


“Her Life Rests on Your Shoulders”: Doing Worry as Emotion Work in the Care of Children With Diabetes

Global Qualitative Nursing Research
Volume 4: 1–11
© The Author(s) 2017
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/2333393617743638
journals.sagepub.com/home/gqn


Lisa Watt¹

Abstract

Research on parents' caregiving experiences in the context of diabetes management have consistently shown that parents experience high levels of pediatric parenting stress, anxiety, depression, and general worry. However, how parents understand their worry is largely unexplored and little attention is paid to the work parents are already actively doing to manage their worry. Adopting Arlie Hochschild's concept of “emotion work” and Dorothy Smith's concept of “work,” this article examines how parents engage in the emotion work of doing worry. Drawing on the analysis of transcribed data from interviews with seven parents caring for children with diabetes, I show how parents expressed worry as an emotion they experience as well as an embodied way of knowing the presence of potential threats to their child's health. Thus, doing worry is an essential aspect of work done by parents to ensure the safety and well-being of their children with diabetes.

Keywords

children with diabetes, caregiving stress, emotion work, worry, institutional ethnography

Received March 2, 2017; revised October 26, 2017; accepted October 30, 2017

Introduction

Type 1 diabetes (henceforth referred to as diabetes) is one of the most common childhood chronic illnesses (Haynes, Bulsara, Bower, Jones, & Davis, 2015; Soltesz, Patterson, Dahlquist, & EURODIAB Study Group, 2007). The medically optimal management of diabetes involves a well-coordinated and intensive daily routine that balances the administration of insulin, constant blood sugar monitoring, a well-regulated and well-timed meal plan, as well as a consideration of a myriad of factors such as the amount of physical activity undertaken and levels of stress, sickness, and growth. It is crucial that children's blood sugar levels be monitored and controlled so as to remain as close as possible to a normal range throughout their lifetimes, as lapses in this complex daily regimen can have devastating immediate as well as long-term consequences for children with diabetes (Diabetes Control and Complications Trial Research Group, 1994). As such, a diagnosis of diabetes in children requires tremendous adjustment and reorganization for the whole family, and places great demands on parents.

As increasing numbers of children are diagnosed with diabetes, and at younger ages, there is growing interest in the experiences of parents who care for their children with diabetes. Previous research on parents' caregiving experiences in the context of diabetes management has consistently shown

that parents experience high levels of pediatric parenting stress, anxiety, depression, and general worry (Hatton, Canam, Thorne, & Hughes, 1995; Lowes & Lyne, 2000; Monaghan, Hilliard, Cogen, & Streisand, 2009; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Even though the daily routines of diabetes care are demanding, these studies have found that treatment tasks are not the main cause of parental stress and anxiety. Rather, parents' level of emotional distress is associated with their fear of potential hypoglycemic episodes, concern over the effects of children's fluctuating and unpredictable blood sugar levels, anticipation that others entrusted with their child's care may not be able to enact treatment requirements, and concern over their children's future health and possible long-term health complications (Hatton et al., 1995; Haugstvedta, Wentzel-Larsen, Rokneb, & Grauea, 2011; Monaghan et al., 2009; Patton, Dolan, Henry, & Powers, 2007; Smaldone & Ritholz, 2011; Streisand et al., 2005; Wennick, Lundqvist, & Hallström, 2009). Indeed, much of parents' distress takes the form of persistent worry.

¹McMaster University, Hamilton, Ontario, Canada

Corresponding Author:

Lisa Watt, Postdoctoral Fellow, School of Social Work,
McMaster University, Kenneth Taylor Hall 319, 1280 Main Street W.,
Hamilton, Ontario, Canada L8S 4M4.
Email: wattlh@mcmaster.ca



Much of the research on parents' caregiving experiences in the context of diabetes management focuses on parental adaptation and coping. Parental adaptation to the diabetes diagnosis and the daily demands of care is understood to be critical to parents' abilities to manage diabetes and to successfully care for their children with diabetes. Embedded in psychological discourses, worry refers to a "mental distress or agitation resulting from concern usually for something impending or anticipated" (Merriam-Webster Online, 2017), and it is often understood to be passively experienced by individuals and is seen as a sign of negative adaptation or a failure to cope (Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011). How parents understand their worry is largely unexplored and little attention is paid to the work parents are already actively doing to manage their worry. Feminist concepts of emotion as work can offer new ways of understanding and appreciating parents' accounts and practices of worry. This knowledge will offer insights on how to better support parents caring for children with diabetes.

Emotion as Work

The term "emotion work" was first introduced by Arlie Hochschild (1983) to refer to an individual's intentional effort to manage or display one's own feelings to influence those of others in desirable ways (DeVault, 1999; Steinberg & Figart, 1999). Hochschild (1983) makes a distinction between "emotional labour" and "emotion work": The former is required by employers in paid employment, whereas the latter refers to the unpaid efforts that occur in family and personal life, often conducted by women (as cited in DeVault, 1999). It is important to note that "emotion work" refers to the efforts—the act of trying—taken in a broad sense to shape, evoke, or suppress a feeling, and not to the outcome which may or may not be successful (Hochschild, 1979, p. 561). Moreover, emotion work can be undertaken by oneself upon the self, by oneself upon others, and by others upon oneself (Hochschild, 1979, p. 562).

In the context of caregiving research, the idea of "emotion work" is significant as it draws attention to the often neglected emotional dimension of caregiving, which involves the emotional interactions between the caregiver and the care recipients and the management of their emotions. A number of scholars underscore emotion work as an intrinsic, albeit invisible, part of caring work (Clarke, 2006; Mac Rae, 1998). In viewing emotion as "work," the experience of a particular emotion is no longer understood as a passive state experienced by caregivers or care recipients. Nor are emotions such as worry necessarily an indicator of an individual's maladaptive coping. Rather, it is suggested by Clarke (2006), in her research on the health care work of mothers of children with cancer, that these emotions are a "rational," "normal," and often necessary response to caring for a sick child (p. 59).

Dorothy Smith (1987) also offers a conception of work relevant to understanding how parents engage in doing worry

when caring for their children with diabetes. "Work," in Smith's (1987) conception, is understood as the activities that people do that require some effort and some acquired competence, occurring in real time under definite material conditions and means (p. 165). These activities are connected to the activity of others in and beyond a local setting. The notion of "work" directs

analytic attention to the practical activities of everyday life in a way that begins to make visible how those activities gear into, are called out by, shape and are shaped by extended trans-local relations of large-scale coordination (what Smith calls relations of ruling). (McCoy, 2006, pp. 110–111)

In taking up this notion of "work," my attention is drawn to the practical activities that parents do on a day-to-day and moment-to-moment basis, and how this work is connected to the work of others to identify trans-local relations shaping local practices (McCoy, 2006). As well, I will explore the knowledge that informs these practical activities.

Adopting Hochschild's (1983) concept of "emotion work" and Smith's (1987) concept of "work," worry or worrying is understood as an aspect of emotion work involving active, skillful engagement: I call it "doing worry." In this article, I seek to explore the emotion work of doing worry that parents engage in when caring for their children with diabetes using Hochschild's and Smith's frameworks.

Method

Design of the Larger Study

The results described here draw on data from a larger study using institutional ethnography (IE) to examine the social organization of School Health Support Services for children with diabetes in Ontario schools (Watt, 2015). IE is a method of inquiry developed by Canadian sociologist Dorothy Smith (1987, 2005, 2006) to investigate the social relations embedded in aspects of people's everyday life circumstances that trouble them (McCoy, 2008). This method of inquiry typically takes up people's experiences in everyday life as the starting point of inquiry, and further explores the institutional contexts shaping the experiences and routine practices of people in the local setting (Smith, 1987, 2005). The method of in-depth interview was chosen for its ability to generate rich information and was used to explore what parents do to care for their children with diabetes. However, the use of in-depth interviews in IE differs from traditional qualitative research in a significant way. The goal of talking to parents is not to understand their perceptions or the meaning of these experiences (Smith, 2005), nor to reach data saturation. Rather, the goal is to investigate the social organization of the experience (Smith, 2005); I seek to learn about institutional work processes and how parents engage in institutional work. In this case, the institutional work processes under study concern the diabetes care children actually

receive in school. Parents' experiences constitute the beginning stage of this IE, and typically a small number of interviews are conducted for the purpose of developing and refining the direction of the research.

Ethical Approval, Recruitment, and Participant Information

Ethical approval was obtained from the University Research Ethics Board on April 23, 2011. Parents of children aged 18 years or younger with diabetes were invited to participate as long as the child was at least 12 months post-diagnosis. A recruitment email with information explaining the nature and purpose of the study and a consent form was sent to the organizers of two parent support groups, who were asked to forward this information to their members. Parents who were interested in taking part in this study (9) contacted me directly to arrange for a face-to-face interview at a location and time of their choice. The participants were self-selected and identified as the main caregiver for their child. One parent was hospitalized before the interview took place and another parent did not meet the inclusion criteria as the child was only 1 month post-diagnosis.

At the time of the interviews, the average age of the parents was 44, ranging from 34 to 53 years old. All parents and their spouses had college or postsecondary education. They had an average of about 5 years of experience in caring for their children with diabetes, ranging from 1 year to over 10 years of experience. Their children were diagnosed with diabetes between the ages of 9 months and 14 years of age. Two of the parents had more than one child with diabetes in their household. The parents were from two-parent middle-class families.

Interview Process, Transcription, and Pseudonyms

Seven parents (five mothers and two fathers) were interviewed between May to July 2011. Participants provided informed written consent for their participation and for the interview to be audio-recorded and transcribed. During the interview, they were asked general questions about their caregiving experiences, such as daily routines of diabetes care, what knowledge they drew on to care for their child, rewards and challenges, what they found helpful and unhelpful in the process of caring for their child, and who helped them. On average, the interviews lasted 109 minutes (ranging from 71 to 185 minutes). The interviews were transcribed verbatim immediately after each interview. All identifying information was removed from the transcripts. The participants' names used in this article are pseudonyms to ensure participants' confidentiality.

Analysis

Data analysis occurred during the interviews as well as when the transcripts became available (Smith, 2005). Guided by

Smith's conception of work, I read through the transcripts and paid close attention to parents' accounts of practical activities they were engaged in when caring for their children with diabetes. Using MAXQDA software, I classified the different activities parents were engaged in into different categories of work, for example, "teaching work," "coordinating work," "advocacy work," "preparation work," and so on (VERBI Software, 2013). Following my observations during the interviews, I also created the category "worry work" because all the parents repeatedly verbalized in the interviews that worry is a significant and challenging part of caring for children with diabetes as shown here: "Just the emotional strain that, hm . . . the worry, the . . . the feeling like her life rests on your shoulders, that's the hardest part" (Brenda, child aged 6, diagnosed at age 5); "When I'm not around it I can notice it, I can notice I don't have to worry. So there's a challenge, I'm worried all the time" (Steve, child age 13, diagnosed at age 9).

Intrigued by parents' articulation of worry, as well as their wealth of knowledge and their expression of feeling empowered and actively engaging in managing their child's poor blood glucose (BG) readings, I decided to take a closer look at this seemingly contradictory account. I conducted a second read through the selected interview segments under the category "worry work." Informed by the analytic questions suggested by IE scholars (McCoy, 2006), I focused more closely on how parents talked about their worry, how they understood their worry, and what they actually did to manage their worry. In my analysis, I was also guided by these questions: What evokes the need to do worry? What knowledge and skills do parents draw on to do worry? How does doing worry arise in relation to others and their work? I then drew on Hochschild's (1983) conception of "emotion work"—the efforts taken to shape, evoke, or suppress a feeling upon oneself and others—to organize the findings.

Feminist Methodology and Reflexivity

Feminist methodologies and feminist epistemologies have recognized the situated character of scientific knowledge and how the researcher's biography and social location shape the research relationship in complex ways (Griffiths, 1998). As a parent of a child with diabetes, I am both an insider and an outsider to this research (Griffiths, 1998). As a researcher, I purposefully chose not to become a member of the support groups to minimize my influence on the participants. I was introduced to the potential participants as a student researcher and a parent of a child with diabetes. I believe our shared identity as parent caregivers allowed me to build a trusting relationship with the participants, which enabled them to share their experiences, thoughts, and feelings with me more readily. During the interviewing process, I was cautious to not assume what I know, I asked many clarifying questions, and requested that the participants describe in concrete details

how and what they do to care for their child's diabetes. My familiarity and knowledge with diabetes carework was helpful in eliciting more in-depth information. I held back from sharing my experiences, thoughts, and feelings during the interview and instead I reflected and summarized what the participants shared to double check and ensure I understood what they meant.

At the same time, being a parent relatively new to diabetes management, there were moments when I felt like an outsider during the interviews. I was less savvy and knowledgeable than the parents I talked to. The amount of work they engage in and their knowledge base set me apart. I began to think about how our diabetes carework is organized in similar and different ways. I was also curious about the contrast between their extensive knowledge base and skills and their articulation of worry. My experience as a parent caregiver provided an entry point and a subject position for me as a researcher to understand how diabetes carework is organized (Smith, 2005).

In the "Findings" section, I describe how parents understand and come to experience worry, and the knowledge parents draw on in "doing worry." I then show the actual practices of "doing worry" that parents engage in competently and actively to manage—contain, or express and amplify—their worry and that of others, including their children, family members, and the professionals who are involved in their children's care.

Findings

"Knowledgeable Vigilance": Being On-Call for Diabetes 24/7

Parents described initially learning of the complex and intensive diabetes management regimen as being similar to climbing up a steep curve; they were required to learn a large amount of information about diabetes care instantly, as their children rely on them to know how to treat diabetes to stay alive. The knowledge of the diabetes management regimen was conveyed to the parents as part of the professional work process of diabetes education and treatment conducted by diabetes nurse educators at pediatric diabetes clinics. Diabetes education practiced at the clinics follows the Clinical Practice Guidelines of the Canadian Diabetes Association which entails BG monitoring, BG and ketone testing, insulin administration and dosage adjustment, carbohydrate counting and nutrition, exercise, and prevention, detection, and treatment of hypoglycemia (Wherrett, Huot, Mitchell, & Pacaud, 2013).

Parents initially followed the diabetes management regimen closely. Over time, as diabetes knowledge became embedded through their everyday practices, they came to the realization that nothing about diabetes is predictable. As Steve articulates, "You'd think there would be a science to it but there isn't. Like, it changes every day." Indeed, diabetes

is not the type of illness whereby good results can be guaranteed if you follow a standard treatment procedure; a child can do the same activities, eat the same food, and follow the exact same diabetes care procedures on two separate days and BG readings can be different. Diabetes is constantly on the move: As May (child aged 16, diagnosed at age 9) exclaimed, "Diabetes never takes a break." Lily (child aged 17, diagnosed at age 14) described diabetes as an "exhausting 24/7 disease."

Through their repeated experience of doing diabetes care, parents identify the complexity of this work, as there are many changing factors that need to be taken into account; flexibility and constant adaptation is required to achieve optimal glycemic control. Achieving optimal glycemic control means keeping the child's BG level within a normal range for their age as much as possible. Doing so is critical to prevent acute problems (hypoglycemia and Diabetes Ketoacidosis [DKA]) and minimize the risks of developing long-term complications (such as heart attack, stroke, kidney failure, blindness, and amputation due to microvascular and neurological complications; Diabetes Control and Complications Trial Research Group, 1994).

Acutely aware of the possible consequences of poor glycemic control, parents work tirelessly 24/7 to keep their child's BG within a normal range. Bob (child aged 15, diagnosed at age 10) summarizes the goal of diabetes care for his child as the achievement of the "best possible quality of life for her. Minimum of intrusions in her daily life with the best possible blood sugars and no bad lows." He goes on to explain how he achieves this optimal care:

I mean if I try and do insulin regimen and it doesn't work it's obvious very quickly. And then, I either go back to what I was doing if it's better than the new thing I've tried or I tweak the new thing and make it work better. That's what managing diabetes is all about. Your child's insulin needs are always changing, the patterns . . . the patterns . . . like governing the amount of insulin they need over a 24 hour period are always changing so you need to be flexible. You have to be flexible, you have to be able to adjust.

Here, Bob tells of how he fine-tunes his daughter's insulin regimen by paying close attention to her BG patterns for a 24-hour period to decide on an insulin regimen that works best to keep her BG level within range. Knowledgeable of the many factors that change his child's insulin needs, he emphasizes the need to be flexible, and to make adjustments accordingly. Here, he explains the need to be alert at all times to his child and her changing needs and circumstances to manage diabetes well:

It's the fact that every hour of the day . . . and possibly of the night as well at some level you have to be conscious of the diabetes and what you need to do to be managing it. It maybe doesn't take a lot of your time or a lot of your conscious effort but it's always there.

In addition to being watchful to the changing BG patterns and always having diabetes on his mind, other parents explain the importance of taking extensive notes to keep track of their child's various activities, types and amounts of food consumed, and events that may be associated with the changing BG readings. In the following quote, May provides an account of how taking notes and analyzing them has helped her to figure out what works and, in relation to her son's significant athletic pursuits, to become more confident in caring for his diabetes:

I would say what I've had to do is keep up with him. He comes home and decides to go skateboarding for 2½ hours, snowboarding all day. It's like how do you, what strategy, what do you do? What works? And so writing down what works. Every half an hour we give him a box of Smarties. Did that work? Yes it worked. Remember that for next time . . . He played soccer so it was like ok his soccer, he'd come off the field and he'd be sky high so we would treat him with insulin and he would be crashing low so then we realized you don't treat that you just let it go, it'll come down by itself . . . Writing down, remember what we did before, keeping good notes.

May is attentive and meticulous. She pays attention to the immediate moment, as well as to the overall trend of how certain food or activities affect her child's BG level. Through repeated experience, she has learned that following the protocol (correcting high BG by injecting insulin) does not work on every occasion. In the instance cited above, she describes learning that high BG after soccer games is likely due to increased adrenaline from excessive physical activity and no action is required. Whereas on other occasions, a high BG reading may signal a lack of adequate insulin in the body or a miscalculation of the amount of carbohydrates consumed, and an injection of insulin is required to keep the child's BG level within range. Each time, she documents the unique patterns of her child's diabetes-related care needs for future use. It is from their practice knowledge that parents emphasize the persistent, unrelenting attention and vigilance that is necessary precisely because managing diabetes is like chasing a moving target.

Not only do parents need to be alert during the day, they also describe being on-call throughout the night. Brenda explains her worry stems from her knowledge that children die from extreme hypoglycemia during the night: "Kids do die from it, children just don't wake up sometimes, it happens, it's not common. Thank God. But it does happen and people don't, I don't think they get that." Though Brenda is relieved that this is not a common occurrence, this does not prevent her, and other parents in this study, from being constantly watchful. They know intimately the experience of waking up in the middle of the night to check their children's BG, finding it unexpectedly low, and having to force feed their sleeping children carbohydrates. It is the watchfulness and vigilance of these parents that keeps their children safe throughout the day and night. The unpredictability of

diabetes is the reason why Joy (child aged 5, diagnosed at age 9 months) is hesitant to feel confident about "managing" diabetes:

I am less nervous because, I don't want to say you can predict those [low blood sugar], but you kind of have a better feel of when they may occur sometimes, because diabetes is not a perfect science, it will throw you off. But I think . . . we try to test him, that's just for our peace of mind [laughed]. Yeah, I think that's always, they [low blood sugar levels] still scare me.

After caring for her child with diabetes for more than 4 years, Joy has accumulated knowledge and experience about her child's diabetes care, and is feeling less anxious about "managing" diabetes. She describes being more able now to make an informed guess as to when her child may experience low BG levels, and hopefully intervene before it happens. However, this does not put her at ease; she is still scared because her child, lacking the ability to feel low BG levels, is unable to alert her when he is experiencing low BG. More importantly, diabetes is unpredictable and will often throw her off at the least expected times. Therefore, Joy feels that it is foolish to feel confident, as it might lead to lapses in diabetes carework, which may put the child at risk. As she is most concerned about the effects of prolonged periods of low BG on her child's cognitive development, and potential death, she resorts to doing frequent BG testing throughout the day and night, which eases her worry (more on this in the next section).

It is with this wealth of knowledge about diabetes and extensive experience of doing diabetes care with their children that parents experience worry. While parents describe diabetes as being always on their minds and their need to be alert 24/7, I hear from their accounts that they experience different degrees of worry. For example, Kylie describes being worried when her older child (age 12, diagnosed at age 2) was in kindergarten because of an instance in which her son's lethargic behavior was understood as misbehavior by the teaching staff. He was left slumped over in a chair in the principal's office until the nurse came during the nursing visit and found him in a coma caused by an extreme low blood sugar level. Here, we see how the work of observation, so critical to the effective management of diabetes, can be compromised by assumptions that an adult has about a child, or labels that have been applied to the child. In contrast, she feels at ease with her other child (age 9, diagnosed at age 5). Kylie's daughter is perceived as well-behaved and responsible; teachers are thus unlikely to attribute diabetes-related symptoms to "problem" behaviors. More importantly, her daughter can and will perform necessary diabetes self-care reliably. Joy speaks of feeling reassured when her child is at school with a consistent nurse that has repeated experience of providing care for her child. Joy's assessment is that this nurse has acquired knowledge about her child and her child's care, and is able to perform the work

skillfully, as proven by her ability to keep blood sugar levels within range by adjusting intake of carbohydrates according to changing BG levels.

From these accounts, we see that parents draw on their embodied practice knowledge and engage in a process of thinking through the various factors, such as their child's BG patterns, their response to diabetes treatment, their personality and maturity in "managing" diabetes, the environment, and the competence of the individuals caring for their child, to determine if the child is safe. Seen this way, parents' accounts of their experience of worry is an indicator of whether their child's health and well-being is at risk. It is a result of their engagement in what I call the work of "knowledgeable vigilance." Here, I use the term "knowledgeable vigilance" to refer to complex practices that involve knowledge of a normal BG range and the short-term and long-term consequences of out of range BG, monitoring BG, observing a child (and the child's responses to insulin, food, sickness, physical activity, and other factors) in the moment and over longer periods of time, and responding to the child's changing needs and circumstances to sustain a normal BG range. Parents' feeling of worry is invaluable. It is essential to the diabetes carework that keeps their child safe. In these interviews, I hear parents describe doing work that manages or suppresses the worry for themselves, and others, particularly their children. At other times, parents attempt to induce worry in others, such as teachers and health care professionals, who do not understand diabetes or diabetes care, with the goal of keeping their children safe. What follows is a description of the work of doing worry.

Doing Worry: The Relational Aspect of Emotion Work on Oneself and on Others

Managing worry. Working to achieve a "satisfactory" number. Having knowledge of the changing nature of the child's BG levels and insulin needs, many parents resort to keeping watch and frequently checking their children's BG level to ensure it is within range. This is particularly difficult throughout the night. Joy expresses that the most challenging aspect of caring for her child with diabetes is the worry of the possibility that her child may experience severe hypoglycemia during the night. To relieve this worry, Joy resorts to setting an alarm to wake up in the middle of the night to check her child's BG levels. She explains the number representing her child's BG level provides her with information that gives her comfort:

I still test him in the middle of the night, and I know that not everyone does, but for us, it's just peace of mind, it's knowing that for those 12 hours that he's asleep. Hm . . . if we test at you know 11, and we test at 3, 99.9% of the time it's absolutely fine, but what if something happens, what if he's high. And do you want him to be high for 12 hours, no, we can do something about it. Again, we're empowered to do something about it, so we just do. But what if I didn't, what if something happened in the middle of the night when he's sleeping. I think that is the worry.

In addition to paying attention to her child's immediate well-being, Joy is also attentive to the long-term effects of prolonged periods of high BG levels on her child. Waking up throughout the night relieves her two worries: the worry of her child's potential death due to severe hypoglycemia and the worry of possible long-term complications. Other parents set up a different set of routines. In the following quote, Bob explains his night time diabetes care routines for his child:

Depending on how the day and the evening have gone, if she's gotten a lot of exercise, if she's had weird foods there is often a need to measure at night. So we've actually adjusted our family's routine. I'm self-employed so I have very flexible hours and I will simply stay up at night working on my work and keep measuring until I'm satisfied that we've got nothing to worry about for the rest of the night . . . But until I've got a trend that I'm satisfied with I'll stay up and keep working and measuring every couple of hours.

Bob describes how he works at getting a "satisfactory" number. He takes into consideration the activities and the food his child consumed during the day, the BG trend (which is the BG pattern of the past few days), and his child's current BG level to adjust insulin needs. He keeps checking and making adjustments until he gets a "satisfactory" number. He considers a "satisfactory" number as one that gives him nothing to worry about throughout the night and allows him to go to bed peacefully. Kylie, Steve, and Lily describe similar routines. They too rely on a "good enough" BG number at bedtime to decide whether or not to get up in the middle of the night. Achieving a "satisfactory" number gives parents peace of mind. The activities that ensure that BG levels stay in range are exactly the activities that help to manage their worry.

Containing worry: Building positive attitudes toward lifelong diabetes care. Being mindful that diabetes is a lifelong illness, parents are wary of the emotional burden of having a chronic illness on their children. They are concerned that their children will resent living with diabetes and that might influence how their children will or will not engage in diabetes self-care in the future. Parents work at not letting diabetes take over their children's lives and creating a positive experience of living with diabetes for their children. May's son is 16 and "manages" his diabetes himself. She offers support and supervises from a distance. Here, she describes how she tries not to let diabetes dominate and mediate her relationship with her son:

I had to really watch it because my first question to him in the morning was what's your blood sugar and now I had to really change that and say did you have a good sleep? You know what's your day hold for you today? Like wow how late were you up last night? Did you get that essay done? What's your blood sugar?

As mentioned in the previous section, knowing a "satisfactory" number gives parents peace of mind. May's need to ask about her son's BG in the morning stems from her worry about whether his diabetes is being well managed. However, she makes an effort to hold back her need to know and

attends to aspects of him and his life beyond diabetes. Here, she does not want her son to know that she is anxious to know his BG level. Instead, she suppresses her automatic response to ask about his BG to create a “normal” family life and a relationship with her son that is not solely mediated by diabetes. This is her attempt to not let diabetes dominate their life, and to try to minimize the possibility of her son resenting being treated only as a “diabetic” and not as a person.

Brenda is careful in how she responds to her child and the type of messages she gives her daughter about living with diabetes. She describes a process of constantly thinking through what she says and does to prevent her daughter from understanding her diabetes as limiting.

I don't want her to resent any of these, I don't want her to feel like diabetes is, makes my life suck . . . it's like everything I answer her will have implications because I am sending a message to her with everything that I do. And then where I feel like I am so cautious when I say no about something, why am I saying no to this, you know, she wants to go do an activity say with a friend somewhere, and how do I say “no, because you are diabetic, I can't, I can't let you” because then she is going to really hate it [sighed] and so I'm so conscious of trying to prevent that.

Here Brenda describes two worries: worry about the activity on the child and worry about the effects of expressing her worry about the activity by saying no. Her worrying about diabetes keeps her child safe, but expressing her worry about diabetes to the child might lead the child to dislike diabetes. Brenda cautiously chooses to downplay the role of diabetes in the hopes that her child will not resist having diabetes. Ultimately, she is worried that if her child hates diabetes, she will be less likely to engage in diabetes self-care in the future, putting her at risk.

Joy is aware of her diabetes-related worries, and how her child may pick up on these and become worried himself. She works at not expressing her worry in front of her child. She also works actively to change her relationship to the BG numbers by removing her feelings related to the number and instead focusing on the number as a type of information and the ways she can take action in response to that information. She does not want her child to activate a feeling of worry every time he sees an out of range number. She explains,

It's hard not to transfer that worry onto him all the time. I know I don't want him to feel worry not going to places, or doing things or that sort of thing, so a lot of it, you just try and, I don't want to say keep to yourself . . . So, I try not to make it about this specific number, yeah, but what I can do about that number. I don't want him to feel anxious waiting for that thing to tell us what it is. No, it's not that, it's we can do something about it. The fact that we see it and we know what we can do, that part is comforting . . . I don't want him to be anxious about it, so in return, I can't be anxious about it. It's a number, that is what it is. And more about what you do about it. So that's sort of our approach to it. When he's low, we tell him, [name of child] you are low right now, do you feel funny, do you feel, 'cause we are trying to get him to identify his lows.

By treating the number as information, Joy directs her focus toward using the number representing her child's condition in that moment to best care for her child. At the same time, she tries to activate his embodied knowledge of what it feels like when he experiences high BG, and what it feels like when he experiences low BG, so he can alert her sooner to do something to keep his BG in range.

Parents recognize that caring for and living with diabetes is hard for themselves and their children respectively, but it can be managed. Having worked through her own fears, Kylie describes how beneficial it is to help her children to do the same:

You know maybe cause I think how I felt about diabetes was reflected in him. So when I started figuring out that I didn't have to, I didn't have to be scared I started to be able to give him that right. Like saying to him I know you're scared but it's going to be ok. Then all of a sudden it means something if I believe in it right.

In her efforts to support her son and understand his fears, Kylie realized that her worries and her son's fears were interconnected; she discovered that his BG levels improved as his emotional turmoil declined. Parents' experiences bring forth the importance of emotional work in chronic illness management and the need to support children with diabetes emotionally as well as medically. Parents' work of containing their worry as shown in this section also highlights the importance of providing parents with support to contain their own reactions to their children's diabetes. The lack of adequate support to help parents manage their worry work may lead to increased parental stress and its associated negative consequences.

Releasing worry. Parents shared that knowing they are not the only ones that are worried allows them to feel more normal and less isolated. Parents asserted that it was validating knowing other parents caring for children with diabetes share the same frustrations, concerns, and worries about their children. Joy finds attending support group meetings to be helpful:

I am in a diabetes support group with moms and I find I've learned a lot from what other moms do . . . I think it would have felt more, isolated. Like, I am doing this for my child that I know will be taken care of, but I don't know that I am being taken care of or that I have a group that I can say, oh my goodness, today is making me crazy, and I can't figure it out and diabetes is not fun right now and I don't want to say that in front of [name of child] or I don't want him to feel that, I don't want him to think that I, you know, he's causing me this frustration.

Joy not only learns from other parents' cumulative knowledge and experiences of providing day-to-day diabetes care, more importantly, the meetings provide a space where she can talk about her frustrations, concerns, and worries, and ensure she is taking care of herself to continue to take care of her child.

Kylie reflects on the ways she is coming to terms with her own fears and the difficulties of caring for her children with diabetes, while recognizing her need to acknowledge and release her fears:

I think I'm stronger because you can't live in fear for your whole life so I've had to really figure that out and process that. Recognize that how I felt would impact on them. You know like so much stronger in the sense of being self-aware. And coming to terms with something that's not easy. I'm not trying to say like it's not easy, it's not like a pity party. Sometimes I let myself have a pity party, like I'll just say yea this really sucks and I'll let myself have those moments and I never use to I use to be just like that's the way life is just you just deal with it. But then you can't, then when you kind of explode or have the big meltdown, you realize ok sometimes I just need to let myself have the pity party and acknowledge that this is really hard.

Kylie's reflection highlights her changed perception of a "meltdown." Rather than seeing it as a sign of a failure to cope, she now accepts it as a normal aspect of caring for her children with diabetes and realizes that when she gives herself permission to experience these emotions, such as worry, fear, and frustration, it helps to make her stronger, and more able to take care of herself and her children.

Amplifying worry. Parents identified diabetes as an invisible chronic illness that can at times put their children at risk, particularly when there is limited knowledge and much misunderstanding about diabetes and diabetes care in the community. In contexts where parents have to leave their children under the care of another caregiver such as a family member or school caregiver, they often find it critical to amplify their worry about diabetes (with other caregivers) and the serious consequences of not following diabetes care, to influence others. Brenda expresses frustration toward one of her family members below. Her attentiveness and vigilance is being judged as being controlling:

I had a comment from a sister-in-law that, "you are way too strict with her, you should just let her enjoy it." I can't, it's her life. I am not doing this because I want to control her . . . It is her life I am protecting, I am protecting her eyes, her kidneys, her limbs, her heart, this isn't just about you know freedom at Christmas, she has this, it doesn't take a break, and they don't get that. There are repercussions from not taking care of it in one day, and there can be very serious repercussions.

Brenda tries to convey her knowledge and the consequences of poor diabetes care to her sister-in-law without much success. Realizing her sister-in-law is not convinced, she decides not to entrust her with the care of her child.

Other parents also conduct ongoing assessments of the competence of other people when they engage in diabetes carework for their children, including in schools, and health care settings. Kylie shares one incident during her older son's

hospitalization where she had to intervene to ensure his safety. Kylie's son was frequently hospitalized during the initial years of diagnosis due to seizures or sickness. On one of those occasions, her son's BG was very high and the nurse was going to follow the doctor's orders to administer two units of rapid insulin. Knowledgeable about her child's BG patterns, and the effects of that amount of insulin on her child, Kylie raised concerns that two units would cause her child to experience severe hypoglycemia. She expressed her worry with the intent of influencing the nurse. The nurse went and checked with the endocrinologist and returned insisting on the same dosage as ordered by the endocrinologist:

She came back and she said "[name of endo] said give 2 units and if you're refusing medical treatment for your child you're going against doctor's orders." And I was like . . . So I said to her ok if you give him 2 units bring me juice. I need juice on hand because I'm telling you I really think he's going to go low. So she went ahead, she gave him 2 units. She did bring the juice and sure enough 2 hours later he was 1.8.

Lacking knowledge derived from daily diabetes care for this child, the nurse, and the endocrinologist were not convinced by Kylie. To be proactive in minimizing the effects of possible hypoglycemia, Kylie asked for juice in advance so she had the resources to treat hypoglycemia in the event that her son experienced low BG levels due to the excessive insulin dose. Parents often have to assess when it is necessary and effective to articulate their worries for the interests of their children.

Discussion

Based on the qualitative interviews conducted with seven parents of children with diabetes, I have explored parents' engagement with worry as a form of emotion work to ensure the safety and well-being of their children with diabetes. Adopting Hochschild's (1983) conception of emotion work as an individual's intentional effort to manage one's feelings to influence their own feelings or those of others, I have attempted to make visible the practical activities parents of children with diabetes engage in to manage their worry. While Hochschild (1983) conceives of feelings as emerging in relations and interactions with people, the use of Smith's (1987) concept of work in this analysis expands the understanding of feelings and emotion work by making explicit the role of knowledge in shaping how parents think about, and come to experience worry and the work they do to manage it. I have shown that parents' experience of worry arises from, and is informed by, their extensive knowledge of how to keep their child safe; that is, their knowledge of the importance of maintaining a normal BG range, the consequences of having out of range BG, and the complexity and unpredictability of diabetes management. Over time, parents in this study developed an embodied way of knowing and

competence in detecting potential risk or danger to their child through their every moment-to-moment, day-to-day relentless engagement with doing diabetes care for/with their children. I refer to these complex practices as the work of “knowledgeable vigilance.” It is from this embodied way of knowing, caring, and practicing knowledgeable vigilance that worry—a feeling of concern about something bad that might happen to their child—emerges or not. Parents actively and skillfully engage in work that manages their worry. Once they are able to achieve a satisfactory BG reading, and their children are in the care of other competent caregivers who are drawn into the knowledge and activity needed to care for their child, they can relax.

The knowledge presented here offers a new way to understand worry in the context of parents caring for their children with a chronic condition. Their experiences of worry are directly linked to the knowledgeable, experienced activity of caring for their child with diabetes. While the experience of worry is described as challenging by parents, their accounts show that it is also a form of necessary work: parents’ “doing worry”—their effort to contain and amplify worry—is essential to ensuring their children’s safety and well-being. Given this new understanding, attention should be paid to parents’ expression of worry to decipher whether parents are struggling to cope with the situation or if their expression of worry is embedded in a wealth of knowledge and acts as a signal indicating that something is amiss in their child’s care.

One important way to decipher whether parents are struggling to cope is to identify whether parents are in a constant state of worry and whether their experience of worry is intentional. The findings in this study show while diabetes and diabetes management is constantly on parents’ mind, the illness is not always in the foreground and parents do relax when they manage to get a satisfactory number and when their child’s health is in the care of competent caregivers. Their experience and expression of worry is intentional, as it is informed by their practice of knowledgeable vigilance. As well, parents are actively engaging in activities that manage and contain worry for themselves and their children. Their work of managing and containing worry is an effort to not let diabetes take over their lives and to establish a new “normality” for their children and family; it is their intention to put their child’s “health in the foreground and illness in the background” (Loomis & Conco, cited in Paterson, 2001, p. 24). This approach is best illustrated with Bob’s quote: “Best possible quality of life for her. Minimum of intrusions in her daily life with the best possible blood sugars and no bad lows.” In practicing knowledgeable vigilance and managing worry when it arises, parents are attempting to stay ahead of what diabetes may throw at them; they are ready to take action to keep their children healthy and minimize the diabetes’s interference with their children’s lives. It is important to note that there are other parents of children with diabetes who may experience constant worry and are lacking of the skills and knowledge to manage their worry. Unlike the

parents in this study, other parents may not be practicing knowledgeable vigilance. As such, their experience of worry may undermine their ability to care for their child’s and their own well-being.

A few parents highlighted the helpfulness of having physical and emotional space where they can express their worry, frustrations, and dislike toward diabetes. Some days, doing diabetes care is very challenging and difficult, and they need to release their worries to continue to care for their children. This emotional release is a normal part of caring for children with chronic illness. Parents indicated that they needed to take care of themselves emotionally to take care of their children. Caring work does not consist only of completing a list of tasks. Caring “refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others” (Baines, Evans, & Neysmith, 1991, p. 11). Parents in this study emphasized emotional demands, and the necessity of self-regulating their emotions, as the hardest part of caring for a child with diabetes. Therefore, it is important to provide parents with emotional support and an avenue to support a better understanding of the dimensions and conditions of their emotion work. Parents described support groups to be helpful. However, not all parents are able to access the help from support groups, or find it suitable. More options should be available for parents to access emotional support, perhaps during regular diabetes clinic follow-ups. Emotional support for parents should also go hand-in-hand with emotional support for children. As Kylie pointed out, it is possible that parents’ emotions can affect children’s BG levels and their diabetes management. Parents are concerned about their children’s future long-term health, and emotional supports are critical to assist children in the development of a positive approach to lifelong diabetes self-care routines.

Parents in this study have an average of 5 years’ experience in doing diabetes care; their experiences range significantly from about 1 year to over 10 years. While they have developed the skills and competence to care for their children with diabetes, none of the parents interviewed expressed full confidence in, or mastery of, their child’s diabetes care precisely because of the unpredictability of diabetes. This is consistent with the research conducted by Wennick and Hallström (2007) where the parents in their study described only being able to make “qualified guesses,” indicating they do not have full control over the results of treatment. Similarly, Smaldone and Ritholz (2011), and Sullivan-Bolyai, Knafl, Deatrick, and Grey (2003) also found that parents did not report achieving mastery in diabetes care for their children. Given the ever-changing nature of diabetes, parents need to be equally dynamic and adaptable in doing diabetes care for their children, which can result in the feeling that they will never be proficient enough in diabetes care. It is important to help parents recognize the difference between mastery of outcomes and their competence and knowledge in doing diabetes care. Parents’ sense of uncertainty is a reflection of their deep knowledge of the

unpredictability of diabetes and the unpredictable outcomes of interventions. As mastery of outcomes is not possible, parents will benefit from encouragement that they are making the best informed decisions for that moment based on the information they have.

Two limitations of this study are identified. First, findings are based on interviews conducted with a small number of parents and therefore cannot be understood as representative of the experiences or activities of all parents of children with diabetes. It is also not my intention to do so. These interviews were conducted as part of the first stage of an IE that began by identifying trans-local social relations embedded in local experiences and practices. Given the small number of participants, it is possible that other parents of children with diabetes experience and understand worry differently and may not manage worry the way the parents do in this study. Second, the parents interviewed in this study were recruited from support groups; they may differ in some significant way from parents who do not attend support groups. For example, parents who attend support groups have the time and resources to do so. They are likely to be more aware of their need for support. Moreover, these parents were from middle-class two-parent families and all had postsecondary education; they are more likely to have adequate literacy skills, and social and material resources to obtain a wealth of knowledge about diabetes management, and to engage in diabetes carework in a way that enables them to do worry work compared with parents who are differently positioned in society.

In conclusion, in taking up worry as a form of emotion work, the experience of worry is made visible as a useful tool for parents to assess their children's needs and the circumstances they are in, and allows them to care for and ensure the safety and well-being of their children with diabetes. Parents in this study are actively engaging in ways to manage—contain or express—their worry and that of others. As such, it is useful for professionals—physicians, nurses, Community Care Access Centre coordinators, teachers—to listen to parents express their worries and concerns, and the circumstances in which they experience worry, to better support them in understanding the relationship of their worry to their effective response to their children's diabetes care needs.

Acknowledgments

With deep appreciation to my daughter for her strength and passion for life, and for granting me permission to share our experiences. I am thankful to the parents of children with diabetes who shared their caregiving experiences in this study, as well as parents of children with diabetes in the online diabetes community. Their stories inspired me. I am grateful to Dr. Christina Sinding, Dr. Susan Turner, and three anonymous reviewers for their thoughtful and valuable comments on this article.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by The Canadian Institute of Health Research Doctoral Research Award.

References

- Baines, C. T., Evans, P., & Neysmith, S. M. (1991). Caring: Its impact on the lives of women. In C. T. Baines, P. Evans, & S. M. Neysmith (Eds.), *Women's caring: Feminist perspectives on social welfare* (pp. 11–35). Toronto: McClelland and Stewart.
- Clarke, J. (2006). Mother's home healthcare: Emotion work when a child has cancer. *Cancer Nursing, 29*(1), 58–65.
- DeVault, M. L. (1999). Comfort and struggle: Emotion work in family life. *Annals of the American Academy of Political Science and Social Science, 561*, 52–63.
- Diabetes Control and Complications Trial Research Group. (1994). Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. *Journal of Pediatrics, 125*, 177–188.
- Griffiths, A. (1998). Insider / outsider: Epistemological privilege and mothering work. *Human Studies, 21*, 361–376.
- Hatton, D. L., Canam, C., Thorne, C., & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing, 22*, 569–577.
- Haugstvedta, A., Wentzel-Larsen, T., Rokneb, B., & Grauea, M. (2011). Perceived family burden and emotional distress: Similarities and differences between mothers and fathers of children with type 1 diabetes in a population-based study. *Pediatric Diabetes, 12*, 107–114.
- Haynes, A., Bulsara, M. K., Bower, C., Jones, T. W., & Davis, E. A. (2015). Regular peaks and troughs in the Australian incidence of childhood type 1 diabetes mellitus (2000–2011). *Diabetologia, 58*, 2513–2516.
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology, 85*, 551–575.
- Hochschild, A. R. (1983). *The managed heart: Commercialization of human feeling*. Berkeley: University of California Press.
- Lowes, L., & Lyne, P. (2000). Chronic sorrow in parents of children with newly diagnosed diabetes: A review of the literature and discussion of the implications for nursing practice. *Journal of Advanced Nursing, 32*, 41–48.
- Mac Rae, H. (1998). Managing feelings: Caregiving as emotion work. *Research on Aging, 20*, 137–160.
- McCoy, L. (2006). Keeping the institution in view: Working with interview accounts of everyday experience. In D. E. Smith (Ed.), *Institutional ethnography as practice* (pp. 109–125). Lanham, MD: Rowman & Littlefield.
- McCoy, L. (2008). Institutional ethnography and constructionism. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 701–714). New York: The Guilford Press.
- Merriam-Webster Online. (2017). Worry. Retrieved from <https://www.merriam-webster.com/dictionary/worry>
- Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviors among parents of young children with type 1 diabetes: Associations with illness characteristics and parent functioning. *Families, Systems, & Health, 27*, 28–38.

- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33*, 21–26.
- Patton, S. R., Dolan, L. M., Henry, R., & Powers, S. W. (2007). Parental fear of hypoglycemia: Young children treated with continuous subcutaneous insulin infusion. *Pediatric Diabetes, 8*, 362–368.
- Rearick, E. M., Sullivan-Bolyai, S., Bova, C., & Knafl, K. A. (2011). Parents of children newly diagnosed with type 1 diabetes: Experiences with social support and family management. *The Diabetes Educator, 37*, 508–518.
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of parenting children with type 1 diabetes diagnosed in early childhood. *Journal of Pediatric Health Care, 25*, 87–95.
- Smith, D. E. (1987). *The everyday world as problematic: A feminist sociology*. Toronto: University of Toronto Press.
- Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Walnut Creek, CA: AltaMira Press.
- Smith, D. E. (2006). *Institutional ethnography as practice*. Lanham, MD: Rowman & Littlefield.
- Soltesz, G., Patterson, C. C., Dahlquist, G., & EURODIAB Study Group. (2007). Worldwide childhood type 1 diabetes incidence—What can we learn from epidemiology? *Pediatric Diabetes, 8*(Suppl. 6), 6–14.
- Steinberg, R. J., & Figart, D. M. (1999). Emotional labor since the managed hearts. *Annals of the American Academy of Political Science and Social Science, 561*, 8–26.
- Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: The role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology, 30*, 513–521.
- Sullivan-Bolyai, S., Knafl, K. A., Deatrick, J., & Grey, M. (2003). Maternal management behaviors for young children with Type 1 diabetes. *American Journal of Maternal/Child Nursing, 28*, 160–166.
- VERBI Software. (2013). *MAXQDA 11: Software for qualitative data analysis*. Berlin: Sozialforschung GmbH.
- Watt, L. (2015). (Un)safe at school: Parent's work of securing nursing care and coordinating School Health Support Services for children with diabetes in Ontario schools. *Journal of Sociology and Social Welfare, 42*(2), 103–126.
- Wennick, A., & Hallström, I. (2007). Families' lived experience one year after a child was diagnosed with type 1 diabetes. *Journal of Advanced Nursing, 60*, 299–307.
- Wennick, A., Lundqvist, A., & Hallström, I. (2009). Everyday experience of families three years after diagnosis of type 1 diabetes in children: A research paper. *Journal of Pediatric Nursing, 24*, 222–230.
- Wherrett, D., Huot, D., Mitchell, B., & Pacaud, D. (2013). Canadian Diabetes Association 2013 clinical practice guidelines for the prevention and management of diabetes in Canada: Type 1 diabetes in children and adolescents. *Canadian Journal of Diabetes, 37*(Suppl.1), S153–S162.

Author Biography

Lisa Watt, PhD, recently completed her doctoral degree in Social Work at McMaster University, Hamilton, Ontario, Canada. She is currently a Postdoctoral Fellow, and a Sessional Faculty in the School of Social Work at McMaster University.