 pound man is sitting on my chest* [emphasis added]. As I walk down the stairs each morning, I have to stop for a moment and take a deep sign before jumping into my, our new life.

[Participant 1 – Mother of a recently diagnosed 12-year-old boy]

We have all been there, and many of us still are! We are 1 year into our first diagnosis and 2 weeks into our second. There are definitely moments when I am not sure that I can even put one foot infront [*sic*] of the other, and my vision goes blurry and I am sure that some sick *cosmic joke* [emphasis added] has been played on me because how could two of my beautiful daughters have diabetes when we did everything right, and we have no family history?

[Participant 6 – Mother of recently diagnosed 5- and 7-year-old daughters]

We have lost two 13 year olds this year in the type 1 community whose parents were doing everything right. I admit, I am overly sensitive. Not even a month into this *roller coaster ride* [emphasis added]. But as I laid in bed last night feeling scared and woke up this morning with the same thoughts...it has been pointed out to me to expect these highs and lows and not to beat myself up over them.

[Participant 1 – Mother of a recently diagnosed 12-year-old boy]

Structurally, the “roller coaster ride” proceeded from the initial diagnostic discovery to eventual acceptance of a “new normal.” Analysis of the online discussion thread revealed four stages of the ride: catastrophic, social support, cathartic release, and “new normal” that illuminate the experience of becoming a parent of a child with type 1 diabetes as expressed in the parents’ collective dialogue.

Catastrophic

A catastrophic event explains a sudden and devastating situation. Parents talking about the diagnosis of their children with type 1 diabetes described the initial shock and suddenness, and they mentioned feeling stunned, overwhelmed, helpless, deeply upset, and blind-sided. Most parents did not anticipate the discovery because their children seemed happy and healthy, and they commonly felt the worst part was not being able to do anything:

What one may not so easily anticipate is the proverbial axe falling on a loved one while you stand helplessly by wishing it could be you instead of them but knowing full well that you do not get to make that choice. And so it was when I learned that my son had type 1 diabetes. To say I was

blind sided would be grossly understating the situation. He wasn't sick. He was happy. Active. Excelling in school. Upon dismissal of this wishful thinking we were fast tracked into the surreal world of endocrinologists with a blur of doctor appointments, lab tests, needles, pharmacies, carb counting, finger pokes, blood checks, injections 4 times a day, a whole complex and somewhat intimidating array of goods and services...a polite way of saying your life has been hijacked. At first I was numb. I wanted a do over. I didn't sign up for this and really wanted to withdraw from my family being a contestant. Each morning I would wake up and realize the reality and then cry.

[Participant 1 – Mother of a recently diagnosed 12-year-old boy]

I don't cry every day anymore (in fact I haven't for over a year), but I occasionally get very overwhelmed for her. My heart still breaks if I could [sic] think about it too hard. Not to minimize at all what they are going through, but sometimes I think it's worse on the parents because we feel so helpless at times. I would rip out my pancreas and give it to her in a heartbeat, if I could!

[Participant 14 – Father of a recently diagnosed 13-year-old girl]

With the first drop of the roller coaster, the overwhelmed parents were fast tracked into a surreal world. They wanted to trade places with their children, but they had no choice. They wanted to exit the ride, but they were helpless and there was no getting off. The frightening fall was emotionally exhausting for these parents who wanted to protect their children.

Social support

Following the rapid diagnosis experience, parents needed support to sustain them through the ride. The roller coaster carried parents beyond the first and daunting drop, and they desperately sought advice from the tudiabetes.org® community. Support was shared and received from other parents of children with diabetes who had also experienced the roller coaster ride. Thus, sustaining strength was found through social support.

Some parents shared support through information and practical advice. They talked about resources that were helpful to them. These parents felt helpless about the diagnosis, but they regained control through information seeking and sharing. While they could not leave the roller coaster ride of intimidating loops and curves, information about treatment options and medical technologies mitigated their sense of helplessness:

As with anything, I would be careful about what you find on the internet.

There are great resources and not so great ones. I like Children with Diabetes website, the Pink Panther Book (from the Barbara Davis Center) and sites like TuDiabetes, with real experiences to draw from.

[Participant 19 – Mother of a recently diagnosed 14-year-old daughter]

We've been doing the same as you described, reading up on the condition and looking at all the best options that are available for him to manage his condition. The one big difference that I feel gives me more hope than anything else with diabetes today is that the internet is linking all our individual battles and experiences into a strong closely knit dynamic problem solving community. I am fully convinced that this will provide us all with the elements to solve each problem we are faced with in the best possible way.

[Participant 28 – Father of recently diagnosed 6-year-old son]

In addition to seeking and sharing information, other parents offered support through encouragement and empathy. They understood the intimidating roller coaster ride with its ups, downs, drops, and unexpected curves. These parents shared stories of their own experiences, and their language conveyed assuring messages:

I know your pain, I know your burden, I know your anxiety, I know your stress. I carry it all too...There is a huge online community of parents coping with this and without them I am not sure I would be ok. And I am more than ok now. Are you on facebook? If you are willing I could friend you and set you [up] with an amazing group of people. There is also a blog that has helped me so much...It is a huge relief for me.

[Participant 10 – Mother of a recently diagnosed 13-year-old boy]

The good news is that my daughter and so many kids diagnosed DO NOT LET IT AFFECT THEIR LIVES AT ALL!! My daughter is the same spunky, smart, funny and sweet girl she always was and always will be. Your son is the same person as well. Diabetes will not stop your son from doing ANYTHING he wants to do...Hang in there and know that every parent on these boards feels the same as you...and it will be ok...I have learned so much from the parents and people here. It has been a huge comfort to me to know so many others feel the same way and life with T1 [type 1 (diabetes)] is still a great, happy life, just with a little extra work. We are in Rhode Island, by the way :) Hang in there!

[Participant 34 – Mother of a recently diagnosed 4-year-old girl]

We can so relate to your story as we have all experienced exactly what you are going through...Please know that we are here to help you in anyway [*sic*] that we can. I am very grateful for the close relation that we have developed with other parents of type 1 children. Those relationships really do help.

[Participant 14 – Father of a recently diagnosed 13-year-old girl]

Cathartic release

Equipped with social support from the tudiabetes.org® community, many parents were positioned to experience cathartic release. They apparently accepted and even appreciated moments of the roller coaster ride, and they shared stories of humor and strength. Some parents expressed humor to release emotional tension:

Thanks for the welcome [name omitted]. I love the proudness in your words that you have for your little guy. My son came home from school yesterday and was being silly talking in a silly voice. He said to me, I was so thirsty today, you would think I had diabetes or something. It made me laugh.

[Participant 1 – Mother of a recently diagnosed 12-year-old boy]

I chuckled when reading it because today my son has a doctors [*sic*] appointment today...and I thought to myself, maybe I need to have her write me a prescription for some 'happy pills' so that on the days that I feel so low, I have help. Yesterday I left the house, not knowing where i [*sic*] was going.

[Participant 1 – Mother of a recently diagnosed 12-year-old boy]

These parents also recognized their children's strength, and this realization contributed to their sense of emotional release. In many cases, the children adapted to the roller coaster ride with relative ease. The following excerpts illuminate the parents' perceptions of their children's strength:

It will always be a challenge, it will always be a scare, I will always wish that it could just go away. Allow yourself to feel however you feel, and just do the best you can. Our kids are so much stronger than we think, and this process opens your eyes to that...Take care of yourself and each other. Sending hugs from Utah!!

[Participant 34 – Mother of recently diagnosed 4-year-old boy]

Next week is my 11-year-old daughter's 1 year D [diabetes] anniversary. She is just such an amazing person. She inspires me every day as she handles this condition with such grace and humor. I hate that this happened to her but she doesn't let it get her down as a matter of fact she seems stronger, more confident and more comfortable in her own skin than she did before. She went to a FANTASTIC diabetes camp last summer. She let me read her camp journal. It had a page '3 things that I like about myself' and '3 things I would change about myself'. I was floored that her three things included her very mild asthma but not her diabetes.

[Participant 21 – Mother of a recently diagnosed 11-year-old girl]

“New normal”

The unrelenting roller coaster ride persisted, but the journey eventually became second nature for these parents. The final stage of the roller coaster ride embraced the passing of time and the adaptation of a new routine. After the initial shock, quest for support, and occasional sense of release, parents described a new normal that evolved with the passing of time. While the ups, downs, and curves continued, their way of thinking adjusted, and counting carbohydrates and testing blood sugars became second nature. As one parent wrote, “you grow your ‘diabetes brain.’” Another encouraged with these words: “Know that your feelings are very normal and that time is going to help.” The passing of time was clearly an important theme:

I promise you that eleven months from now your life will feel different (in a good way) than it does today. This last year in our lives seems like ten years. We’ve learned and experienced and grieved and overcome so much...I will say that the passing of time (acceptance? knowledge? who knows) and the pump have made an exponential difference in our day to day lives...He shared that during the time he wore the AP [anabolic pump] that for the first time in his memory he actually forgot sometimes that he has T1D [type 1 diabetes] because testing and dosing wasn’t the first thing he did every morning and the last thing he did every night. Isn’t that wonderful and hopeful?...Stay strong – the new normal will find you.

[Participant 21 – Mother of a recently diagnosed 11-year-old girl]

Daily life with [name omitted] is kind-of like this: There are days when you ALMOST don’t remember that he has diabetes...except for regular testing and use of the pump...those days are pretty golden...when his BGs [blood glucose levels] stay between 100 and 200 all day and he’s a normal

little boy for all intents and purposes...and there are days when I literally scream "I HATE DIABETES!!" and I'll cry...Most of the days fall somewhere in-between...but the vast majority lean closer to the "comfortable" side...and it does get easier. It does become more normal...more routine.

[Participant 41 – Father of a 7-year-old boy, diagnosed three years ago]

In summary, parents used vivid language to talk about the initial experience of becoming a parent of a child with type 1 diabetes. The overall experience for parents was likened to a roller coaster ride that eventually reached a "new normal." Themes of this daunting and deeply emotional ride included catastrophic event, social support, cathartic release, and new normal.

Discussion

This study explored the communication of parents within a non-moderated virtual health community surrounding the diagnosis of a child with type 1 diabetes by analyzing the textual discourse of a particular tudiabetes.org® discussion thread. Related studies examined virtual health communities and online support groups to determine their ability to improve diabetes self-management, affect clinical outcomes, change health behaviors, mobilize peer support, and provide emotional support (Eysenbach et al., 2004; Heisler, 2009; McKay et al., 2002). Researchers generally agree virtual health communities offer potential to enhance patient empowerment and self-care (Demiris, 2006; Heisler, 2009; van Uden-Krann et al., 2008), but Heisler (2009) acknowledged much research remains for this new area of inquiry.

Our study was unique in seeking to understand the communication patterns of parents within an online virtual health community, especially surrounding the diagnosis of a child with type 1 diabetes. Another study considered communication within virtual communities in health-

care by reviewing the process and frequency of communication between members (Demiris, 2006). Klenn et al. (1999) examined an Internet cancer support group that conceptualized a typology of information exchange. The categories included information giving and seeking, statements of encouragement and support, statements of personal opinion, and statements of personal experiences. These categories parallel the social support stage of the roller coaster ride depicted in this present study.

While many studies discussed concepts related to information exchange and social support within virtual health communities (Demiris, 2006; Eysenbach et al., 2004; van Uden-Krann et al., 2008), none identified diagnosis as a catastrophic event or revealed the acceptance of a “new normal.” One study explored the use of humor as a coping mechanism; van Uden-Kraan et al. (2008) classified amusement as an empowering aspect of online support groups for patients with breast cancer, arthritis, or fibromyalgia. The present study reproduced findings related to social support; however, diagnosis as catastrophic, release through humor, and movement towards a “new normal” emerged as unique constructs within the context of this research. These new findings likely stem from the particular focus of this research on parents’ dialogue surrounding a diagnosis experience.

Future studies in health communication should explore these findings to understand their potential relevance to other health diagnosis experiences. An implication for future investigation would be the empowerment provided by virtual health communities. As identified by van Uden-Kraan et al. (2008), empowering processes include the exchange of information, experience of emotional support, sharing of experiences and the helping of others.

Limitations

Further research should expand on the results presented here. This study explored a particular discussion of parents of children with type 1 diabetes within a virtual health community. The findings of this study are limited, based on the small sample size and the explicitness of participants, and should not be generalized to other health conditions or contexts, as respondents were highly active users of a specific virtual health community. A quantitative study exploring a larger sample size of participants in online virtual health communities might provide an appropriate method to validate the results of this qualitative study. Furthermore, future studies could explore whether increased Internet usage also increases the number of people sharing their experiences with chronic illnesses, such as diabetes, online.

Conclusions

In summary, this study offered a detailed snapshot of how people talk about their initial experiences of becoming parents of children with type 1 diabetes through the tudiabetes.org® virtual health community. Parents described their lives passing as normal when suddenly their children were diagnosed with type 1 diabetes. They were fast tracked into the surreal and unfamiliar world of a serious chronic health condition. These parents wanted to trade places with their children and exit the ride, but they were helpless. Frantically, they began a new life of information seeking and social support as they swooped down the first curve. The ride persisted, and they experienced new loops and curves along the way. Bolstered with social support, these parents occasionally appreciated the surrounding view and experienced hopeful moments of cathartic release through humor and recognition of their children's strength. Although the ups, downs, and curves continued, these parents eventually accepted a new normal. Parents discussed these experiences in vivid language and appreciated the interactive forum offered through the tudiabetes.org® community.

Health communication research is a vibrant area of study designed to increase knowledge about communication patterns and challenges. As previous studies have shown, more knowledge is needed to enhance the overall quality of communication for those affected by chronic illnesses (Glasgow et al., 2003; Kreps, 2001; Nutbeam, 1996). Although virtual health communities are rapidly emerging and offer promising solutions for peer-to-peer support, communication within these communities lacks consideration and offers a productive research line within health communication.

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