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**PERFORMING DISABILITY:
AN AUTOETHNOGRAPHY OF PERSEVERING AND BECOMING**

A Dissertation in
Lifelong Learning and Adult Education

by
Carol Rogers-Shaw

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The dissertation of Carol Rogers-Shaw was reviewed and approved by the following:

Adnan Qayyum
Assistant Professor of Lifelong Learning and Adult Education
Dissertation Adviser
Chair of Committee

Craig A. Campbell
Assistant Teaching Professor of Lifelong Learning and Adult Education

Joseph M. Valente
Associate Professor of Education

Gail L. Boldt
Professor of Language and Literacy Education

Susan M. Land
Director of Graduate Studies for the Department of Learning & Performance Systems

ABSTRACT

This uniquely formatted split-page autoethnography tells my story of learning to live with disability for more than 40 years. It presents the results of my personal narrative inquiry in the form of a layered account of embodied learning. This account offers an evocative autoethnography and analyzes disability in the context of an ableist society. It begins with my diagnosis of diabetes. Then it describes the effect of my disability on my identity, my marriage, my role as mother, my friendships, and my career. Finally, it closes with my near-death experience. I have reflected on my experiences as lived and as written. I set these experiences within the body of research on disability and within the context of adult education and lifelong learning. I examined the culture that has shaped who I have become/am becoming as a disabled person, as a researcher, and as a writer.

Keywords: disability, autoethnography, identity development, adulthood, performance

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INTRODUCTION

Why Autoethnography? How Autoethnographic?

There is no truth beyond experience. (Bochner & Ellis, 2016a, p. 32)

Stories have always been a part of my life.

My mother didn't save my dolls or my bikes or my skates, but she did hold on to my Nancy Drew books. They now sit on a shelf in my daughter's bedroom, my name printed neatly on the inside cover of each of them in my childish handwriting. I grew up reading those mystery books, living in a world of adventure and imagination. Books were treasured presents on my birthday and Christmas each year, filling hours on warm, sunny days lying on the backyard grass and on dark winter nights curled up on the couch under a thick woolen blanket. Of course, my experience with books led to my career as a high school English teacher where, for more than 30 years, I passed on my love for literature. MacIntyre (2007) said, "I can only answer the question, 'What am I to do?' if I can answer the prior question, 'Of what story do I find myself a part?'" (p. 216). When I've thought about who I am, I've realized there are many stories to tell. This background has drawn me to autoethnography, a form of qualitative research where the self is the subject of the study and personal writing and reflection on one's own life connect to broader sociocultural issues. I have lived a life focused on reading, writing, telling, and understanding stories. To me,

stories are powerful precisely because they engage learners at a deeply human level. Stories draw us into an experience at more than a cognitive level; they engage our spirit, our imagination, our heart, and this engagement is complex and holistic. Good stories transport us away from the present moment, sometimes even to another level of consciousness. They evoke other experiences we've had, and those experiences become real again. (Clark & Rossiter, 2008, p. 65)

I am passionate about writing stories, reading stories, understanding the authors' meanings, and revealing readers' personal connections to stories. In this dissertation, I want to be a storyteller. I want to write a story that people want to read. I also want to be a researcher who seeks to find the meanings within the stories told and set those stories within a broader sociocultural context that enables others to understand. Reconciling these two goals has led to my use of a split-page format. I have chosen this particular structure in order to offer a new method that unites the aims and techniques of both evocative and analytic autoethnography, the two ends of the autoethnography continuum that are explained in more depth later. The split-page format allows me to have it both ways, to tell an emotional story and to complete an academic analysis. I recognize my desire to weave in stories of myself as I "live in the midst of multiple plotlines, which shape [my] research landscape" (Clandinin et al., 2015, para. 24); my stories are my research.

Stories are not just a product, a text with pages to turn; I am a continuous and changing story.

Stories are the way we become aware of who we are (Clark, 2010; Clark & Rossiter, 2008; Rankin, 2002); they are how we make meaning of our experiences through the narrative process (Bochner & Ellis, 2016a, 2016b; Clark, 2010; Clark & Rossiter, 2008; Irwin, 1996; Polkinghorne, 1988). The sharing of stories enhances the audience's understanding of their meanings and encourages connections with others. Narratives highlight the social construction of identity (Clark, 2010; Clark & Rossiter, 2008; Frank, 2002). We learn by listening to stories, by telling stories, and by understanding the stories of which we are a part. I recognize how much my research reflects who I am. My story reflects Hardy's (1968) contention that we "dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative" (p. 5); we "finally die by narrative too" (Greenhalgh & Hurwitz, 1999, para. 5). My narrative tells of my dreams and my hopes, my despair and my uncertainty, my search and my learning, my memories and my love.

I always liked school, but school learning is not the only type of education we encounter throughout our lives.

My mother, my aunt, and my uncle were teachers. We always had stories to read and workbooks to complete. I played school with my dolls. I loved to go to school and have particularly fond memories of many of my teachers. And then I became a teacher, and I still liked school. A lot of adult education occurs beyond the classroom doors. So, the question is what this autoethnography says about my lifelong

learning. As a work of academic research, this dissertation reflects my study of adult education. My learning to live with disability has been reflective of adult education. It has been self-directed and experiential, it has taken place within a social context, it has been very much about my emotions and my body, and it has become a story.

Adult education assists adults in getting better at what they do, offers adults opportunities to find more satisfaction in life, helps adults solve problems, and relates to the present rather than serving solely as preparation for the future. Over the past 40 years of living with a disability, I have learned to manage diabetic self-care practices, solved problems of health complications, and created a better life for myself. Adults' need for "immediacy of application" (Hanstock, 2004, p. 81) focuses learning on what will help them cope more effectively with real-life situations. The reality of my disability has driven my lifelong learning, beginning as an emerging adult and continuing today as a mature adult. The specific knowledge I needed to acquire, including elements of self-care, has evolved over time. My learning, whether guided by a doctor, gleaned from printed and electronic texts, or resulting from personal trial and error, has been driven by my motivation to stay healthy. Brookfield (1995) argued that "as we examine learning across the lifespan the variables of culture, ethnicity, personality and political ethos assume far greater significance in explaining how learning occurs and is experienced than does the variable of chronological age" (para. 2). I argue that the presence of disability, too, is far more important in relation to learning than life stage.

I learn through stories, my stories and the stories of others.

Narrative is a source of wisdom, a way of communicating, an inquiry process, a tool for sharing knowledge, and a way of being and becoming. Narrative learning has a place in adult learning because stories enable us to make meaning out of our lives. Narrative inquiry is one way to examine and comprehend experience, and autoethnography is one manifestation of narrative (Clandinin & Huber, 2010; Rossiter, 2005). Autoethnography reflects narrative learning in several ways. Autoethnography creates a narrative that can be a relational learning experience for the writer, the story participants, and the readers. The writing process and the story created are both vehicles for learning. According to Merriam and Baumgartner (2020),

[narrative] facilitate[s] learning that all adults can relate to—stories that surround us, that define us, that we can construct, analyze, reflect upon, and learn from. Stories can be used to understand content, ourselves, and the world in which we live. Narratives are also windows into development and transformational learning. They enable us to make sense of our experience, which is what adult learning is all about. (p. 266)

Rossiter (2005) explained that narrative learning is "concerned more with human meaning than with discrete facts, more with coherence than with logic, more with sequences than with categories, and more with understanding than with predictability and control" (p. 60). As a work of research, my narrative focuses on the meaning of my experiences with disability, relates a coherent story over time, connects my experiences to the broader understanding of disability within our society, and attempts to enhance the discernment and empathy of my readers.

Learning from narratives illustrates "a view of human experience in which humans, individually and socially, lead storied lives. People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories" (Clandinin et al., 2015, para. 3). Narrative is an appropriate way for me to approach my exploration of disability as it allows me to present life experiences while recognizing that storytelling is crucial to understanding and sharing individual lives; storytelling is a part of living those lives (Clandinin et al., 2015; Clandinin & Connelly, 1998; Clandinin & Huber, 2010; Connelly & Clandinin, 1990; Creswell, 2013; Rossman & Rallis, 2017).

In describing narrative, MacIntyre (2007) said, "We are never more (and sometimes less) than the co-authors of our own narratives. Only in fantasy do we live what story we please" (p. 213). Rankin (2002) saw an individual as a character in several stories, as a major character in her own story and as a minor character in others' stories. She believed "identity is not just the fulfilment of personal potential, nor simply the appropriation of stories, but a dialogic relation between this potential and the unique circumstances of place and time in which we live" (pp. 7–8). We are who we are in relation to others.

I want to amplify the voices of disability by writing an autoethnographic counter-narrative.

Ferri (2011) discussed the importance of writing disability narratives that break down dominant, norm-centered discourses, including autobiographies that counter deficit-based stories. If, as she argued, “a central defining feature of disability studies aims to dislodge the medical model of disability, replacing narrow and deficit-based understandings of disability with alternative knowledge claims grounded in disabled people’s subjective and situated experience” (p. 2271), then including my own experiences within my academic writing is a way to allow the “personal to inform the social ... becom[ing] an intervention into the politics of knowing as well as the politics of representation ... [a way] to talk back to dominant scripts and point to a more embodied form of social critique” (p. 2279). It is my intention that my stories will contribute to the reader’s understanding of what it means to live with a disability. Disability studies in education advocates using stories in research to promote dialogue, share life experiences, provide counter-narratives, and disrupt ableism. This research is emotionally evocative and politically conscious (Valente & Danforth, 2016). It is the kind of research I have always wanted to do. I will share what I have learned about living with disability over my lifetime, and I will continue to learn through creating my own narrative.

I have chosen to complete an autoethnographic dissertation because it allows me to tell my story and examine who I have become/am becoming. Autoethnography “seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis et al., 2011, para. 1) while enhancing our empathy towards those who are different from us (Ellis et al., 2011, para. 4). Like other autoethnographies, my stories are complicated and meaningful. They express how I think and what I feel, and in telling them, I can make sense of who I am (Ellis et al., 2011). My autoethnography explains how I found meaning in my experiences of disability and offers my stories with the goal of providing readers with the opportunity to recognize shared experiences or to understand the experiences of others who are unlike themselves. It can “contribute to others’ lives by making them reflect on and empathise with the narratives presented ... [as they] become aware of realities that have not been thought of before” (Méndez, 2013). Therefore, my writing can be educational, informative, and evocative.

Creswell (2013) referenced Ellis (2004) and Muncey (2010) in describing autoethnography as qualitative research “written and recorded by the individuals who are the subject of the study ... [and] contain[ing] the personal story of the author as well as the larger cultural meaning for the individual’s story” (p. 73). In this study, my personal narrative is used to “understand a self or some aspect of a life as it intersects with a cultural context ... and invite readers to enter the author’s world and to use what they learn there to reflect on, understand, and cope with their own lives” (Ellis, 2004, p. 46, as cited in Ellis et al., 2010). As they read the pages I’ve written, readers will become part of my story.

Interest in autoethnography has increased over the years. Autoethnography research has likewise become much more accepted, as is apparent from its visibility in journal publications, conference proceedings, and dissertations in which it has been used as both methodology and method (Bochner & Ellis, 2016a; Hughes & Pennington, 2016). Journal publications, in particular those that are part of a peer review process, have helped to legitimize autoethnographic research (Hughes & Pennington, 2017, “Legitimizing Autoethnography” section). Autoethnography appeals to “students and seasoned scholars whose personal connection to research (and the people they studied) had been stifled and inhibited” (Bochner & Ellis, 2016b, p. 212) by the strictures of traditional academic writing. Autoethnography allows qualitative researchers to explore human emotion in a way that provokes both thought and feeling while sharing their own vulnerability (Bochner & Ellis, 2016b). It can be an effective tool of narrative inquiry and critical social research (Hughes & Pennington, 2017, “Anticipating the Future” section). In critical reflexive narrative inquiry, “the researcher takes an active, scientific, and systematic view of personal experience in relation to cultural groups identified by the researcher as similar to the self (i.e., us) or as others who differ from the self (i.e., them)” (Hughes & Pennington, 2017, “Autoethnography” section). A critical lens allows autoethnographers to “create spaces for marginalized voices, identities, and populations through the use of their personal experiences, understandings, and theorizing” (Hughes & Pennington, 2017, “Process” section). My autoethnography examines disability through a critical lens.

I want to break your heart.

What particularly motivates me to pursue autoethnography are the ideas in Behar's (1996) *The Vulnerable Observer: Anthropology that Breaks Your Heart*. To me, storytelling offers more opportunities to break one's heart than academic writing. Behar described the experience of anthropology: Loss, mourning, the longing for memory, the desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant hindsight, a sense of utter uselessness of writing anything and yet the burning desire to write something, are the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful. (p. 3)

This passage moved me as a writer and as a researcher.

Behar (1996) compared writing vulnerably with skill and nuance to writing in a traditional scientific style that she argued takes less skill. Writing vulnerably is more dangerous as its failure to move the reader is more humiliating. The same is true for writing autoethnography. The fear of writing a bad story that no one wants to read is another vulnerability to face. If "the exposure of the self who is also a spectator has to take us somewhere we couldn't otherwise get to" (Behar, 1996, p. 14), then autoethnography must do the same. It must allow readers to respond in a way that reveals their own vulnerability, their own connection to the participants and the researcher.

Behar (1996) asked, "Does emotional response lessen or enhance intellectual understanding?" (p. 16). My answer is that in qualitative research, it not only enhances understanding but is also necessary for understanding. It produces a stronger connection between the research and the reader. Autoethnography can heighten comprehension of research subject matter and move public policy by drawing on the reader's emotional connection to the writer.

My autoethnography does not merely tell my own story with the presence of other characters woven into the storyline; it is a narrative about "me," about "us," and about "them."

Ellis et al. (2011) identified several forms of autoethnography including indigenous/native ethnographies that tell the stories of colonized and economically disadvantaged people; narrative ethnographies that include the researcher's experiences in the analysis of others; reflexive, dyadic interviews that concentrate on participants while reflecting on the researcher's interactions with the participants during the interview process; reflexive ethnographies that highlight the changes the researcher undergoes during research work; interactive interviews that are collaborative and result from multiple interviews with a known subject; community autoethnographies that are co-constructed within community relationships; and personal narratives that tell how the researcher views herself within a cultural group (Ellis et al., 2011, pp. 278–279).

After making the decision to pursue autoethnographic research and write about introspection as a method of research that combines social science research and experiential writing, Ellis described being called schizophrenic by reviewer Norman Denzin. Denzin told her she "was caught between two camps—hard social science and interpretive/imaginative/humanistic inquiry" (Bochner & Ellis, 2016a, p. 30) and that she couldn't "have it both ways" (p. 30). This was a dilemma that I, too, encountered as I began my autoethnographic dissertation. The debate between the two camps in defining autoethnography has been ongoing and sometimes contentious (Anderson, 2006a, 2006b; Denzin, 2006; Ellis & Bochner, 2006).

Ellingson and Ellis (2008) described the divide between evocative and analytic autoethnography:

Qualitative research can be productively thought of as existing along a continuum. Artistic interpretivists anchor one end, whereas scientific positivists hold down the other. ...

Autoethnographers have begun to distinguish themselves from one another by separating evocative from analytic autoethnography. Analytic autoethnographers focus on developing theoretical explanations of broader social phenomena, whereas evocative autoethnographers focus on narrative presentations that open up conversations and evoke emotional responses. (p. 445)

On the continuum of autoethnography, I find the appeal of storytelling, artistry, and creativity is central (Bochner & Ellis, 2016a), yet I also recognize the position of those who promote analytic

autoethnography where there is a stronger emphasis on analysis and cultural connections (Anderson, 2006a).

I have been drawn to evocative writing, but I do not want to choose between two dichotomous options.

Evocative autoethnographers focus on telling personal stories that are accessible, emotional, and “sensitize readers to issues of identity politics, to experiences shrouded in silence, and to forms of representation that deepen our capacity to empathize with people who are different from us” (Ellis et al., 2011, p. 274). They do not strive for objectivity and depersonalization. Rather, they recognize that the personal is always part of research; the researcher chooses the subject to study, the setting to explore, the participants to interview, and the questions to ask. These decisions can be driven by personal experience (Ellis et al., 2011) just as my interest in studying adults with disabilities comes from having a disability, having a child with a disability, and teaching students with disabilities. Research is never entirely neutral; it is always shaped by our experiences, and autoethnography embraces the acknowledgment of the researcher’s experiences (Ellis et al., 2011). However, importantly, autoethnographers should look at experience analytically:

Otherwise [you’re] telling [your] story—and that’s nice—but people do that on *Oprah* (a U.S.-based television program) every day. Why is your story more valid than anyone else’s? What makes your story more valid is that you are a researcher. You have a set of theoretical and methodological tools and a research literature to use. That’s your advantage. If you can’t frame it around these tools and literature and just frame it as “my story,” then why or how should I privilege your story over anyone else’s I see 25 times a day on TV? (Mitch Allen, personal interview, May 4, 2006, as cited in Ellis et al., 2011, p. 276).

In particular, the theoretical tools that can help autoethnographers include the experiences of others. These tools set the personal stories within a cultural context, and while the analysis may appear through the reflection, the emphasis in evocative autoethnography is the vulnerability and emotion of the personal stories in which the “fine dissection of a particular personal experience that the writer has lived through will frequently mean sacrificing opportunities to craft a broader ethnographic account” (Denshire, 2014, p. 835). I want to find a way to use these theoretical tools while staying true to my goal of telling a good story.

Analytic autoethnography, described by Anderson (2006a) as an alternative to evocative autoethnography, has five essential elements: “(1) complete member researcher (CMR) status, (2) analytic reflexivity, (3) narrative visibility of the researcher’s self, (4) dialogue with informants beyond the self, and (5) commitment to theoretical analysis” (p. 378). The visible and direct connections to theory distinguish it from evocative autoethnography. Analytic autoethnographers can begin the process as either outsiders who become deliberately and deeply engaged in the group, although they retain the identity of researchers and so are still separate from other participants, or insiders who study their own cultural group. In either case, “the autoethnographer’s understandings, both as a member and as a researcher, emerge not from detached discovery but from engaged dialogue” (Anderson, 2006a, p. 382). The analytic autoethnographer’s reflexivity is rooted in “an awareness of reciprocal influence between ethnographers and their settings and informants” (Anderson, 2006a, p. 382). Rather than the outward view of a traditional ethnographer, there is a more inward view toward the self. As with evocative autoethnography, researchers are clearly visibly in autoethnographic texts through their own experiences and feelings; they are not just objective observers whose voices are silent. However, their own stories are “used, in part, to develop and refine generalized theoretical understandings of social processes” (Anderson, 2006a, p. 385) in which they consider data other than their own experiences and the views of others than themselves. The most significant difference between the two forms is the understanding of the conscious attention to analysis:

The purpose of analytic ethnography is not simply to document personal experience, to provide an “insider’s perspective,” or to evoke emotional resonance with the reader. Rather, the defining characteristic of analytic social science is to use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves. This data-transcending goal

has been a central warrant for traditional social science research. (Anderson, 2006a, pp. 386–387) The evocative style does not offer generalization while the analytic form does.

While there may be a “similarity in goals among autoethnographers, in terms of visibility of self, strong reflexivity, engagement, vulnerability, and open-endedness” (Bochner & Ellis, 2016a, p. 211), the place one finds oneself on the evocative/analytic continuum highlights the differences in types of autoethnography. The challenge is to figure out how to balance the “systematic, ‘scientific’ methodologies of ethnography with the evocative, creative, and artistic elements and forms of storytelling” (Bochner & Ellis, 2016a, p. 67). As the story is so important to me, I find myself moving away from the analytic end of the spectrum where “stories are used either to illustrate a proposition or to reach a theoretical explanation akin to the ‘discussion’ section of traditional research reports” and where “stories are data useful for abstracting and generalizing” (Bochner & Ellis, 2016a, p. 210). I am much more drawn to the evocative side, where I can attempt to write vulnerably and break your heart. Yet because writing is at the core of autoethnography, talking about the writing is important, too. Some researchers have used layered accounts to find this balance. In my autoethnography, I have used elements of a layered account to tell my stories, although the format I have chosen has unique aspects that provide a different structure than traditional layered accounts.

There are layers to my story.

According to Ronai (1995), layered accounts importantly involve the readers in co-constructing knowledge:

The traditional narrative form in science force-feeds the reader a particular understanding of the world masquerading as *the* understanding of the world. The layered account offers an impressionistic sketch, handing readers layers of experience so they may fill in the spaces and construct an interpretation of the writer’s narrative. The readers reconstruct the subject, thus projecting more of themselves into it, and taking more away from it. (p. 396)

A layered account draws on many points of view and presents them to the reader as representations of lived experience, inviting readers to participate in a dialogue with the author, contributing their own thoughts, feelings, interpretations as they investigate their own meanings of the stories told.

Researchers use layered accounts for many of the same reasons others write evocative autoethnographies. These reasons include to increase accessibility to a wider readership, ground research in personal experience that may be hidden in other research, focus on self-reflection in order to understand and acknowledge one’s own positionality, draw connections between social interactions and cultural identity, and evoke emotional responses that can drive social change (Boylorn, 2008; Ellis & Bochner, 1992; Magnet, 2006; Neville-Jan, 2004; Pitard, 2016; Rambo, 2005; Ronai, 1992, 1995, 1997; Smailes, 2014). Autoethnographers using layered accounts may introduce themselves as the subjects of their stories, as the objects of analysis, as the sources of data linked to theoretical interpretation, and as the writers of their stories. In this way, the reader learns about the autoethnographer in a variety of ways, offering expanded means of access (Ronai, 1995). The researcher’s self-reflection also provides readers with a model for practicing their own critical self-reflection on the topic (Spry, 2001), expanding the opportunity for dialogue between writer and reader. Authors of layered accounts often use systematic sociological introspection as their technique. According to Ellis (1991), systematic sociological introspection explores, through self-examination, “how private and social experience are fused in felt emotions” (p. 23). Through conscious awareness of how one thinks and feels, a researcher can “generate interpretive materials from self and others useful for understanding the lived experience of emotions” (Ellis, 1991, p. 26). Layered accounts acknowledge the need not just to express emotions in a story but also to examine what those emotions are, why they surfaced in the story, and what they might indicate. Layered accounts attend to the “private arguments or self-dialogues” (Ellis, 1991, p. 25) that come with the feeling of emotion: Am I angry or do I feel jealous or frustrated? What made me feel this way at this time in this situation? What does that emotion mean? In autoethnographies, layered accounts also examine the writing process: What emotions did I write about? Why did I choose a story that expresses those emotions? What does the appearance of these emotions in this story tell about me? What emotions arose as I wrote this story and what do they mean? Authors of layered accounts often distinguish between

the emotional story and the self-dialogue by using asterisks to indicate divisions. Ronai (1995) described the process: “I write myself, I edit myself, interacting with the self I wrote by objectifying it, judging it, and rewriting it in response” (p. 399). Ronai’s autoethnographies depart from the typical research writing process that Ronai argued failed to take into account the personal reasons researchers choose their research topics. She noted that while scientific writing purports to be objective, all writing has a degree of subjectivity as the researcher chooses the subject matter for personal reasons and the researcher’s work reflects their personal identity. We research what interests us for our own reasons. Ronai (1995) said that by attempting to organize articles neatly into literature reviews, methods, findings, conclusions, and so forth, all thinking is forced into a mold yielding an account of the research process that ignores, indeed counts as irrelevant, issues such as who the researcher is and what their motives are for researching the topic of interest (pp. 420–421). In contrast to traditionally presented research, autoethnographies openly acknowledge the researcher’s position; the researcher is both the subject and the object of the research.

Layered accounts, a way to “blend traditional and creative forms, with analysis and story coexisting side by side” (Bochner & Ellis, 2016a, p. 206), have been written about a wide range of experiences, including teaching within a cross-cultural setting (Pitard, 2016), attempting to have a child while chronically ill (Neville-Jan, 2004), examining privilege (Magnet, 2006), understanding identity as a “fat” woman (Smailes, 2014), coming to terms with the effects of a grandmother’s role in childhood (Rambo, 2005), recognizing the influence of television on racial identity (Boylorn, 2008), deciding to have an abortion (Ellis & Bochner, 1992), being sexually abused as a child (Ronai, 1995), relating to a mentally disabled mother (Ronai, 1997), and working as an erotic dancer (Ronai, 1992). Researchers choose to create layered accounts in autoethnographies in order to examine personal identity within a cultural setting, connect readers to a social group through dialogue with multiple voices on lived experiences, consciously increase self-reflexivity, experiment with non-traditional forms, pursue feminist research tenets of reflexivity and criticality, acknowledge and embrace positionality rather than attempt to achieve impossible objectivity, and critique and resist cultural norms by describing oneself rather than accepting how one is described by others (Boylorn, 2008; Ellis & Bochner, 1992; Magnet, 2006; Neville-Jan, 2004; Pitard, 2016; Rambo, 2005; Ronai, 1992, 1995, 1997; Smailes, 2014). Regardless of the rationale writers have for choosing to write layered accounts of their content, layered accounts frequently appear like stream-of-consciousness writing, often with asterisks to mark the shift from story to reflection, from experience to theory. Ronai (1997) described the process as “mak[ing] use of the scientific voice without relying upon it as [the] sole authority” (p. 419); the researcher voice becomes one of many voices she uses to relay the experience of being the daughter of a mother who is mentally disabled. In this way she creates an “interpretive resource” for her readers.

I want to create my own version of autoethnography.

My perception is that layered accounts of autoethnography can be disruptive to a storyline. While the shifts from story to reflection, separated by asterisks, incorporate both personal experience and theoretical analysis and may be inclusive of the goals of this type of autoethnography, as a reader, I want to move through the story as one unit and review the reflection as another facet. Since telling a good story is important to me, I have visually separated my story and my reflection, my content and my analysis, my auto/ethno and my ethno/graphy. I have followed somewhat in the mold of Brian Fawcett (1986), a writer whose book, *Cambodia: A Book for People Who Find Television Too Slow*, revealed the subtext of his fictional stories at the bottom of each page. He claimed that the “intellectual and cultural proposition underlying much of contemporary artistic theory and practice is that reality in art is secured by subtexts ... almost never explicit, [and] believed to be accessible to the cognoscenti if not always to the general public” (“Preface”). This sounds very much like scientific research to me, academics researching and writing for other academics and often not reaching the general public or even the subjects of the research. I want to avoid separation among the researcher, the study participants, and the readers. I want to expand the audience for my research and provoke intellectual discourse on disability, not just within the research community but beyond. Fawcett (1986) argued that this supposition of hidden subtexts “discourage[d] and disable[d] political, social, artistic and intellectual discourse for the general public” (“Preface”). Based on his belief that this intellectual discourse is necessary for effective democracies, he wrote a

collection of stories with accompanying essays on genocide. The reader can focus solely on the narratives at the top of the page, concentrate on the essay at the bottom of the page, or move fluidly back and forth between the two.

I began this autoethnography with several questions: How does having a disability affect my family, friend, and work relationships? How does my embodied learning to live with a disability represent my becoming a person with a disability in an ableist culture? How are struggle and perseverance part of learning to live with disability? Data was then gathered in several ways, including memory writing, semi-structured interviews, email exchanges, and artifact examination. The collected original stories and poems, the interview, email, and letter transcripts, and the photographs were thematically analyzed, grouped by category, and incorporated into the overarching multivocal narrative. The story includes my voice and those of family members and friends. It includes the meanings that I have attached to my own experiences, as well as the perspectives of my husband, my daughters, my mother, my friends, my work colleagues, and my readers. The way in which I have created a multivocal narrative is not only by using my own words, the words of those I interviewed, and the words of scholars I read, but also by including the meanings that I, my family and friends, and academics have attached to the disability experiences of my life.

The narrative became the evocative top of the page story, and it was divided analytically according to story features and themes. My reflections and analysis were incorporated with voices from the research literature on the bottom of each page. Each page is then one whole unit as the reflection and analysis at the bottom responds specifically to the story segment at the top. My reflexivity adds to the authenticity of my study as it is a method I used “to legitimize, validate, and question research practices and representations” (Hughes & Pennington, 2017, “Legitimizing Autoethnography” section). Linking to the current discourse, being open about myself as the subject of the study, adding dialogue with other actors in my narrative, and presenting serious analysis are other ways I brought legitimacy to my study. Each entire page was then examined and revised iteratively as “narrative inquiry is an ongoing reflexive and reflective methodology, [and] narrative inquirers need to inquire continually into their experiences” (Clandinin & Caine, 2008, p. 542). In layered accounts, data collection and analysis can occur at the same time (Hughes & Pennington, 2017, “Autoethnography” section). Once a draft was complete, I shared it with the individuals who had contributed to my story and included their feedback in this member-checking process. For me, autoethnography is a methodology as it is the foundation of my study and a way for me to challenge ableist discourses suggesting that communication of a norm-centered ideal is unattainable with a disability. In autoethnography, I share my own voice as a member of a marginalized community. It is not merely a way to approach data collection and the presentation of findings in a more traditional qualitative study, although there are researchers who bring themselves into their research that may be primarily phenomenological, ethnographic, narrative, grounded theory, or case study. Rather, “autoethnographic methods of data collection and analysis are inclusive of many types of qualitative methods, such as reflective journaling, videotaping, interviewing, and fieldwork” (Hughes & Pennington, 2017, “Autoethnography” section).

Poetry was used in the analytic process and as another way to describe the self-study. As part of the iterative analysis of multiple divisions of the narrative, I created “I” and found poems. I pulled phrases from narrative sections, such as a complete chapter or a single story within a chapter, and wrote and revised the poems, evaluating the significance of the abstracted phrases as they mirrored the essential meanings visible in that segment. Creating poems from the narrative text allowed me to re-examine themes that emerged through my reflection and analysis process, and they offered a crystallization of the narrative’s essence that I then judged for accuracy in regard to the portrayal of the meanings of my experiences and relationships.

In order to address the significance and validity of my study, I included an introduction and conclusion that together offer an alternate representation of the research, explain the evolution of the dissertation and expound on the value of the study to the fields of adult education and disability studies. The goals were to contribute to the academic literature of these fields, offer a creative and stimulating story, and share my emotional vulnerability and reflections as both the subject of the narrative and the writer of the narrative while telling my truth (Hughes & Pennington, 2017, “Anticipating the Future” section). According to Hughes and Pennington (2017), “Due to the intimate nature of identity and

contextualized experiences, autoethnography's centering of the author allows intimate aspects of understandings and experiences, often inaccessible to researchers, to become a part of narratives and contribute to the field" ("Autoethnography" section).

I hope my story evokes meaningful feelings within your own heart.

In this dissertation, I have found my own way to create a layered account that combines elements of evocative and analytical autoethnography. The structure I have chosen meets my goals of telling a good story and taking my place in academia by showing my research knowledge and skills. I have practiced experiential writing that reveals my experiential learning. Merriam and Baumgartner (2020) argued, "Rarely ... are the body and spirit taken into account when we talk about learning" (p. 233). My narrative illustrates that through my experiences of learning to live with my disability and learning to write my autoethnography, "focusing on what [my] body is experiencing and what meaning [I] can make of that experience is at the heart of embodied learning" (Merriam & Baumgartner, 2020, p. 236). I have written the story of becoming disabled, living with disability, and facing death due to disability; this tale occupies the top of my pages. I have reflected on my experiences as lived and as written, set these experiences within the research literature on disability, and examined the culture that has shaped who I have become/am becoming as a disabled person, as a researcher, and as a writer. This essay, the subtext of my story, runs across the bottom of my pages. Denzin (2006) might argue that I am trying too hard to have it both ways. My answer is that my story is written from my heart and from my body, and while the essay portion may contain analysis, it is still my reflection more than it is academic writing based on data collected through traditional methods and presented through a literature review, a discussion of findings, and a conclusion.

Like Ellis, I feel "passionate about describing and communicating the 'lived through' experience of life, with all its sorrows, joys, disappointments, satisfactions, and losses" (Bochner & Ellis, 2016a, p. 30). I invite you as the reader to wander through my story from beginning to end, reading the top of each page, finding your own connections between your experiences and mine. Or maybe you will choose to examine my reflections and analysis of what my story means and what it has been like to write my story by reading through the essay, point by point across the lower part of each page. Or maybe you will combine those endeavors and move with grace and intellectual curiosity between my story and my subtext, just as I moved back and forth between my experiences and my connections to a broader context through self-examination (Ellis, 2007). That's for you to decide. I hope my work can be recognized within the more evocative group of autoethnographers who endeavor to promote change by sharing their stories from their hearts. This is why, like Denzin (2006), "I write my version of autoethnography" (p. 426).

INTERLUDE

“I Remember...”

I left for France
 with trepidation
I had never been on an airplane
I had never visited a foreign country
I had never embarked on a trip
 far away from home
 by myself

I was nervous
But
I was able to put into words
 my excitement
 and my fear

I was 21
I was in love
I was soaking up the experiences
 of study abroad

Then
 later
I remember the doctor’s office
I hadn’t been back in a long time
I heard the diagnosis
I had two thoughts
 OK, I can still live with this
 Daddy’s younger sister died in her twenties from diabetes
I wondered
 what did I have to do
 before it was too late
 and I died

I became disabled
I became diseased
I became defective
I began my life’s journey
 as a diabetic
I began my effort to remain
 as normal as possible
I was ashamed
I wanted
 to be normal
It became more difficult

I remember
I felt self-conscious
I was embarrassed
I hoped
 no one noticed
I didn’t want
 to stand out as different

I felt isolated
I had to face it alone
 no one would understand
I was tired
 emotionally and physically
I lost all control
 of my life
I didn't want
 to talk about it
If I tried to put into words
 how I was feeling
 what I was thinking
I would lose more control

I wanted to avoid
 the stigma
 of being disabled
I did not want
 to draw attention
 to my deficiency

I spent a lot of time crying
I was alone
I thought it was
 my body
 my disease
 my problem
I had to deal with it

I went to the doctor
I learned how to
 fill a syringe
 plunge it into my thigh
I thought
I had to do what they told me
 but
 it wasn't the same life anymore

I felt
I had to keep on going
I wasn't able to articulate the fears
I couldn't find the words
I had to just go on living
But
I no longer had control over my body
I no longer had control over living the life
 I wanted
I wasn't perfect anymore
I was
 different
 diseased
 disabled

deficient

I remember thinking
I just had to deal with it
 but
 I couldn't
I couldn't explain
I couldn't deal with it
I didn't know what to do

I was afraid
I was going to lose
 the person
 I loved most
I didn't know
 how to hold on
 to him

I knew
 it was never going to be
 what we thought it would be

I believed
 if he left me
 there wouldn't be anyone else

I guess
 he threw me a lifeline

I did hold on
 Trying
 to hope
 Trying
 to handle my disability

I felt like a different person
 not one
 I especially liked

I muddled through

CHAPTER 1

The Diagnosis

If you are lucky enough to have lived in Paris as a young man, then wherever you go for the rest of your life, it stays with you, for Paris is a moveable feast.

—Ernest Hemingway, *A Moveable Feast*

Sitting in the golden summer sun sipping wine at Les Deux Magots on Place Saint-Germain des Prés in Paris and contemplating my own moveable feast in the place where Ernest Hemingway wrote, I became disabled. Staring up at the north rose window of Notre Dame Cathedral in Chartres and recognizing the fleur-de-lys of purity surrounding the Virgin Mary cradling baby Jesus, I became diseased. Ambling across the brightly painted, wisteria-covered beechwood bridge over the Giverny lily pond and imagining Claude Monet at his easel, I became deficient. I was 21, I was in love, I was soaking up the experiences of my study-abroad program, and I was beginning my life's journey as a diabetic. Although I didn't comprehend the significance of my body's changes for what they were at that time, these were the moments when my body presented its defects. I might have been a diligent student of a foreign language, but I wasn't comprehending the lessons of embodied learning. What stayed with me from my time in Paris were not only the memories of awe-inspiring works of art, ancient stone buildings and cobbled streets filled with history, and mouth-watering French chocolate from Fauchon on Place de la Madeleine, but also the descent into disability, the distressing nature of disease, the bodily deficiency that has shaped my life. Like Auguste Rodin's "Le Penseur," deep in contemplation in the museum garden on Rue de Varenne, there's always been a lot to think about when trying to manage life with a disability.

As I reread what I have written to introduce my story of disability, I see a lot of words beginning with the letter "d": "disabled," "diseased," "deficient," "descent," "diabetic," "defect," "distressing." These are words whose prefixes mean "off," "privation," "removal," "separation"; they indicate being "apart," "asunder," "away." It's quite a collection of negativity, like the barely passing D grade that while just above total failure certainly isn't a mark of excellence or even of middle-of-the-road proficiency. Yet they are word choices that reflect my gut reaction to being disabled. I recognize there are individuals for whom disability has some positive aspects; they become disabled and make positive life changes, acknowledge what is truly important to them, recognize the value of their differences, or embrace skills that come with their disabilities. This is not my experience.

When I think back on this moment in my life, I can see it as the beginning of my longing to belong with the healthy, the normal. Pehler et al. (2014) described longing in relation to loss. This type of longing is often felt by those with chronic or fatal illnesses who long to go back to the healthy lives they led before receiving their diagnoses. Longing is

the earnest, heartfelt desire for something, some state, or some relationship, without which one's life does not feel complete. It appears as a disconnection within a person's relationships, health, and/or purpose in life due to illness, injury, disability, or death. Although an individual or family primarily experiences longing as feelings of grief, anger, sadness, despair, hurt, abandonment, and vulnerability, hope is also expressed. (Pehler et al., 2014, p. 137)

My experience of disability reflects these attributes. I felt the loss for what I had had in my life before the diagnosis. I saw myself as isolated despite attempting to remain forward-thinking. I asked, Why me? What does it mean? I believed I was powerless to control my situation, and I was afraid.

As I begin to write about my life with disability, I see the presence of longing. Culture presents narrative structures that writers adopt in telling their stories (Garden, 2010). For individuals writing about a disability or illness, the most prevalent form is the recovery story, with an ending that turns the longing into belonging, adversity into triumph. Yet this structure contributes to the view of disability as a deficit that needs to be corrected (Garden, 2010). Part of the ache to belong is a desire to hide the vulnerability of being different and overcome the fear of stigmatization. I recognize the value of the recovery story for some individuals with disabilities, but I don't want to perpetuate the ableism of that narrative. I don't have a "supercrip" story. I have a story of sadness and anger from being on the outside and looking in the store window at what I can't have. I still long for normalcy. I want to savor Fauchon's ganache without fear or shame or guilt.

There are a number of symptoms of type 1 diabetes including extreme thirst, frequent urination, weight loss despite a substantial appetite, mood swings, yeast infections, fatigue, and vision changes, all subtle symptoms I experienced even before I left the United States. While in France, I lived in a room at the Cité Internationale Universitaire de Paris. The plumbing in the old stone building was not modern or efficient. We all laughed about the need to time our jumps in and out of the shower, where the water fell at the beginning in an ice-cold torrent that slowly became hotter and hotter. One had to turn the water on, wait for just the right moment to step into the warm stream, and then finish washing and shampooing quickly before the increasingly hot water scalded. I didn't feel the same camaraderie and humor regarding the other facilities.

I clearly remember feeling relieved that my room was across from *les toilettes* as I often woke up during the night with an incredibly strong urge to urinate, yet I was also very embarrassed and conscious of the loud noise caused by pulling the long metal chain to flush; I hoped I wouldn't awaken other students. I would delay as long as possible, hoping I would fall back to sleep, but eventually I would recognize that wasn't going to happen and furtively sneak across the hall to empty my bladder and then wait, sitting on the toilet in darkened silence in case the urge returned. I thought if I only had to flush once that night, I might not awaken others and be identified. Without knowing it, I began my path toward stigmatization, and I began my effort to remain as normal as possible. I was ashamed of my nocturnal trips across the hall. I did not want to be identified as different from the other students. I wanted to be considered normal.

I remember the size of my jeans shrinking, but I thought, Why worry about losing weight when I could start my day with flaky croissants, *confiture à la fraise* and creamy sweet yogurt, then lunch on fresh baguettes, cheese and pralines, before finishing dinner with an *éclair*, *mousse au chocolat*, or *gâteau opéra*? I just never put it all together. I spent my mornings in classes, my afternoons walking the streets of Paris, and my weekends taking day trips out of the city. I focused on becoming fluent in French and soaking up every bit of the culture that I could. And I looked forward to my regular trips to the mail room where the elderly clerk would carry my letters to the front desk, pretending they were a heavy weight. I would quickly ascend the stairs, sit on the broad window seat in my room overlooking the garden, and read the letters from my boyfriend who would later become my husband. It was an exciting time, and it was easy to dismiss the nagging health issues.

The Greeks "originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier" (Goffman, 1963, p. 1). Stigma is "an attribute that is deeply discrediting" (Goffman, 1963, p. 3); it makes a person less than whole, tainted in some way. Stigmatized individuals often internalize the imposed norms, leading to feelings of shame and efforts to correct the perceived deficit in order to come as close to meeting standards of normalcy as possible. According to Goffman's theory, a discreditable person is one whose differentness is not visible or easily recognized. In the beginning, my diabetes was not clearly visible. A significant question for an individual who is discreditable is whether to disclose personal information about the disability and how much to share (Goffman, 1963). Even before I was fully aware that I was disabled, I wanted to keep the knowledge of my health problems secret. Having a disability affects identity development, whether through the loss of control over one's identity when the difference is visible or the fear of disclosure when it is not. Stigma began to shape how I saw myself at a time when I was trying to figure out who I was becoming as an independent adult, a time when I longed to belong. Now, as I write about my time in Paris, I have more understanding of my disability. As I look back, I feel slightly hopeful in my longing. I wonder if I have found a new normal of longing (Pehler et al., 2014). As I begin to suffer from more diabetes-related health issues, I know that disability is my reality. Today there is more frustration than longing. There is more determination and a refusal to hide. And there is a story to tell.

It became more difficult to ignore the symptoms when I returned to New York for my senior year. While I became totally immersed in my fall classes, the symptoms became more intense. I remember heading to a bar one night with friends. We crowded into several cars and drove out of the city. The bar was dark, and we crowded around a huge table, laughing, talking, and ordering drinks. Pitchers of beer and soda were slapped down on the table, and I quickly grabbed for one, pouring glass after glass of Tab as, almost in one gulp, I downed a full pitcher because I was so thirsty. I remember that scene today, 40 years later, because I felt so self-conscious at the time. I drank an entire pitcher of diet soda by myself; I didn't share it with anyone at the table. I was embarrassed, and I hoped no one else had noticed, although I still didn't recognize my extreme thirst as a symptom of a serious medical condition. I was concentrating on being a part of the crowd; I didn't want to stand out.

At this point, I was very much a typical American college student, an emerging adult (Arnett, 1994, 2000, 2007, 2014). I was focused on completing my senior year of coursework, enjoying my relationships and social activities, and pursuing academic and professional goals. I was trying to figure out the person I was and wanted to be. I was enjoying the independence of living away from home, paying my college tuition through work-study jobs, and making my own decisions. I was optimistic about my future. I was in love and thinking about getting married after graduation and starting life as a grown-up; I was not paying attention to my health.

The answers to the questions about adulthood—about who counts as an adult and when one becomes an adult—vary. Adulthood has been determined by law, chronological age, psychological maturity, and social roles or relationships; it becomes evident through biological, social, psychological, and legal markers (Hansman & Mott, 2010; Schneider et al., 2016; Settersten et al., 2015). One traditional way to look at identity is to consider that a person has a, or several, stable, natural way(s) of being based on cultural practices, values, beliefs, and discourses that define the options that can be used to describe this way of being. According to Weedon (2004), “a wide range of social practices come into play in recruiting subjects to identify with the identities on offer” (p. 6). Society encourages each individual to identify with a culturally proscribed subjectivity and claim it as their own. Not only does one gain a sense of what one is, but also of what one is not. So, one is disabled, or one is not disabled. One is an adult, or one is not. This subjectivity comes from individuals' positions within relations of power, the ways they are subjected to the law, the economy, hegemony, physicality. It is the subject positions individuals adopt or are forced to take in interactions with others and society that shape who they are. The notion of subjectivity is that what an individual is springs from the cultural definitions of a particular subject in relation to other subjects; it is not one way of naturally existing. For me, at this particular moment in college, I found that my identity had changed from a person without a disability to one with a disability although I didn't understand the ramifications of this change at the time.

Baxter Magolda (2008) described self-authorship as “the internal capacity to define one's beliefs, identity, and social relations ... a developmental capacity that helps meet the challenges of adult life” (p. 269). First used by Kegan (1994), the term describes “a shift of meaning-making capacity from outside of the self to inside the self” (as cited in Baxter Magolda, 2008, p. 270). Self-authorship reflects a change from viewing oneself based largely on external constructions of one's identity to recognizing a much more complex and internalized image of oneself (Baxter Magolda, 2008, 2014; Kegan, 1994). As I ventured toward self-authorship in Paris, I moved back and forth from telling my story in English and telling it in French. Who I was might have included disability, but I wasn't writing those words. Today I'm authoring a different version of the story, still moving back and forth, but this time from the honesty of a disabled reality to the desire for something else.

I was tired and emotional that semester. My husband remembers that at some point in the fall, there was what he describes today as more unevenness in our relationship. We had arguments he didn't quite understand, and I took naps frequently. My fatigue reminded me of the months the year before when I had developed mononucleosis. The sadness I felt in the midst of school, work, and social activities felt similar to previous times I had suffered from depression. I thought I needed a check-up, some vitamins, and a relaxing semester break before starting my master's in January. I scheduled a doctor's appointment for one morning in December. Nothing like killing the holiday spirit.

I remember the doctor's office. It was in the basement of his house, in the neighborhood where I had lived as a preschooler. I hadn't been back in a long time, and it was disconcerting, as I had moved on long ago. There was a sense of foreboding, like it would be better to turn around and go back up the stairs. In my recollection of that visit, the consultation room is incredibly white and bright, almost like it is in the movies when the main character has a near-death experience and there's a huge flash of light. For me, there was no walking through a tunnel or watching images from my life flash before my eyes. There was just the clinical room, the feeling of being totally alone, and a vague sense of fear, but no strong emotion, no immediate despair, no confusion, just the clarity of understanding that everything was different now. Other feelings came later.

I had two thoughts immediately when I heard the diagnosis. First, I thought, OK, I can still live with this. And then I thought, Daddy's younger sister died in her twenties from diabetes. So, I wondered, what did I have to do before it was too late, and I died? This memory of my thoughts from long ago sticks with me. I have no memory of what actually happened right after the doctor told me I had diabetes. I don't remember asking questions. I don't remember talking with my mother or the doctor. I don't remember going home. I know I was admitted to the hospital, and in my mind, I have a clear vision of myself sitting in a hospital bed stabbing a syringe into an orange. Diabetes became undeniably real then. There was no turning back no matter how much I longed to be normal again.

What stands out in my memories of the moment of diagnosis is the strong sense of the disconnection of longing that I felt, the "separation, isolation, interruption of life" (Pehler et al., 2014, p. 135). The feelings of being alone and recognizing that a significant change had occurred are foremost in my memory. Unexpected and tragic health events can alter one's life experiences, particularly during periods of intense transition such as the beginning of adulthood (Hendry & Kloep, 2010). For me, the occurrence of my diagnosis during the period of emerging adulthood complicated my adjustment to my disability. Young adults diagnosed with diabetes have to juggle new self-care responsibilities along with the other demands of their lives (Michaud et al., 2018). Since chronic illness and its progression are so highly controlled by the actions of the patient, the burden can increase; I felt much more afraid of the future and guilty about looking back when I worried that I was not taking care of myself right.

With a diagnosis of chronic illness comes a loss of the self (Charmaz, 1983; Helgeson & Zajdel, 2017). In becoming a diabetic, I not only had to deal with the physical manifestations of the disease, but I also had to manage my emotional reaction to and my perception of the disease, including the contradictory thoughts that I could live with it or I could die from it. Helgeson and Zajdel (2017) described how "chronic illness alters an individual's sense of self, as the previously held healthy identity is replaced by an illness identity. ... [I had to] learn how the sense of self can accommodate the illness" (p. 547). In the doctor's office, I felt the enormity of the diagnosis, yet I couldn't comprehend what this new life would hold for me, what I would become.

When I recently asked my mother about her recollections, I realized that although we never talked at length about my aunt, the specter of her early death was always there. My mother remembered, She was very nice. I don't know whether she finished college. ... She was a couple of years younger [than your father], but I can't really remember because she was sick. I think as a baby. Yeah, but I think she had it, you know, early on. I think she was in her early twenties when she died. Oh, she was in the hospital. ... She was very, very nice. And she wasn't a gloomy person from being sick for so long. ... She married a police officer. He was a great big fella. Very nice. I didn't know whether she knew, but I'm pretty sure the parents knew at that point that she had a very little, short lifespan. I don't know because they never talked about it, but when you were in her company she was laughing and talking and, and her husband was very nice. He was a big fellow and they had bought a house. I think like, instead of waiting a couple of years to buy a house, they did these things right away.

Today my mother doesn't remember going to the doctor with me when I received my own diagnosis. She's almost 93 now and forgets a lot of things so it might be because of her age, but I wonder if she's forgotten the details because it was "never talked about it." What is disconcerting today is that my mother called a week after this conversation. She told me she had thought about it, and she remembered more. Then she recited a list of all her family members who had died young. I wonder if she was remembering her own fears so many years later, the same fears I had had at the time. Or am I finding meanings that aren't there, expressions of my own insecurities?

While my mother's recollection of the time period of my diagnosis is nonexistent, my husband's is vague and not very positive. He said, "I think I remember that Christmas vacation was not a lot of fun. Right. I don't think you were in a very good mood. I think you were sleeping a lot, but there were also, there were times where you were pretty rude, stuff like that." Yeah, well, it wasn't a whole lot of fun for me, either. Today I feel embarrassed to think I was such a bitch, but at the time, I was only thinking about myself and how my life had been transformed.

Talking about disability isn't easy. I needed support: the emotional support of caring and listening, the informational support about diabetes that could guide me, and the instrumental support of specific actions such as assisting with dietary changes. However, I experienced social constraints when those close to me complicated my adjustment "by avoiding illness discussions ... or acting uncomfortable when illness is discussed" (Helgeson & Zajdel, 2017, p. 559). I felt abandoned, I experienced despair, and I grieved, all indicative of longing (Pehler et al., 2014, p. 135). I felt tremendously isolated after receiving my diagnosis and experienced a sense of abandonment. Those around me were as supportive as they could be, but they could go on with their normal lives while I was diseased, left behind. The disease was something I had to face alone. It was my responsibility to take care of myself, but I wasn't ready for autonomous diabetes management; the process was overwhelming. I suffered from a lack of easily accessible, understandable information about diabetes, compounded by feelings of tremendous grief. I was crushed by the weight of my responsibilities, by my attempts to navigate the intricacies of diabetes.

I was tired, both emotionally and physically. Fatigue is a frequent symptom of chronic illness and depression (Helgeson & Zajdel, 2017; Katon & Ciechanowski, 2002; Sidell, 1997; Yorkston et al., 2010). Sleep was an escape, a way to hide my hurt, my anger, my sadness, the effects of my longing to be the way I had been (Pehler et al., 2014). Helgeson and Zajdel (2017) pointed out that "one of the most significant impediments to optimal adjustment to chronic disease is mental health status, particularly depression and anxiety" (p. 551). I was depressed, and this complicated my relationships with those around me.

I felt like I had lost all control of my life. I didn't want to talk about it, either, because I thought if I tried to put into words how I was feeling, what I was thinking, I would lose even more control. I also wanted to avoid the stigma of being disabled; I did not want to draw attention to my deficiency by talking about it. Attempting to pass as normal is a way to avoid stigmatization. The problem for me was that there was no way I could live up to the norm even though I wanted to do so; my options became failure or isolation. When I first felt that loss of control, I had no awareness that the rest of my life would be about control, controlling not what I wanted to do with my life but controlling the glucose level in my blood. While I felt a loss of control, the irony was that I was forced to focus minutely on control of another type.

I spent a lot of time crying when I was alone. I thought it was my body, my disease, my problem. And I had to deal with it. I wasn't a child anymore, so I was supposed to be able to handle my own life. I went to the doctor, got the diagnosis, and was admitted to the hospital. There I learned the essential tasks, like how to fill a syringe and plunge it into my thigh, but I really wasn't open to learning much more. I wasn't motivated to accept my diagnosis. I thought I had to do what they told me to do and live my life, but it wasn't the same life anymore. It wasn't like that blissful time in Paris. I hungered for my moveable feast. While diabetes may have been recognized as potentially deadly, I felt a sense of having to just keep on going, living life. Yet I also felt the need to quickly cram in as many experiences as possible in case I ended up like my aunt.

Taylor (1983) used the theory of cognitive adaptation to identify three elements of responding to a traumatic life event such as a chronic illness diagnosis. These elements are: trying to find meaning in what happened, attempting to gain control of the situation, and exploring ways to enhance one's self-esteem despite the situation. An important question in the search for meaning is, "What does my life mean now?" In the quest for control, one asks, "What can I do to manage [life] now?" (Taylor, 1983, p. 1161). At this time, I was focused most overtly on my loss of control. I knew what had caused my disabled state—the onset of diabetes—which made the cause less important. My internalization of stigma was moving me toward weakened self-esteem rather than toward ways of feeling good about myself. Because type 1 diabetes is hereditary and I knew my aunt had had the disease, the "Why me?" question didn't seem paramount. I felt able to acknowledge that becoming a diabetic had always been a possibility rather than a need to curse my fate at succumbing to it. I also think the demands of self-care made me concentrate more on managing my disease than on thinking of the changed meaning of my life.

I was also isolating myself as I internalized the stigma of having a less-than-worthy body. Stigmatization can lead an individual with a disability to internalize her status as other and exhibit "a conscious reluctance to accept [her] own disability" (Liasidou, 2014, p. 126). Despite the presence of disability, I focused on the many life events occurring like graduating from college, looking for a job, and getting married. I pushed the acceptance of and adjustment to my disability under the surface. It's interesting to think about my feelings of isolation at that time even as I sit alone at the keyboard now telling my story. I'm talking about disability, yet I'm largely talking to myself. Yes, my committee, friends, and family have read parts of this dissertation, but I'm still resisting communication. I'm not sure how much I want to talk about my disability. I feel a bit like I can write the story on a page, hand it to my readers, and be done with the talking part. I'm still focused more on concrete tasks—in this case, managing the dissertation process—than I am on the contemplation of meaning. I wonder if I will be better able to reflect on the meaning and maybe also feel good about myself when I've dotted the last i and crossed the last t.

When I originally left for France, I did so with trepidation. I had never been on an airplane before, I had never visited a foreign country where a different language was spoken, and I had never embarked on such a significant trip away from home by myself. I was nervous. My husband remembers my voicing my fears: “I was glad you were going because ... I remember you telling me you were afraid to fly and that you had never been on a ... flight before. ... You were sort of excited about going, but afraid ... I remember I was excited for you.” I was able to put into words both my excitement and my fear about studying abroad, but significantly, when I received my diagnosis, I wasn’t able to articulate the fears I felt then. I didn’t talk about it with my parents because that didn’t seem to be the way to do things, and I couldn’t find the words to describe my fears, so my disability cut me off from others. My husband recollected that time, saying,

I didn’t think a lot. ... I figured it was just one of these things. What I figured was probably what most people who don’t know anything about it figure—you just have to watch what you eat. You couldn’t eat candy, couldn’t eat sweets, couldn’t have sugar. Right. But if you did all that, what’s the big deal? That was my thinking about it. I didn’t think there were other issues and I certainly wasn’t thinking about complications. I wasn’t thinking about that. Diabetes didn’t mean anything to me. ... I didn’t feel like this was like a big deal and maybe I was part of the problem.

I think one reason I wasn’t able to articulate my own fears was that it didn’t seem like I was supposed to acknowledge that it was a big deal. Even one of my own first reactions was, Okay, I can live with this.

I felt like I had to just go on living each day as I always had except for the shots and my diet and not turn it into more than that. But at the same time, it was really hard to accept that I no longer had control over my body. I no longer had control over living the life I wanted to lead. I wasn’t perfect anymore or even close to it. I was different. I was disabled, diseased, deficient. Insulin injections became the way to normalize the body. My hesitation to accept my disability came from a desire to avoid being viewed as abnormal. Despite the reality of having to accept that my body was different from others, I didn’t want to be seen as defective.

Patients with chronic illnesses frequently cannot find the words to describe their situation, nor do they often use effective information-seeking techniques despite their desire to express what they are thinking and feeling. Not only was it necessary for me to learn the technical words of the disease, the various treatment methods needed, and the complications of daily life, but it was also necessary to learn how to verbalize strange new feelings and relationship shifts (Yorkston et al., 2010). I felt isolated, yet I realized that a diabetic’s management decisions are made within the family context. Rintala et al. (2013) noted that “the influence of the family is crucial. Family members are also affected emotionally and behaviorally” (p. 20). My family and I muddled through without much help, and it wasn’t easy. The psychosocial effects were clear (Stuckey et al., 2014). My mood swings and my family’s response to them made visible the emotional burden of my diagnosis, my depression illuminated my changed psychological state, and the stress on our relationships reflected the social ramifications of the disability.

As a diabetic, I have come to understand what it is like to be disabled. Livneh and Antonak (2005) described several effects of a diagnosis of chronic illness and disability including an increase in stress, the experience of crisis, a feeling of grief, a change in body image and self-concept, a feeling of stigmatization, uncertainty, and a change in quality of life, leading to shock, anxiety, depression, anger, and adjustment. For me, the overwhelming feeling was “the realization of the permanency, magnitude, and future implications associated with the loss of body integrity” (Livneh & Antonak, 2005, p. 14). This feeling required psychoanalysis and medication. Other individuals with disabilities experience their own range of emotions and find their own paths for navigating life’s challenges.

I didn't understand diabetes and neither did my family. My husband described his own experiences at that time:

There were just like times you would fly off the handle and [I'd think] like, What the hell did I do? Maybe I was just too easygoing about things because I didn't get what you were getting so upset about a lot of times ... it was harder to understand sort of like where you were coming from a lot of times. I remember, it seemed like your moods were way up and down. So, to me it was just sorta like deal with it, you know? That's kind of the way I've always looked at stuff, just deal with it.

I remember thinking the same way—I just had to deal with it, but I couldn't, and I couldn't explain that I couldn't deal with it. I wasn't aware of how the huge fluctuations in my moods were perceived by those around me. I was concentrating on what I could control, the day-to-day living with the disease. Now I feel sad and a bit guilty that I was making life difficult for people I loved. I didn't realize what was happening because I was so absorbed in my own reality.

A friend recently asked me if my lack of communicating to others what I was experiencing was an assertion of independence, thinking that I didn't need anyone to handle my problems. Drawing on her own experiences, she said, "When we are faced with the fear of being stigmatized, [that can force] us to be independent so as not to 'let people in' and disclose the truth." I don't know whether that notion applied to me at that time or not. I certainly felt the fear of stigmatization, but I think my fear of turning others away by acknowledging how bad it really felt to be diagnosed with diabetes was more behind my lack of talking about it. If I verbalized the depth of my pain, it would become unavoidable and overwhelming. It could paralyze me and turn me into an even more damaged individual. Looking back years later, I am conscious that the fear I felt was acute, but the reasons behind that fear are more convoluted.

My diagnosis was a traumatic event for both me and my family. I felt like a different person and not one I especially liked. My reaction was typical as I experienced "feelings of upheaval, loss of identity and health, worries about the future and the development of serious complications, and concerns about [my] ability to live successfully and to achieve prior life goals" (Weinger & Lee, 2006, p. 668). What I didn't realize, or even think about, was that my family also felt loss and fear, and our lack of communication compounded the trauma for all of us (Weinger & Lee, 2006). Helgeson and Zajdel (2017) emphasized that "chronic illness takes place in an interpersonal context. The illness affects not only the person but also the social environment. ... The well-being of patients and [family] is intertwined" (p. 561). It's a family disease.

Despite research that indicates family members often view diabetes as more worrying than the diabetic herself (Jorgensen et al., 2003; Rintala et al., 2013; White et al., 2007), my family's lack of knowledge led to the opposite perspective. None of us understood the complexities. Family members may experience frustration, particularly from a lack of knowledge. They may worry about the daily struggles of the diabetic, the effects of the disease on relationships, and the burden of care (Stuckey et al., 2016). Our lack of understanding of the complicated nature of diabetes was not uncommon. We were not prepared for the effects of mood swings due to hypoglycemia and hyperglycemia, which add to the emotional burden of family members and result in relationship difficulties (Cox et al., 1987; Frier, 2008; Stuckey et al., 2016). I was too busy trying to figure out how to handle my disability to notice my mood swings, and my mother and husband didn't understand the mood swings were caused by fluctuating blood glucose levels.

My husband me told two stories about the early days of my disability that were hard to hear:

I had started to work. I remember trying to figure out what was going on. Your mother was really concerned [about your mood swings]. Neither of us could figure out what was wrong. She drove to the office a couple of times. I remember sitting in the car talking. ... Nobody understood that it was because of diabetes. We couldn't figure out what it was. Was it depression? Nobody was thinking it was diabetes. I remember going to see the doctor. ... I called him saying I didn't know what to do. He said, "Come in and see me." He was pretty frustrated and confused because he didn't understand why this was so hard. ... He figured it was all related to your diabetes and your ability to handle it. But his concern was if you can't handle it, what's it going to be like? I remember he said to me, "Are you sure you know what you're doing, getting married?" I know what he was implying. ... You had to learn how to deal with something that was a lot harder than I realized.

It's very hard to think of my husband and my mother being so worried that they were meeting secretly to talk about their concerns. They didn't know what to do. I didn't know what to do, either. Today we would just Google "diabetes + mood swings" and have a much better idea of what it all means. Then it might be easier to talk about it, but at that time, there was just so little understanding. It's also very upsetting to think that my doctor was implying that maybe my husband shouldn't marry me because it wasn't going to be easy. It reinforces the idea that disability is undesirable, that someone with a disability will be a problem, that it would be better not to become involved with a disabled person. I felt that way, too; one of my greatest fears at that time was that I was going to lose the person I loved most. I didn't know how to hold on to him when I knew our life together was never going to be what we thought it would be. I believed if he left me, there wouldn't be anyone else who would be willing to put up with a diseased, disabled, abnormal wife.

Brookfield (1994) claimed that "the 'self' that is involved in conducting learning is culturally formed and bound. Who we are and how we decide what it is important for us to be able to know or do ... are questions of culture" (para. 8). The culture that establishes norms and labels individuals with disabilities as deficient affected my ability to learn. My lack of resources was an important component; it limited my ability to understand my disability. According to Merriam and Baumgartner (2020), "What one wants to learn, what is offered, and the ways in which one learns are determined to a large extent by the nature of the society" (p. 5). I could not access information that, due to the medical model of disability, was primarily in the hands of doctors, so most of my learning was informal. Today my learning process would be different, and I'd write a different story, yet still, I hope, an honest one.

In evaluating the value of autoethnography, Le Roux (2017) argued for credibility, saying, "The research process and reporting should be permeated by honesty" (p. 204). Pursuing honest storytelling is difficult. It is not easy to hear about my husband meeting with my mother and my doctor because of their difficulty with the behavioral outcomes of my disability. Yet despite the pain I feel when thinking about the kind of person I was at that time, I want to include my husband's stories and be truthful. I want to tell what my story "does—how it is used, understood, and responded to ... [knowing] that memory is fallible, that it is impossible to recall or report on events in language that exactly represents how those events were lived and felt" (Ellis et al., 2011, p. 282).

What is significant is how these stories fit into the discourse of disability. On the one hand, it angers me to think of Goffman's work on stigma. Goffman (1963) emphasized the role of the stigmatized individuals in following societal codes of behavior, arguing that "normals really mean no harm; when they do, it is because they don't know better" (p. 116). I see the argument being made that my husband and my mother didn't know better. They were only trying to help. I should recognize my role in causing their distress. On the other hand, I'm frustrated that I feel guilty that this was their experience. I don't want to take on their burden; my disability is burden enough. I also don't want to lash out in anger knowing my husband will read my story; I don't want to feel more guilt, but I also want to be honest.

My husband described a time before we became officially engaged:

I remember your being really upset. One day we were in a garage somewhere, and it was like one of those multilevel garages. And I don't remember why you were so upset, but you were really upset. I remember saying to you in the garage, "Well, why don't we get married?" ... That seemed to calm you down and make you happy.

It doesn't seem very romantic to make a decision to marry me in order to calm me down, but that was a moment when I felt like he threw me a lifeline. I thought maybe things wouldn't be what I'd thought. Maybe, just maybe, there was some slim chance of hope for some kind of normalcy. For my husband, my diabetes didn't register as the earth-shattering event it did to me. He said,

I didn't think it was a big deal. I don't think I even realized how big a deal it was for years. I didn't know enough about it at the time, I guess, and you didn't communicate it really well. I probably wish I would've known that it was as big a deal to you as it was, meaning how you felt and what you thought about it because you never said. That was part of the thing that was somewhat frustrating is that you'd never communicate anything about it.

Again, I feel remorse and some guilt when I hear his words. If only I had been able to verbalize my thoughts and feelings, maybe things would have been different. It's also clear that despite the fact that my husband may not have viewed my disability as negatively as I did, and outwardly my disability may not have been as visible and as restricting as a disability that requires accommodations like a wheelchair or a service dog, my inner feelings of a lack of control over my body, my sadness at the inability to function normally, and the abandonment, despair, and grief of longing led me to feelings of oppression.

In the moment my husband suggested we get married, he had the power to change my life because he had the power to choose me as his wife despite my disability. I felt so diseased at that time that I couldn't imagine how I could possibly be worthy of marriage, of lifelong love and happiness. Disability is an interpersonal construction that affects both the visible and invisible life experiences of the person with the disability, the physical and the psycho-emotional sides of life:

Our appreciation of the exclusions that constitute disability should include those that work along psychological and emotional pathways. The oppression that disabled people experience operates on the "inside" as well as on the "outside": it is about being made to feel of lesser value, worthless, unattractive, or disgusting as well as it is about "outside" matters ... A social relational perspective direct[s] attention to the impacts and effects of the social behaviours enacted between the non-impaired and the impaired—in familial relationships, in communal interactions ... The focus is on questions of power, how it is wielded, and in whose interests, and on the decisions made, the words said, and the meanings conveyed in close networks of relationships. At issue are the effects that such encounters have on disabled individuals' sense of self, identity, self-esteem, and existential security. (Thomas, 2004, p. 31)

Looking back now, the idea of getting married so I would feel better about myself, my life, seems so depressing—not what one wants to see when thinking of the romantic notions of marriage. My husband may not have intended to make a marriage proposal that appears to have been an answer to the desperation we were feeling about my emotional state due to my feelings of worthlessness. After almost 40 years of marriage, it's obvious that what we have between us has always been much deeper and stronger than that, but his timing and my feeling that he saved me underlie my psycho-emotional reactions to my internalized oppression, reflecting the relational nature of disability.

Diabetes changed physical, emotional, and relational aspects of my life. I lost the ability to eat as much as I wanted of any food I desired. I had grown up in a family where dessert was always part of the meal, baking was a traditional family activity, baked goods were frequent gifts to family, friends, and neighbors. Now, I couldn't be a part of that family in the same way; I felt abandoned even though my family was still all around me, acting very much the same in lots of ways. I was different; I was excluded from something that had always been very important to me.

My disability shaped all my relationships, not just those with close family members. A friend shared her thoughts:

It's not like I've ever thought of [diabetes] as anything. ... Although I will say when you were going to get that islet transplant, we were, by that time, very close. So, we were talking a lot about what that might be and what that might mean. So that was the first time [your diabetes] fit more into a mold of a disease with a possible cure ... I only remember thinking, It's just something that's going to come in and fix everything. You aren't going to have to worry about all this stuff anymore. By that time, I really had a sense of what [diabetes management] was like every day, all day, all the time, with these crises periods in between. ... Otherwise it just seems much more like it was a part of you. Whether it's a disability, that never occurred to me. And yet it makes all the sense in the world. But it never would have occurred to me to frame it in that way. It's just a fundamental part of you and who you are. ... There were little things. I would watch and your blood sugar would drop. It's not like you're shaky or anything like that. You're just drawn. And then, you do whatever you need, take a piece of candy, give an extra shot, whatever it is. That happened a lot. ... Those moments became, for me, just part of the norm. ... There was always something that was there, that was present.

Islets from a donor pancreas can be implanted in a type 1 diabetic to produce insulin, regulating blood glucose levels in a healthy way. It is an experimental treatment, and at one point, because my diabetes is so brittle, my doctor referred me to a clinical trial. I went through the screening process, but at the moment of acceptance, my fear was too great to continue. The risks—blood clots, side effects from anti-rejection drugs including cancer, the need for multiple transplants, the possible brevity of the effectiveness of the transplant—all made it easier for me to choose the devil I knew rather than the devil I didn't know. It was difficult to walk away from what looked like a cure, a chance to be “normal” again, but my fear of what could happen next was too great. Diabetes had become a part of me by then, albeit a part I still didn't like.

I don't know how well people can understand the complexities of disability without experiencing it. And since disability is different for every individual, I think this lack of comprehension becomes another burden. My story, my relationships are about my disability, my perceptions of it, the ways it is manifested in my life, but the way I live my disabled life is not the way others live theirs. Medical professionals, researchers and scholars, individuals with disabilities, advocates and allies have all tried to explain it. They have created models to enhance comprehension and change the disability discourse. For me, disability is very much about my interpersonal interactions and my inner being, although it's also about the physicality of the disease. The relational model of disability includes psycho-emotional dimensions that “shap[e] in profound ways what people can be, as well as [affect] what they can do” (Thomas, 2004, p. 32). Elements of the relational model of disability include personal manifestations of disability such as impairment effects and self-efficacy; attitudinal and physical constraints within society such as reactions of pity or disgust and mobility barriers like stairs; accessibility issues based on power structures such as testing requirements for educational opportunities; and psychological ramifications such as depression and understanding who one is becoming as a person with a disability (Haslett et al., 2017; Wang, 2019). It's another way my life is, by necessity, complicated by my disability.

Early on, I learned the basics of self-care from my doctor. I read his book and the other materials he had given me, but I was still uninformed in a lot of ways. Once, when I asked my doctor whether he considered diabetes to be a disease or a disability, he responded that what was most significant was how the patient viewed it. He told me that when his patients first receive the diagnosis, there's too much for them to take in. On later visits, though, he recognizes those who will successfully manage their diabetes; they are the ones who see it as a disability, something that will require a lifestyle change, something that forces them to recognize their own limitations and act. Those who view diabetes as a disease and turn over the control of their bodies to doctors they only see periodically for office visits and treatment, as I did that first year, are not as successful. In his experience, if patients see diabetes as a disease, they will not have very tight control over their glucose levels and will experience more long-term side effects because they think of injecting insulin as similar to popping a pill to cure an ailment. If individuals take the perspective that diabetes is a disability, they recognize that the key factor is the lifestyle change necessary to maintain better glucose-level control.

In the beginning, I definitely saw diabetes as a disease. The first doctor I worked with focused on the need for good nutrition, yet there are many factors that go into controlling blood glucose levels and food intake is only a part of the process. At first, I thought it would require balancing food choices and insulin doses: Take in higher-sugar content food; add more insulin. I remember a few "tips" I learned like cooking chicken breasts in low-calorie salad dressing instead of creamy sauces, but I didn't make lifestyle changes that fully addressed my diabetes. I remember thinking, OK, my blood glucose level is low so now I can have a chocolate bar, or I just ate a brownie, so I have to add more fast-acting insulin to the syringe to inject enough to bring down the higher glucose level. Obviously, that was not the best way to handle my disability. The problem was that even if I made good food choices, my health didn't necessarily improve correspondingly.

With a diagnosis of type 1 diabetes, I officially became disabled, yet I was unsure of exactly which label—"diseased," "impaired," "disabled"—to apply to my newly deficient body. The 2008 Americans with Disabilities Act Amendments Act (ADAAA) considers diabetes a disability; the need for an amendment itself reflects the changing definitions of disease and disability. Because I was required to take insulin shots, and I did not outwardly present as disabled or diseased unless I was experiencing symptoms of hyperglycemia or hypoglycemia, it was difficult for me to define my situation. In many ways, it did not matter which label I chose; none of them provided hope for the desired "normal" life. The terms "disease," "illness," and "sickness" have long been part of a medical triad (Boyd, 2000). Susser (1990) described a parallel triad of "impairment," "disability," and "handicap." A distinction between "disease" and "illness" has also been applied to chronic illness. According to Charmaz and Rosenfeld (2010), "Disease refers to the undesirable biological processes that affect individuals, whereas illness refers to the person's experience of the disease, including its psychological and social effects" (as cited in Helgeson & Zajdel, 2017, p. 547).

No matter the choice of term, "the construct of disabled life as incomplete and lacking, with a constant awareness of what has been lost or was never had" (Watermeyer, 2009, p. 92) is a significant part of my life. I discovered that I could describe my diabetes as either a disability or an illness, but in either case, the result was that I was not normal; there were limitations on what my body could do. Society viewed me as sick, no longer ideal. Chronic diseases such as diabetes are frequently listed as illnesses requiring treatment, yet the psycho-emotional effects of chronic illness are disabling. The relational model of disability recognizes that similar to physical barriers that limit participation by people with disabilities, individuals' psycho-emotional reactions can prevent them from participating in social relationships and communal activities. We just don't see the inner barriers the way we see the outer barriers. But no matter what it's called, it's still not good.

After my diagnosis, insulin injections became the treatment that would work to normalize my body and break down the glucose that I am not able to do so naturally. I get annoyed when someone tells me they are afraid of needles and could never inject themselves the way I did. I want to scream at them, “If the alternative is death, you’ll definitely figure out a way to do it!” I have in many ways reconciled myself to the view of diabetes as a disability, an ever-present part of my life that requires constant accommodation. The change hit me hardest when I switched from giving myself insulin injections to using an insulin pump. There were moments between my four daily injections when I could forget I was a diabetic, but once the pump became a permanent appendage, beeping and vibrating as often as once every hour of the day and night, requiring constant filling and calibration, there was no longer any chance of forgetting my impairment. There is no more hiding that I have diabetes when the alarm starts sounding in public. The pump and the continuous glucose sensor patch on my arm announce to the world that I am different. I used to be fearful of being exposed as a diabetic and judged to be less worthy. My feeling of a loss of control of my own body reflected society’s view of my lacking self-control. It’s generally assumed that diabetics don’t pursue a healthy lifestyle; they eat too much and exercise too little. Today I care less about what others think or say; I don’t even care when I’m pulled aside in the security line at the airport. I watch my husband stroll through the metal detector as I hold up my pump, the tube clearly attached to my stomach; point out the arm patch; and pull up my shirt to reveal and explain the sensor. As my husband gathers our carry-ons and puts on his shoes, I submit to the invasive wand and hold out my hands and my pump so that they can be swabbed to check for bomb residue. I really don’t care who is watching or what they are thinking. I just want to live. I just want to make it through another day, even if it’s spent managing my symptoms, hoping things don’t get worse.

The officer in the airport security line singles me out as different, as suspect. The medical accoutrements of my disability lead to my being judged as a possible danger. My body must be further investigated so I can be deemed safe and acceptable. Moral judgments have always been a part of disability, evident in disability models, those abstract tools that provide ways to understand disability.

In the medical model widely accepted by those without disabilities because of common understandings of illness, disability is viewed as a health issue. Individuals comprehend becoming sick, going to the doctor, and following the prescribed treatment; after finishing the medicine, the patient is cured, “back to normal.” When the medical model is applied to disability, there is that same movement toward normalization as the impairment is “a defect in or a failure of a bodily system that is inherently abnormal and pathological” (Goodley, 2011, p. 7).

This model emphasizes the abnormality and focuses on the part of the body that generated the disability rather than on the whole person. After the diagnosis, I felt that I was forced to change the way I saw myself because of the role of medicine in my life. I was no longer a typical college student; I was first and foremost someone with a disease. My disability was diagnosed, and insulin was prescribed to lessen the effects of my impairment as there was no cure. I was immediately put in the role of patient. Control of my own body was taken away and placed in the hands of medical professionals (Areheart, 2008; Donoghue, 2003; Fisher & Goodley, 2007; Goodley, 2011; Haegele & Hodge, 2016). At that time, I didn’t understand what diabetes was doing to my body, and I relied on the doctors. Today I find it frustrating that the medical model of disability to which I am tied does not recognize my own more intimate understanding of my own body. I now know much more than the doctors about my own body, but my knowledge is not valued in comparison to the knowledge of medical professionals who want to put me in the same category as other diabetics despite our differences (Areheart, 2008; Barton, 2009; Donoghue, 2003; Goodley, 2011; Haegele & Hodge, 2016). Because my disability is the result of a chronic disease, how I live my life as an individual with a disability is closely tied to the medical world. I can’t escape the medical model and its judgments.

The reality of disability is more complicated than defining and labeling would make it appear. The terms “disease,” “illness,” “sickness,” “impairment,” “disability,” and “handicap” are not distinct, but rather they overlap and exist sometimes concurrently. I don’t remember a defining moment when I recognized that I was disabled, maybe because I initially saw diabetes as a disease to be treated rather than a disability, but I do remember experiencing grief, feeling a loss of control. I had always felt that I could accomplish what I set out to do. I was also a perfectionist. Then suddenly, I could no longer control my own imperfect body. During the first year and a half after my diagnosis, my focus was on my engagement and wedding planning, graduating college and looking for a job, starting my career and setting up an apartment in New York City. With type 1 diabetes, there is often a honeymoon period immediately following the diagnosis and prior to the beginning of insulin treatment. At this time, it can seem like the diabetes has gone away, that one is no longer disabled. I don’t know if I experienced a honeymoon period because I didn’t understand my disease. The signs that my body wasn’t normal and was reacting to the presence of disease were subtle. I have in many ways reconciled myself to diabetes as an ever-present part of my life that requires constant accommodation. There aren’t any more moments when I can forget I am a diabetic.

I remember my husband commenting about how much I ate on the night we got engaged. We went to a small French restaurant on 57th Street in Manhattan, and after a wonderful meal, we walked the short distance to the park on the Hudson River. Beneath the moon, the stars, and the lamplight, Tom proposed. It was one of the most beautiful moments of my life, yet to this day, I remember his comment about what I ate. He told me I must have been very hungry since I ate so much. He wasn’t criticizing or mocking me—it was just a statement of fact—but given my hyper-consciousness about being diseased, disabled, and different, it still stings. It was like the parking-deck decision to marry in order to stem the tide of hysterical tears. It seems my disability has to intrude, always, even on the best parts of my life. The proposal and engagement are early instances that remain clear in my mind, but they are typical of how disability insidiously creeps into every moment.

My overall sense of that time of being newly disabled is that of largely trying to ignore my disability as much as possible and cling to normalcy in any way I could. I could focus on being a normal college graduate starting a new job, a normal young adult moving away from home, a normal bride walking down the aisle. That came to a crashing halt when I was hospitalized the week of my wedding. Just as my husband and I were ready to head to the mountains of Germany, Austria, and Switzerland on our honeymoon, my diabetes honeymoon ended. Just as we planned to toast and feast on our wedding day, my disabled moveable feast from Paris reared its ugly head.

Living with a chronic illness requires one to maintain a lifelong focus on managing symptoms. Adapting to this change in life circumstances is a “value-laden process” (Gordon & Feldman, 1998, para. 4) that requires one to re-evaluate her life’s purpose and find new meaning, a new sense of herself, her place in relationships, and her role in society. For me, the adjustment to diabetes was an emotional burden, a complex psychosocial process, a constant struggle in day-to-day symptom management, an experience of grief for physical loss, a creation of a new identity, and an increase in knowledge (Harris et al., 2015). Learning how to live with a new view of oneself is not easy. The fact that there is no cure for diabetes makes it difficult to accept the diagnosis. Returning to normal is never a possibility; a person with diabetes will always be seen as imperfect, a hard thing to swallow for a perfectionist like me. Looking back on life prior to the diagnosis, one typically sees a rosy picture of good health and freedom, a much more perfect life (Gordon & Feldman, 1998). During my period of adjustment, I experienced depression, anger, frustration, anxiety, uncertainty, and vulnerability, and I had no idea of what was to come.

CHAPTER 2

Married to Disability, Mothered by Disability

“The River” is how you learn the adult life and you choose your partner and you choose your work and that clock starts ticking and you walk alongside not only the people you’ve chosen to live your life with but you walk alongside of your own mortality and you realize you have a limited amount of time to raise your family, to do your job, to try and do something good. That’s “The River.”

—Bruce Springsteen in concert (as cited in Masley, 2016, para. 15)

Walking down the aisle of the church on my wedding day, I felt the presence of my disability walking alongside me. The day was bright, sun filtered in through sparkling stained-glass windows, my gown was white, the bridesmaids' dresses lavender, my mother's pale blue. There were smiles and there was love. But there was also darkness hovering in shadows, the inescapable presence of disease, of tragedy. I felt pretty, and I also felt betrayed by a body that couldn't manage my stress, but the clock was surely ticking, and there were a lot of somethings I wanted to do.

Ten days before our wedding, my husband's father died. He had been diagnosed with cancer soon after we became engaged so I never got to know the person he really was; I saw him more as a patient, suffering the debilitation of a ravaging disease. The night he died, my husband visited him in the hospital. Tom left the hospital in the Bronx and took the long subway ride back to our apartment in Brooklyn. He had just arrived when the dreaded phone call came with the news we didn't want to hear. It was one of those incredibly sad times when you want desperately to do something to change the direction of life, but circumstances are beyond your control. Again, as he had at the moment of my diagnosis, Tom felt, "Okay, deal with it. I mean, my father was so sick by that point, that if he died that week or the following week, it was going to happen. We knew what was going to happen."

The next several days remain a blurry memory of the wake and funeral. I do clearly remember sitting in the limousine with my husband's family, parked in the cemetery waiting for the pall bearers to carry the casket to the gravesite, and thinking that the entire week had a surreal feel. It was like a movie was playing out before me. I could see what was happening, but I felt like a miscast character reading from a script. I wasn't prepared to find myself in the position of bereaved daughter-in-law, just as I hadn't been prepared to play the role of disabled adult. More grief, more bereavement, more stress, and therefore, more health complications.

When I write about grieving for my husband's father, that grief is in stark contrast to the disability grief I experienced. Death of a loved one is a concrete loss with mourning rituals. What I felt when diagnosed with diabetes was a more abstruse loss. I didn't understand what it meant, how my body had changed and would change, what the future held. As a mother parenting a child with a disability, Green (2002) described the "loss of an imagined reality, a reality that is no less important or deeply mourned because of its imaginary nature" (p. 21). The story one has constructed for oneself about what life will be like is disrupted by a disability diagnosis. My imaginings of my courtship, my wedding, my marriage, my motherhood were abruptly changed when I became a diabetic and I had to re-envision what my life would look like. These visions have had to be adapted throughout my life, reflecting ambiguous loss or nonfinite loss and chronic sorrow.

As part of his work with parents of children with disabilities, Olshansky (1962) defined chronic sorrow. Decades later, Patrick-Ott and Ladd (2010) expanded on Olshansky's work, noting that individuals who are disabled and their families "experience the continued grief of chronic loss over and over again as [the] ... disability prevents normal development and expected life experiences" (p. 75). The juxtaposition of the loss of my husband's father and the loss of my imaginings of my future highlight my mourning process in which "in a manner parallel to that evidenced following the loss of a loved one, [I] exhibit[ed] feelings of grief, bereavement, and despair [where my disability] serve[d] as a constant reminder of the permanency of the condition. [And] daily triggering events act[ed] to remind [me] of the permanent disparity between past and present or future situations" (Livneh & Antonak, 2005, p. 12). Chronic sorrow is never-ending and pervasive as the source of the loss, my diminished health, is always present. Dealing with the lasting effects of disability brings about recurring losses (Harris & Gorman, 2011; Olshansky, 1962; Patrick-Ott & Ladd, 2010; Roos, 2002). At the center of chronic loss is "a painful discrepancy between what is perceived as reality and what continues to be dreamed of" (Roos, 2002, p. 26). The ups and downs of the chronic illness correspond to the emotional ups and downs of grief that result from hopes and expectations that are dashed by reality.

Tom and I both remember there were people who asked if we were going to postpone the wedding. We felt we just had to push through the pain, the uncertainty, the mixed emotions. It seemed like we had struggled to get that far so it didn't seem right to stop, even if it also didn't seem entirely right to keep going. The weekend following the funeral, the weekend before the wedding, my diabetes raged out of control. The stress affected my blood glucose levels, and I couldn't get them back under control, so I ended up in the hospital, the first of many emergency admissions of my life. My clearest memory of that week was when I asked when I could go home; after all, I was getting married on Saturday. The doctor gave a long and complex response explaining the complications of my condition. The words that stand out the most in my memory are when he said there might have been significant kidney failure and I might be in the hospital for a while. To me, that was just unacceptable. My response was a plain and simple *No!* I was getting out of the hospital, I was getting married, I was going on my honeymoon. Tom and I had kept on going through all the difficulties of the past two years, and I wasn't about to stop now despite what the doctor had said. I believed I would be okay. I knew my body, and I knew things couldn't be that bad. I just needed a couple of days of rest and insulin adjustments, and I'd be fine. Tom recalled my sister-in-law's call to tell him I had been hospitalized:

I remember the tone of her voice kind of being like, don't panic. I was like, I don't panic, you know? You were now in the hospital, and I thought, Oh, this is interesting. I don't ever remember thinking about canceling the wedding. I just remember thinking that the honeymoon trip we were going to take wasn't going to work. There was a lot that had to be done mostly in terms of figuring out the trip. Obviously, I was concerned about how you were feeling, but I got the sense that you just had to get your blood sugar adjusted. It wasn't fun, obviously, but I don't remember feeling like, hey, your being in the hospital was something that was long term or something that would make a huge difference. I didn't feel that way. I thought, okay, there was a lot going on and, and you probably weren't eating right, so you've got to get your blood sugar adjusted and then everything will be back to normal. I didn't feel it was like the sky was falling. I just didn't feel that way.

Tom headed for the travel agent, cancelled our honeymoon to Europe, and booked a trip to Bermuda instead. I couldn't manage traveling through the Alps of Austria and Switzerland, but a week on the beach at a resort would be fine.

According to Freud (1917/1964), mourning has an end, whereas melancholia does not. The melancholic person experiences continued sorrow and cannot move past the feelings of sadness over her loss. It was difficult for me to move past the melancholia of disability during the first few years of our marriage. The symptoms of melancholia include "painful dejection, cessation of interest in the outside world, loss of the capacity to love, inhibition of all activity and a lowering of the self-regard feelings to a degree that finds utterance in self-reproaches and self-revilings" (Freud, 1917/1964, p. 244). Freud (1917/1964) emphasized the distinction between mourning and melancholia when he said, "In mourning it is the world which has become poor and empty; in melancholia it is the ego itself" (p. 246). This sense of inferiority played out in the connection between my disability and my psyche. While I mourned the loss of a healthy body for a period, the melancholia was much more pervasive, a more difficult burden for Tom and me to bear.

My disability is not merely the product of my health or the effects of the stigmatization of society; it "arises as a complex interaction of factors" (Shakespeare, 2013, p. 5). The effects of my impairment and our marriage both have affected how my disability has played out in our lives and reflect understandings that we have developed through our relationship. The burden of my disability is shared within our marriage; my disability does not have to be borne by me alone. The importance of our relationship and dialogue is crucial. Yet in the beginning of our marriage, it was difficult to discuss the effects of disability on our daily lives.

The wedding took place, and maybe it wasn't exactly what we had envisioned, but I think it was representative of who we are and how we have approached our life together. We handle challenges and keep on going, treasuring the good stuff despite the bad stuff that comes along. There was joy and there was grieving, but above all there was sharing. We did it together. Since the start, my diabetes has been part of our relationship; we can't avoid that.

There was a moment when we checked in at the resort in Bermuda, and I just burst out crying. I think it hit me that the imagined start to married life had been lost. Tom said, "We didn't want to go to where we ended up, but it was like there was no choice." The lack of options and the loss of control always seem to be the themes of dealing with disability. There was a whole line of people waiting to check in who had probably just gotten married; our planned special honeymoon was no longer special, unique, reflective of us. It was typical, common, and marred by disability. It may have been the perfect choice of honeymoon destination for a lot of people, but it wasn't the one we had spent months planning, the one we had anticipated with excitement. Yeah, it wasn't the end of the world after all, but it was disappointing. Tom said,

It was fun, but I thought there were parts where you were not feeling great and I couldn't tell if it was the diabetes or you just were like, What am I doing here? A couple of times you just went back to the room to sleep, and it was obvious you weren't happy, but then again, there was so much going on before the wedding that I wasn't sure what it was all about. I wasn't sure if you were not feeling well physically or if it was just that too much had happened in the last two weeks, if you were thinking to yourself that it was a mistake we just made. It certainly wasn't what we wanted. It wasn't what we planned.

However, I do remember touring the island on motor scooters, discovering pristine beaches with pink sand beaches and bright aqua water, drinking strawberry daiquiris at the poolside bar, taking a bus to an exclusive restaurant we could barely afford, and laughing at the tacky Bermuda Museum. It just wasn't what had been imagined, and the feeling of sadness did not diminish.

Ambiguous loss "complicates grief, confuses relationships, and prevents closure. ... It lies at the root of much depression, anxiety, and family conflict. ... There is no official notice or ritual for such unclear loss. Yet, the trauma devastates people" (Boss, 2010, p. 137). The concept of ambiguous loss was developed to address the loss of someone who was gone but not dead—someone who was in the military, for example, or someone who was present physically but not cognitively, someone with dementia, for example. Because ambiguous loss is a "relational disorder ... [where] ambiguity ruptures the meaning of loss, ... [and] people are frozen in both coping and grieving" (Boss, 2007, p. 106), it has been applied to the experience of illness and disability. In this case, someone is physically present, but their body has undergone a significant change (Betz & Thorngren, 2006; Harris, 2011; Patrick-Ott & Ladd, 2010). I've experienced fatigue, insomnia, anxiety, depression, irritability, and anger, all symptoms of ambiguous loss (Harris & Gorman, 2011). Our honeymoon reflected both coping and grieving.

Similarly, nonfinite loss and its corresponding grief can begin with a diagnosis. The related sorrow over the loss and dread for the future can continue throughout life as one is always unsure of what will happen and must adjust to a change in what "should have been, could have been, or might have been" (Harris & Gorman, 2011, p. 2). It blocks the realization of previous goals and dreams. A person experiencing nonfinite loss does not perceive her life experiences as normal and feels unable to control both current and future circumstances. Those close to the individual who has suffered a nonfinite loss often do not truly understand the loss as they do a loss like the death of a loved one (Bruce & Schultz, 2001, 2002; Harris & Gorman, 2011). Both ambiguous and nonfinite loss highlight the ongoing and exhaustive nature of grief that sharply changes one's outlook and brings about identity and relationship changes from feelings of shame and worthlessness (Harris & Gorman, 2011, p. 7). Our honeymoon was only the beginning of my experience of ambiguous and nonfinite loss.

After returning from our honeymoon, I found it hard to maintain enthusiasm and stay involved in meaningful events. I didn't like the person I had become. Tom said, "There were times when you were really moody. I remember lots of Saturday afternoons just walking around downtown Brooklyn because you weren't feeling well and were in the apartment, sleeping. I don't know if it was driven by diabetes." At first, we thought my sadness was from all that had happened in a short period of time, but again, without enough understanding, we didn't really know what was connected to my diabetes and what wasn't. Tom described it:

I just thought it was a lot of things coming together all at the same time. I think in the first few years, that made it harder. I think that probably I should have done some homework to figure out that some of these things were more related to diabetes. I remember you saying that sometimes, but it was hard to put two and two together.

My husband had been a lifeguard on the Jersey Shore throughout high school and college. We frequently drove from New York City down to the shore for weekends. I remember that when we were first dating and would make the trip down the Garden State Parkway, we would sail through the tollbooths without stopping and Tom would flick his wrist and send the quarter into the bucket. I thought it was incredibly cool. Later trips down that highway were less ideal. I remember thinking that if I were driving, I could just speed up and smash into the tollbooth and end my life. Tom said,

I remember one time your telling me that you had gone out and tried to walk in front of a bus on Atlantic Avenue. I remember your telling me that. I was like, What am I supposed to do here?

That was partly the problem. I didn't know what to do. How do you get somebody help? I didn't understand.

Fortunately, we knew enough for me to start therapy.

It's difficult to write about thoughts of suicide. I have always been a perfectionist, and although I can deal with imperfection and disappointment, as a newlywed I still had those images in my mind of what my life should be. It was difficult to reconcile who I thought I was, who I wanted to be, and who I was as a person with a chronic illness. My experience of grief became an exploration of what I valued and what I believed about myself. Betz and Thorngren (2006) wrote that "when people lose their previous state of health because of illness or injury, they may no longer be able to do the things most important to them. ... They lose their identity and way of being in the world" (p. 360). I knew I was different, but I didn't know who I was.

Bartram (2013) discussed the importance of psychotherapy for dealing with disability. The loss felt when disability occurs is complicated by self-accusations, and in my case, the loss of "the anticipated and imagined" wedding and beginning of married life. Some lives are judged to be more grievable than others (McGuire, 2010), and at the time of my wedding, I was dealing with the sense that my grief over losing my "imagined wedding," complicated by the disability that took away my "imagined future life," didn't seem as grievable as my husband's loss of his father. How could I possibly complain about a less than perfect wedding day when he was mourning the loss of his father? Yet for those dealing with disability, "the mourning process is never complete" (Bartram, 2013, p. 170) and melancholia persists. In the early stages of illness, it is difficult to move away from this discourse of loss. I wavered between stoicism and depression such that "a constructed mystique of loss [was] everywhere around [me], whilst the flesh and blood reality of [my] disabled life ... often [remained] unarticulated, disguised, dampened down or drowned out" (Watermeyer, 2009, p. 101). Dealing with the sense of loss was one of the most difficult aspects of my disability experience and required that I undergo psychotherapy for depression.

I remember my therapist's office. It was dimly lit, and yes, there was a couch, but unlike the typical therapy cartoons, I didn't lie down and bare my soul. It was a little more like Dr. Melfi and Tony Soprano. We sat opposite from each other in armchairs with a low table between us. I don't actually remember much specific discussion about my disability, but obviously that was at the core of my depression. We spent a lot of time on relationships and self-esteem. I suppose it helped, but needing therapy wasn't something I was proud of, and I thought the sooner I could move beyond it, the better I would be. I guess I felt that it was one more setting shrouded in stigmatization and contributing to my feelings of failure, of not being "normal" enough. Life felt like a ride on a seesaw.

Just as my glucose levels went up and down, my depression came and went, my anger flared and dissipated. This made married life difficult. According to my husband,

Living in the city, we used to do a lot of stuff and I liked that a lot. I remember going on some decent trips. That was the hard thing. I thought we had lots of the things that we had fun with and then there would be these things that would come up that I didn't understand why you were either depressed or angry. I never felt like you would talk about it. All the stuff we used to do in the city I used to think was great. I thought things were pretty darn good. Other than it was just sort of erratic. It seemed like I couldn't figure out why you seemed so unhappy. Right. Because at times things seemed like they were really good, like when you were teaching, and we were doing the basketball coaching together. That was all fun. You know, I just thought we were in a pretty good position. We were living in a really good neighborhood in a really good area and we didn't have a lot of money, but there wasn't a lot of stuff we couldn't do. It was just hard for me to understand.

One of the difficulties of learning to live with my diabetes was understanding hypoglycemia, which occurs when my blood glucose levels fall too low, and hyperglycemia, which is when my blood glucose levels rise too high. Both are serious medical complications. We didn't always know whether moments when I wasn't feeling right were due to my diabetes. Because of this, it was difficult to know how to treat the situation. For example, I ended up in the hospital several times, but it was not always clear at the outset of symptoms whether I was having difficulties with glucose-level regulation that I could handle on my own or whether I needed emergency care.

There are several factors that can lead to hypoglycemia such as taking too much insulin, not eating enough, drinking alcohol, and exercising. Usually symptoms of hypoglycemia begin before one's glucose level reaches a dangerous low, but if the symptoms are not pronounced or recognized, a diabetic may not realize her glucose level is dangerously low. If symptoms such as shakiness, sweating, dizziness, heart palpitations, blurred vision, a tingling sensation around the mouth, an inability to think clearly, and an inability to move smoothly aren't recognized, then the hypoglycemia cannot be treated in time to avoid a severe reaction. There are also other, less distinctive symptoms that are difficult to immediately connect to low blood sugar. These include irritability or moodiness, anxiety or nervousness, and headaches. Severe hypoglycemia can lead to seizures and unconsciousness, and falling victim to extreme hypoglycemia is a significant fear of diabetics (Cox et al., 1987; Frier, 2008; Nefs et al., 2015; Wild et al., 2007).

I've described my life as a ride on a seesaw, but Andersen and Kornblum (1984) used a different metaphor, noting that insulin-dependent diabetics "walk a tightrope, balancing between high and low blood sugar levels. ... Because stress influences blood sugar control, and blood sugar levels, in turn, influence emotional equilibrium, the diabetic ... copes with a complex feedback cycle between physical and psychological states" (p. 18). This cycle is difficult for me to manage, and its effects complicate my relationships because it is difficult for others to handle as well. It's clearer to Tom and me today as we've gained knowledge and experience, but it's still not simple.

One Sunday when I was about four months pregnant, I woke up feeling tired and nauseous, but that was not a rare occurrence. My husband left our apartment and headed out to the co-op we had bought that was about a mile away. He was planning to spend the day painting. After he left, I thought maybe if I took a shower, I would start to feel better. My glucose levels were a little high but not significantly so. As I started to shower, I was overcome with nausea and barely made it to the toilet. Then the diarrhea started. I finally collapsed on the bathroom floor, soaking wet and shaking. I thought I was having a miscarriage. It was devastating. I knew I needed help, but this was before cell phones, and there was no landline at the co-op. I reached for a towel but couldn't make it. I grabbed the sweatpants and t-shirt that had fallen on the floor and, between throwing up and emptying my bowels, I tried to get dressed as I lay on the floor. Eventually I was able to crawl to the next room and reach the phone. I called friends across the street, but they were not home. Finally, I woke up a hungover friend who lived several blocks away. I explained that I was sick and needed help. He called 911 and raced to the apartment. When I hung up, I managed to get to the door and unlock it. Then I fell to the floor. When the EMS arrived, he ran the mile to the co-op to get Tom. It turned out that I had appendicitis and had to have emergency surgery, but the symptoms were very similar to those I experience with severe hyperglycemia or hypoglycemia. There's always the question of how to know when I can handle the situation by myself and when I need medical assistance. In this case, I became so sick so fast and because I was pregnant, I knew I needed to get help. My husband remembers the day:

I was painting one of the bedrooms, and that's the only way I knew he was outside the window. I happened to be standing on a ladder, and I saw him yelling. He told me that you were being taken to the hospital. I ran back to the apartment. That was scary because you had to have surgery and obviously you were pregnant. ... I do remember, though, after the operation was done, they said that they could take a look at the baby at the time and everything looked fine. And I remember thinking, you know, okay, you had surgery, is everything really fine? But it's sort of like the doctors said everything's fine. You seemed to be recovering. So, what else can we do except hope that they were right? You can't second-guess them all day long. They said that we were lucky, really lucky, that you got to the hospital.

The hardest part is knowing when to make the call and fearing if I make it too early and then I recover quickly, I'll look foolish, that I should have handled it on my own. Or fearing that if I wait too long, I won't recover at all.

When a child is born, parents become "more aware of their own mortality. For diabetic parents, the birth of a child acutely underscores the possible long-term serious health consequences of their disease" (Anderson & Kornblum, 1984, p. 22). The overwhelming emotion I felt at this time was fear, fear for my health and my child's, fear that we could both die. It is common for diabetic mothers to experience "increased levels of anxiety, diabetes-related distress, guilt, a sense of disconnectedness from health professionals, and a focus on medicalisation of pregnancy rather than the positive transition to motherhood" (Rasmussen et al., 2013, p. 1), as I did due to further loss of control of my body during and after pregnancy. Fear added to the burden.

As a diabetic, I was labeled "at risk" as soon as I became pregnant, and I knew I had to pay particular attention to my glucose levels or there could be adverse effects on both me and my baby. While many women worry about the health of their babies during pregnancy, the added pressure of diabetes made that worry a constant presence. What was also significant was that after birth, like many diabetics, I focused on the baby rather than my own health. I made a lot of trade-offs in self-care choices like what or when to eat, essentially "putting 'diabetes in the background' whilst dealing with everyday life" (Rasmussen et al., 2011, p. 1986). It wasn't smart, but it was the only way to cope.

Disability complications played out in both my pregnancies. When I think about my younger daughter's birth, it's no wonder that she went to Penn State and pursued a career in sports. By the end of my pregnancy, I looked like I could play defense for the Chicago Bears; anyone viewing the defensive line from a distance would have had trouble distinguishing me from Refrigerator Perry. I had gained over 60 pounds, and it showed in my huge blimp-like stomach, my bloated face, and my swollen feet. When my older daughter's godfather came for a holiday visit, I opened the front door to greet him. His jaw dropped and he blurted out, "Oh my God!" Just the kind of reaction every pregnant woman eagerly awaits. The baby wasn't due until the beginning of February, but complications required a rush to the hospital a few days after Christmas.

My oldest daughter wasn't happy about being sent next door to stay with the babysitter and await her grandmother's return from Massachusetts. She envisioned giving birth similar to hiking a football. She had eagerly anticipated standing behind me as I bent over and grunted "Hut, hut, HIKE," at which point her little sister would come flying out into her waiting hands, followed by endzone-style celebrations for the family star quarterback who had done such a great job welcoming her little sister into our world. When she did first arrive on the scene, the anesthesiologist in the delivery room excitedly exclaimed that she could play for Alabama, as despite being over five weeks early, she was rotund and portly thanks to my diabetes. Of course, my husband added to the football metaphor by nicknaming our precious baby Ditka, fitting due to her chubby cheeks, rounded shoulders, and lack of a discernible neck, and Beezer, a shortened form of Beasley Reece. Tom remembers our daughter being in the neonatal intensive care, saying, "That was hard. I don't think I understood quite how hard that was for you until I started reading the stories you wrote," referring to the autoethnographic stories in which I explored my life through the lens of disability.

For women who are disabled, giving birth can change the way they view their bodies. Some women with disabilities have found that motherhood shifts their attention away from what is wrong with their bodies toward seeing their bodies as valuable (Grue & Laerum, 2002, p. 676). For me, though, pregnancy and childbirth led to added focus on what was wrong with my body because I couldn't do it the "normal" way. Mothers with disabilities often feel the need to strive for perfection. They can't take for granted that they will be good mothers; they "tend to be quite reflective ... and they seem carefully to monitor their own performance in their role as mother[s]" (Grue & Laerum, 2002, p. 678). I knew the fear of becoming a "bad mother."

Thomas (1997) argued that concerns related to disablism, the mother's impairment, and health consequences all factor into childbearing decisions. I remember being told that I had to get pregnant sooner rather than later in order to avoid serious complications. After my first child's birth, I was told to wait at least five to seven years before having another one, and after my second child's birth, I was told another pregnancy would kill me. Those warnings from doctors placed me within a medical risk discourse that was disabling and increased the pressure on me to be a "good mother." This discourse also revealed negative attitudes from "we know best" healthcare personnel whose medical advice is rooted in cultural assumptions. According to Thomas (1997), "Despite its apparently 'scientific objectivity,' medical knowledge inevitably draws on deep-rooted cultural antipathy for, and prejudices about, people with 'abnormalities'" (p. 627). The attention was on my bodily deficits, not my mothering strengths.

I wrote about the birth of our second daughter:

Like Julie Kaomea (2005), I, too, felt “from the moment my daughter was cut from me, our separation was sudden, harsh, severe” (p. 81), undoubtedly influencing our journey forward. Kaomea described seeing her daughter six hours after birth “in her fish-tank-like incubator, with a mess of wires hooking her up to a series of monitors, an intravenous needle in her bandaged arm” (p. 82). I, too, remember that image, captured in a Polaroid photograph now tucked away in a pink chocolate cigar box, along with a hospital bracelet and newborn bib emblazoned with a bright yellow and turquoise stork. The photograph, showing my daughter in her incubator a few hours after her birth, was taken as I lay in a dimly lit treatment room with my own intravenous needle pumping burning magnesium sulfate through my veins to treat postpartum preeclampsia. I remember sobbing because I couldn’t see my daughter, hold her, kiss her. A nurse, recognizing my misery, took the Polaroid snapshot and brought it back to me, but like Kaomea, all I could think was, “How did this happen, what did I do wrong?” (p. 82). As I look at the photograph now, I see a beautiful baby girl that I’ve always loved with fierce protectiveness and pride, and I still feel the pain. Not the pain from the cesarean surgery but from the overwhelming sense of not being good enough.

As a diabetic, the complications from my pregnancy and delivery set me up as a failure in the eyes of my doctors and the nurses. It was not until later that I realized they set me up as a failure in my own mind, too. My excessive weight gain did not fit the model of what doctors call a “normal” pregnancy. My C-section five weeks before the due date was not “natural.” The need for my daughter to be whisked away immediately to the neonatal intensive care unit did not reflect a “typically healthy” birth, and my inability to cuddle with and nurse my baby precluded the opportunity for “traditional bonding.” My daughter was not even a day old, and already we were “different.” I wonder, in these circumstances, When does one begin to be a parent?

... At the moment of my daughter’s birth, I began “failing” as a mother because I did not live up to the ideal. This was continually reinforced through conversations with medical personnel and other young mothers in which they extolled the virtues of stress-free natural deliveries, breastfeeding, and the importance of immediate maternal bonding—experiences denied me because of health complications. Their assumptions and surety that they were doing motherhood the “right way” chipped away at my confidence. Immediately I knew I had to make up for my dismal start. I had to “save” my child from a lifetime of suffering at the hands of her inadequate mother! (Rogers-Shaw, 2019, pp. 219–220).

When I wrote about my daughter’s birth, I used Kaomea’s (2005) concept of “always already failing” because I felt that disability put me in the position of failing. My body had failed to work normally and no matter what I did, no matter what I tried to do, that failure was always already there. Goodley (2011) noted that a “key site of the oppression of disabled people pertains to those moments when they are judged to fail to match up to the ideal individual; when they are categorized as embodying the failing individual” (p. 78). Thomas (1997) questioned how disablism is manifested throughout the journey to motherhood. One way I experienced disablism is by becoming part of the medical risk discourse that restricted my choices. For example, I was told by medical authorities how many children I should have and when. Another way I internalized the effects of disablism was by feeling vulnerable and insecure due to others’ prejudicial attitudes about breastfeeding or maternal bonding. In both cases, the “unspoken evaluative assumptions” (Thomas, 1997, p. 640) of disablism were disempowering. I did not believe I could make the right decisions on my own, and I sensed that the decisions I did make reflected failure.

There was another time I clearly remember lying on the bathroom floor trying to get control over my body, vacillating about calling for an ambulance. It was a weekend afternoon, and I was home with my younger daughter. I had not been feeling well all day and had stayed in bed. At some point, I started vomiting and had diarrhea. I called out for my daughter and asked her to bring me some soda to sip. The problem at that point was that my glucose levels had been high but were dropping quickly. Anything I tried to eat, I vomited up, including pills for the nausea and diarrhea. I tried to sip on sugared soda to keep my blood sugar up. Again, as I lay on the cold tile of the bathroom floor, I debated whether I needed her to call 911 or whether I could avoid upsetting her with that task and could last a little longer until maybe things turned around. Ultimately, I realized I wasn't in control of my body, and I needed medical attention. The guilt I felt when I asked her to call for an ambulance was enormous. All I could think of when the EMS carried me out of the house on a stretcher was what would happen to my daughter, how she would manage, but I was also too sick to do anything about it. It was a devastating experience to have to rely on her rather than to take care of her.

There are health issues that I don't discuss with my daughters because I do not want to burden them with worry and anxiety. I feel terribly guilty for not sharing challenges like a near-death experience. I know they will be upset and angry when they find out I didn't tell them, but it is too difficult to add to my own burden by knowing I'm increasing theirs. It's also selfish. A "good mother" is supposed to ease the anxiety of her children, but when I'm stressed about my own health, it's too difficult to try to ease their worry. It's easier to deal with it myself and not let them know.

My stories of motherhood and disability reveal the clashes between socially acceptable descriptors of motherhood and the reality of mothering with a disability. Parents with diabetes often describe two significant challenges: first, "the uncontrollable moodiness and irritability that occur when the parent's blood sugar level is low affect other family members," and second, "the diabetic parent's constant additional responsibility for self-care frequently conflicts with the needs of other family members" (Anderson & Kornblum, 1984, pp. 22–23). Children are burdened with adapting to a diabetic parent's mood swings and health care issues. This can lead to "role-reversal, with the children taking responsibility for the parent's well-being" (Anderson & Kornblum, 1984, p. 23), as shown when my daughter had to call an ambulance for me. I was supposed to be the adult, the person in charge. Surrendering that position and becoming dependent on a child is a hard reality of disability.

Additionally, children of diabetic parents can experience fear, including "fear of abandonment triggered by acute symptoms or hospitalizations, fear of parental disability or death, fear that this disease will happen to them" (Anderson & Kornblum, 1984, p. 24). These complexities of the diabetic parent-child relationship have made me more conscious of "try[ing] to live up to society's expectations of 'good' mothers" (Kingston, 2007, p. 176), despite having a very different journey than mothers without disabilities. Having a disability can make it difficult "to speak of [one's] own needs and aspirations, without imposing any moral judgments" (Kingston, 2007, p. 177). When one is unable to live up to the socially constructed ideal of a "good" mother, she becomes the other mother, the "bad" mother. I am desperate not to be a bad mother. When I remember this incident, I feel guilty. I wish I had been able to control my glucose levels and did not have to rely on my daughter. I do not want to be a burden to my daughters and increase their anxiety.

Always needling at the edges of my consciousness are questions about the effects of courtesy stigma on my family. Courtesy stigma is a type of stigma that is applied to those who are closely associated with a person who has a stigmatizing trait. Although family members may not have the chronic illness, because they are connected with someone who does, they experience the same disapproval from society that the chronically ill family member receives. I remember feeling the stigma of moral judgments regarding my disability when my daughter came home from school one day extremely upset that a classmate had given an oral presentation on diabetes and stated that it was the result of one's being overweight, clearly implying that the disease was a personal failing that should be avoided. My daughter felt the shame of that implication.

With type 2 diabetes, the pancreas produces insulin, but it does not produce enough to manage the sugar in the blood. Obesity can contribute to the insulin resistance that is seen in type 2 diabetes, leading people to assume that diabetes is caused by overeating and a lack of physical activity. That simple assumption is inaccurate as genetics, metabolism, and other physiological factors all play a part in the onset of diabetes. With type 1 diabetes, the pancreas does not produce insulin at all due to genetics or the effects of viruses. I have type 1 diabetes, but the increasing incidence of type 2 diabetes has led to social stigma that applies broadly, especially when individuals do not understand the facts about the disease. Social stigma results from an individual being viewed as failing to meet societal norms and suffering from moral judgments and discrimination based on that difference. As my daughter's tears fell, I tried to explain to her the nature of my illness and the strategies I used to manage my health, but she only felt the sting of her classmate's insinuation that her mother was somehow at fault and morally inferior for having become a diabetic. Even today as an adult she said,

I get annoyed and defensive if anyone implies that people with diabetes have it because it's a choice. I've always thought that anyone who says that has never lived with or known someone with type 1 diabetes. It also makes me mad because it's always said with this implication that it's because the person doesn't take care of their health—they don't eat healthy or work out enough. You have always paid more attention to what you eat and how you work out than anyone else I know.

Courtesy stigma, also called stigma by association, is "complex and often subtle" (Green, 2003, p. 1362). Research shows that courtesy stigma can negatively affect family members as they become subjected to prejudice and discrimination, experiencing increased emotional distress (Bos et al., 2013; Goffman, 1963; Green, 2003; Green et al., 2005; Larson & Lane, 2006). Elements of courtesy stigma include "blame, shame, and contamination" (Larson & Lane, 2006, p. 248) as family members may be blamed for the disabled state of the individual, may be embarrassed by the person's disability, or may be viewed as less worthy because of their association with the disabled person. Courtesy stigma is similar to an infectious disease where the stigma spreads from the person with a disability to those associated with them. It can be spread both consciously and reflectively (Pryor et al., 2012). In her work on mothering a child with cerebral palsy, Green (2003) asked, "Does the belief that people with disabilities are stigmatized by others in the community contribute to emotional distress [of family members] in the form of subjective burden (embarrassment, guilt, shame, resentment, worry and other emotional upset)?" (p. 1362). When I answer "yes" to this question, my own disability burden becomes heavier. I do not want my daughters to feel embarrassed or ashamed or worried because I have diabetes; I do not want them to be devalued simply because they are connected to me (Bos et al., 2013). I do not want them to experience the stigma my daughter faced during her classmate's presentation. It's a mother's job to protect her children, and courtesy stigma is another area where I feel I am falling down on the job.

Tom related a similar reaction that people have to diabetes when their knowledge doesn't extend to the differences between type 1 and type 2 diabetes. He said,

I've been able to have conversations with people about diabetes and it's, you know, based on your experience, based on your being a diabetic. Food—I mean, most people still seem to think diabetes is one of these things that's related to diet, right, and weight, right. And, you know, lack of exercise and smoking—just a bad lifestyle. Almost everybody who knows somebody who's a diabetic, it's type 2, right? There are only a few cases that I've really had conversations with people who are type 1 diabetics, and obviously they understand it completely differently.

Even if an individual has type 2 diabetes that can sometimes be treated with diet and exercise, having diabetes shouldn't be perceived as some kind of moral failing. It's a difference in the way the body works.

My feeling of a loss of control over my own body reflects society's view of my lacking self-control. It's compounded by fat-shaming as well. I gain weight when my insulin requirements increase, often due to stress. It's extremely difficult to lose weight or maintain a lower weight at that point. Feeling that I look “less healthy” because I've gained weight adds to my stress and anxiety, increasing the need for insulin, and then increasing the possibility of weight gain, a vicious cycle that damages one's self-esteem. Even if those around me understand, it's hard not to see myself as a diabetic first, as disabled, as in need of care. Tom explained his view:

I don't feel like I have to make you take care of yourself. I mean, you probably think I do because of all the crap I do about exercise and food. But you know what, it's not driven by your diabetes. It's just somehow a long time ago I got convinced that those things make a difference. You have to believe me; it's not driven by the fact that you're a diabetic. I don't look at you as, “Oh, there's Carol the diabetic.” I don't even think about it. I mean, maybe that is really bad because I know you have to think about it all the time, but maybe that's also an indication of how well you manage it. I don't think about you that way.

While I don't want to admit it, it's hard to believe him sometimes and not view him as a diabetes martinet. Every time he suggests a salad or a bike ride when I'd rather eat chocolate cake and lay on the couch watching television, it's hard not to connect it to my diabetes. I've internalized the stigma, and while rationally I know it's not necessarily connected, emotionally I can't separate it.

Taking insulin to control blood glucose levels can result in weight gain (Kaufman, 2006; Khan, 2004; Russell-Jones & Khan, 2007; Willing et al., 1990), and weight gain can lead to increased stigmatization. Disease stigma highlights society's views that a person with a chronic illness is lacking acceptable moral stature. Societal attitudes link health status and morality as “people implicitly evaluate the condition of the body using moral discourse, and ... the use of such rhetoric reflects the cognitive appraisal of [ill health] as immoral” (Hoverd & Sibley, 2007, p. 391). Someone who is overweight is viewed as being lazy, irresponsible, and undisciplined (Hoverd & Sibley, 2007). The perceptions of a person being unhealthy and lacking morals lead to stigmatization (Roberts & Weeks, 2017). Roberts and Weeks (2017) argued that “we often devalue people deemed unhealthy, frequently blaming them for their poor health” (p. 484). As my weight has fluctuated and my physical presence has changed from appearing healthy to looking less healthy, “the terms ‘healthy’ and unhealthy’ have become markers of [my] moral worth, [as] people who do not look after their health [are] considered irresponsible and lacking self-control” (Petersen, 1997, as cited in Reeve, 2002, p. 5000). Similar to Smailes (2014), I may be privileged due to my status as white, well-educated, and wealthy, but as a woman who is 60, disabled, and at times fat, I also experience marginalization. For me, the link between weight and diabetes complicates my disability status and increases the stigma I have internalized.

I also feel terrible because I know I add to Tom's worry. It's difficult to hear him talk about the dangers I could face without enough food or insulin. It's difficult to hear him describe what it's like for him:

I think you sometimes push the envelope. And what would happen, right, if you did get really sick and you didn't have enough food and we're in the middle of the damn woods on a hike? What am I going to do? Run back? Okay, I could do that. But what are you going to do sitting there in the middle of the woods? It doesn't happen that often, but there are some times when I feel like you could be a little bit more conscious of how far you are pushing the envelope. When we go on a long bike ride or something like that, I don't really get as concerned about that because I feel like on a bike, I can find something. We're not going so far away from civilization. But I do feel like there are those times when we've gone hiking, I don't think that if some problem occurred, there would be enough food and you would have enough insulin. I wonder at times when you're driving, do you have enough in the car in case the car broke down. I never know.

There's not only the burden of dealing with a disability, but there's the pressure of not burdening those you love.

For my younger daughter, there was the natural curiosity of a child, wondering what it's really like. She said,

It always just seemed normal to me. You had to prick your finger, and I thought it would hurt to do that all the time. I always had to go upstairs to get your blood testing stuff when you were downstairs because [her older sister] made me so she didn't have to. I thought that pricking your finger all the time must hurt, but I wanted to try it to see what it was like.

Now she has chronic Lyme disease and understands my diabetes on a different level:

Diabetes can be like chronic Lyme disease because when you don't feel well, you can't do everything like normal, but medicine can help. When I feel sick, I can't do anything until I feel better, and I have to manage my sleep and eating and exercise. If I don't manage it well, I get really sick. I guess it's now more of just a disability than a disease, too, because I have to miss things or can't eat certain things, so I don't get sick, and it's like a disease when I do get sick. Maybe you understand me because when you start to feel sick, you can't really do anything either until you start to feel better from resting. Sometimes what makes you feel better also helps make me feel better.

I wish more than anything that my daughter did not have to have the same types of experiences I have had.

Many parents with diabetes recognize that "diabetes is a genetic 'disease' whose inheritance patterns are poorly understood" (Anderson & Kornblum, 1984, p. 18). While diabetes tends to run in families, there is not a clearly defined hereditary link. Maybe that's why I've never been overly concerned that my daughters were likely to inherit the disease. There are too many other factors to consider. During my pregnancy, I was much more concerned about the immediate health complications for myself and my baby than I was about possible future developments. Yet here I am with a daughter with a chronic illness that might have similarities to my own disability. That's devastating. Knowing what I know, acknowledging what I have experienced, I don't want her to experience the challenges of a lifelong disability. I see in her a strength and determination that gets her through, but my heart breaks when she's exhausted and suffering from symptom flare-ups. I want to yell at God and say, Isn't my suffering enough for one family? I'd gladly take on additional burdens if it set her free, but that's not possible. I just have to hope I show I understand.

My older daughter said she doesn't remember a specific incident where she recognized me as a diabetic or learned about my disability:

I just feel like as long as I can remember it's been a part of your life. I'm sure there was some time when I was younger that I asked and you told me, but I can't remember when that was. I remember always seeing you check your blood and give yourself insulin shots, and I remember being told when I was a kid that one of the reasons we always had diet soda in the house was because of your diabetes but that I wasn't allowed to drink it unless it was a special occasion. I've always known that you have different snacks with you in case of emergencies, but I never thought much of this.

Yet my daughters do get worried. When she was younger, my older daughter worried that she would become a diabetic and my husband had to reassure her. At other times, he has had to explain that if I'm not in a good mood, it's not that I'm mad at them. It's like, "Hey, maybe Mommy's not feeling well right now." He sometimes attributes that to the fact that my blood sugar may be off or something related to diabetes is causing my reactions. When I've been in the hospital, they worry and can be really scared. My husband has to try to calm them down. It saddens me to know I've upset them. The anxiety of trying to handle it all alone in order to avoid burdening others, along with the stress of dealing with the disability itself, can get to be too much sometimes.

When I asked my family about the effects of my diabetes on their childhood, my older daughter said,

I've always thought of it as a chronic disease, but once you started the Ph.D. program and started talking about it as a disability, I've considered how for you it must feel like a disability. Growing up, it was always a chronic disease that you had to take medicine for and manage, but I never felt like it limited you as my mom in any way, so I never thought about it as a disability. I understand now that this is a very narrow definition of disability, but growing up, I never thought that my mom was disabled. I'm not sure that I see you "as a diabetic." I've always known that it's part of your life, but I see you as my mom, as a teacher, as a student, as a friend. I've never thought of you as "a diabetic." For me it's always been that my mom "has diabetes," but I've never assigned the identity of "diabetic" to you. I've always grown up in a house with people who have never hesitated to go to the doctor when someone is sick. I grew up knowing that if something is wrong, it's important to talk to your doctor. As a result, I talk to my doctors a lot more, and I think that keeps me healthier. As an adult, I've realized [those conversations] are pretty rare and that can result in other people developing very serious health issues because they don't go to the doctor regularly. Similarly, I know that sick days are meant to be saved in case of an emergency; I don't waste them. I've seen what happens [to co-workers] when you don't grow up with that mindset and how hard that can be in an emergency. I'm more mindful of trying to eat healthier and work out. I've never seen your diabetes as something that holds you back or that makes you any less of an amazing mom. If anything, I think it makes you stronger.

Besides feeling the burden of worrying my children, I regret that I've increased the burden on my husband who has to explain my disability to my daughters. I'm glad that they are comfortable discussing my disability with him, but I wish they didn't have to. These feelings contribute to the chronic sorrow of disability. There is always a dull ache of grief in the backdrop of my life. It's not exceedingly crushing at any particular moment, but its constant presence is exhausting and colors the way I look at life. It dims the happiness a bit.

I'd really like to write my own supercrip story, portraying myself as the heroine in the story, a romantic Prometheus striving for knowledge and understanding, but what I really feel like is Sisyphus, pushing that boulder up the hill. No matter what my family says, what's clear to me is that there's a different soundtrack playing in the background for their memories and mine. Tom described our marriage:

If you said to me, how big a deal has [your diabetes] been? I don't think it's been huge. Meaning I don't feel like, damn, what a burden this is. I just don't feel that way. I never have. It's obviously been a hell of a lot more of a burden for you than it is for me, but on balance you know, it's minor at the end of the day. Maybe minor is the wrong word, but it doesn't matter. It's been 38 years [that we have been married] and it's been pretty damn good.

Yes, it has been "pretty damn good," but to me it still isn't minor, and it still does matter. I can't get away from my disability. I've learned to live my adult life as disabled. I've chosen my partner well, but as the clock ticks, I'm walking alongside not only the people in my life but also my disability. My mortality is deeply tied to that disability and colors how I've spent my time being a partner, raising my family, doing my job, trying to do something good.

Betz and Thorngren (2006) described narrative therapy as a way "to be heard and validated and also to explore alternate meanings around the experience of ambiguous loss" (p. 363). I may not be creating a supercrip story, but maybe I am recognizing that I am "the author of my life [where] [w]ithin each life is a multitude of stories that could be told about our experiences. Some stories are more meaningful and useful than others" (p. 363). I'm still looking for the meaning of my story.

Green (2002) argued that narrative provided a way to cope with trauma and grief. She asked herself if writing about her own daughter who has a disability helped her cope as a mother, responding, Perhaps. Certainly, the fact that these verses popped into my head without conscious effort and ran through my mind with such annoying persistence that I was forced to write them down is evidence that some unconscious part of myself needed to express these emotions in written form. Equally important for me, however, is the fact that it is the experience of mothering Amanda that encouraged, even compelled, me to write. (p. 30)

Does writing my story help me cope with my own nonfinite loss, my ever-present grief brought on by my diagnosis? I don't know. Does it reflect part of the mourning process? Maybe, but that seems too simple. I think the reasons that I'm writing my story are more complex.

Frank (1995) described three types of illness stories: the restitution narrative, the chaos narrative, and the quest narrative. In the restitution narrative, there is a diagnosis, a treatment, and a move toward returned good health, not a story I can tell. Then there's the chaos narrative in which the patient doesn't get better. Well, that one fits me. While "most people would likely prefer to avoid stories of chaos, they must be uncovered in order to enhance understanding of the meaning of illness" (Thomas-MacLean, 2004, p. 1649). Is this what I am trying to do—enhance understanding by describing the painful chaos of my disability? Maybe. And lastly, there is the quest narrative in which there is a sense that something good can come from the experience of illness. My first reaction to that is "Hell no," but maybe I need to see where it's all going. Although it seems to me the chaos narrative is most applicable, "chaos narratives are the most difficult to hear because of their rawness and poignancy. These may be the most important stories to hear as they encapsulate the myriad of feelings and beliefs associated with ambiguous loss" (Weingarten, 2001, as cited in Betz & Thorngren, 2006, p. 364). I'm not sure how important my story is, but it's certainly difficult to write. I really do feel like Sisyphus, not only as a person with a disability, but also as a person writing about a disability.

CHAPTER 3

Disability at Work and Among Friends

When those who have power to name and to socially construct reality choose not to see you or hear you ... there is a moment of psychic disequilibrium, as if you looked into a mirror and saw nothing. ... Yet you know you exist and others like you, that this is a game with mirrors. It takes some strength of soul—and not just individual strength, but collective understanding—to resist this void, this nonbeing, into which you are thrust, and to stand up, demanding to be seen and heard.

—Adrienne Rich, “Invisibility in Academe”

You ask me how I’m going to live / the rest of my life ...
But I’m already living the rest of my life / not under conditions of my choosing.

—Adrienne Rich, “Contradictions: Tracking Poems”

Looking in the mirror is never easy. There's the chance of seeing the skin blemish, the tired eyes, the clothes that don't fit quite right. As I begin this chapter, it is clear to me writing provides another type of mirror where one wonders if the writing is honest enough, truthful enough, accurate enough, meaningful enough. Do I dare look closely? Will I see all the imperfections? Will I be satisfied with the portrait that's reflected in my words? It definitely takes "some strength of soul," and my experiences as a woman with a disability in the workplace and among my friends show the need for "collective understanding" in order to "stand up" (Rich, 1986/1994, p. 199).

My closest friends come from my years of teaching when we came together as resisters of bureaucracy and discrimination, colleagues finding inspiration from each other, companions on life's journey of laughter and love, sisters from other mothers, and mothers ourselves who needed comfort and support through tough times and celebratory toasts by the fire to acknowledge triumphs. The question is how I became the teacher I was, the friend I am.

I remember thinking as a young mother teaching full-time that I was glad I had a career even though there were moments when I envied stay-at-home moms. I knew if something happened to my husband, I could take care of my children; we could still live a good life. We weren't dependent on him, and that made me proud. How did I develop a sense of independence and the confidence to do what I've done? And why didn't becoming disabled erase those feelings that I could do it, whatever the "it" was? I'd have to say it was because of the family I come from, the role models I've always had.

Rich's mirror reminds me of one of the first graduate classes I took on my way to writing this dissertation: "Social Theory and Lifelong Learning." I did a presentation on the ideas of George Herbert Mead. As I write my story, I wonder if I'm recording that double dialogue. I record my "dialogue with the social world, externally" as I share my story with readers and explain how others have reacted to a person with a disability, as I determine my place in society as a person with a disability. I record the dialogue "between the 'I' and the 'Me'" (Mead, 1929/2013, p. 162) as I try to figure out who I was, who I am, and who I am becoming in this narrative. Mead argued that an individual should look at oneself objectively and impersonally because the social group defines the individual. We think as preparation for conversation with others. Then after interacting, we think again, and we react to the social environment. These thoughts and actions contribute to who we are. Mead (1929/2013) said, "There can be different selves, and it is dependent upon the set of social reactions that is involved as to which self we are going to be" (p. 164). Depending on those with whom we interact, different sides of ourselves will appear; social situations control what part of the individual is visible. In this way, there are times I am foremost a person with a disability, or a wife and mother, or a friend and co-worker, or a teacher.

While Mead may have seen the self as social rather than biological, as a result of social interaction, for a person with a disability, the body can drive that social interaction and reactions from others. So while the self might not be innately biological in Mead's view, the condition of the body influences interaction. For me, what I perceive to be others' perceptions of me as a person with a disability colors how I look at myself. If our selves are mirrored in the reactions of others, my mirror is cracked and my view is distorted by my disability. For example, if others see diabetics as overweight slouches who make unhealthy decisions, how can any weight gain I experience not make me feel less worthy? I guess my favorite quotation by Mead (1934/2015) is, "A multiple personality is in a certain sense normal" (p. 142). There's something rather fitting for a discussion of disability to take what's described as a disorder—multiple personality—and call it normal, although that's not exactly the situation Mead was describing.

There's a photo on the wall in my dining room in sepia tones and a faded gilt frame. My great-grandmother, seated in the center, stares straight ahead at the camera, her smile frozen stiffly, almost as if in fear, as she holds a newborn baby in her lap. My mother, her brother, her cousins, sit or stand on the couch around their grandmother, framing her within the frame. The oldest child is maybe six. Judging by the age of my mother, the photo was most likely taken in 1930 or 1931.

Surely outside the frame would be their mothers and aunts—my great-aunts, Kitty, Julia, Sophie, Margaret, Pat, Grace—and my grandmother Ella. Five of the cousins in that generation would grow up to be teachers, one marrying another teacher, following in the footsteps of their Aunt Kitty and Uncle Joe, the first American teachers in my immigrant family. So, yes, I do come from a long line of educators. As a teacher myself, and as a mother who has two daughters in higher education, I've continued the tradition and passed it on.

There was clearly a family emphasis on education. My great-grandmother and great-grandfather were in the first wave of family emigration from Ireland, and their home became the initial stop for successive family members; my great-grandfather's grocery store was the first workplace for many. Education was the way up in their new world, and teaching was a valued profession for both women and men, although it's the women I remember as the strong ones. My great-uncle Joe and my uncle Bob were the charmers, with Irish wit and good looks, natural storytellers and entertainers. It was the women whose careers took them around the world, teaching at embassy schools or supporting their families when their husbands' careers faltered, or serving as modern working-mother role models before it became commonplace.

Also in this picture is a young child who might have had an undiagnosed disability. When my own daughter was diagnosed with learning disabilities, my mother and aunt recognized a similarity with their brother. They remembered my grandmother sitting with him each night at the kitchen table, practicing his spelling words. And they laughed thinking of how they had assumed that when he didn't remember what they said that he just hadn't listened, rather than recognizing he might have had a processing disorder. I also learned recently that my mother's first years teaching in the 1950s were in what she describes as a "special health class" of ten elementary school students, any five or six of whom might be absent on any given day, maybe the beginning of self-contained special-education classes. And what does that say about how I, an individual with a disability, came to teach children with disabilities? I think besides the emphasis my family placed on the value of education, there was a strong sense of helping others. My great-grandfather offered opportunity to newly arrived immigrants, and my mother taught special-needs children. The question I seek the answer to is how much of who I am today is self-determined and how much is driven by my disability.

Elements of self-authorship include understanding one's own identity, recognizing how one comes to this understanding, and acknowledging the relationships that contribute to this understanding (Baxter Magolda, 2001, as cited in Torres & LePeau, 2013). The traditions of my family are a part of who I am; they have contributed to my identity. Research studies have shown that self-authorship is a long process by which individuals move from relying on external authorities for decision-making, to using both external and internal resources to make meaning, to finally developing their own beliefs and values that become the core of their life views and decisions (Barber & King, 2014; Baxter Magolda et al., 2012; Hodge et al., 2009). For me, the journey of self-authorship included coming to an understanding of myself as disabled, following a career that expressed who I was, and developing close relationships with friends whose values mirrored mine. My process toward self-authorship involved learning to trust myself, becoming a confident decision-maker, responding effectively to life circumstances, having a clear sense of myself, and prioritizing my own belief system (Baxter Magolda, 1998; Hodge et al., 2009). It's how I became a good friend and an effective teacher.

As an individual with a disability and the mother of a child with a disability, I approached teaching students with disabilities in a way that was inextricably linked to who I am. I wrote about my daughter's school experience:

Early in high school, [my daughter] asked for teacher or classmate notes for lectures to compensate for her auditory processing issues. Her request was denied; she was told it was against the honor code as it would give her an unfair advantage. When she came home and told me the school's response, I seethed with anger. And I fought back. I set out to become a warrior parent. ... The response [she] received from school illustrates a lack of comprehension of learning disabilities. The teachers, operating on ableist assumptions that hold all students to the same standards, did not understand that providing her with accurate class notes would diminish the disadvantage she experienced, not provide her with an advantage. (Rogers-Shaw, 2019, p. 226)

I did not want to be like my daughter's teachers. I wanted to find ways to help my own students resist these ableist attitudes. Students with learning disabilities are often viewed as lazy, unmotivated, disruptive. I strove to counter those ideas and move past the diagnoses, the labels.

One particular course I taught was called a modified English class. It was designed to cover the same curriculum as general-education classes but with accommodations that would facilitate success for students with disabilities. It was the stop between a special-education resource room and a fully mainstreamed class. I taught the same books and assigned many of the same papers, but I proceeded at a slower pace, made sure to break down assignments into manageable pieces, scaffolded work, and built upon students' own prior knowledge. The students recognized that they were in a "different" class, and they longed to move on, to transfer to "regular" classes. It was important for me to assure them that they could handle the same literature and write the same essays even if we did things in a slightly different manner. It was important for them to feel like they could belong in the college-prep classes and that they could eventually find success there. I also fought on their behalf during discussions on their placement for the next year, urging administrators to transfer these students as soon as possible.

It was always important for me to help my students so that when they graduated from high school, they could leave behind the categorization of themselves inscribed by others through their K-12 disability labels; I wanted them to be able to author their own lives.

Working with students with disabilities reflected back to me who I was. During the process of self-authorship, a person shifts from viewing oneself based on others' perceptions, such as the image attached to disability labels, to acknowledging a more complicated sense of oneself (Barber & King, 2014; Baxter Magolda, 2008; Baxter Magolda, 2014; Hodge et al., 2009; Kegan, 1994; Torres & LePeau, 2013). The identities of mother, friend, teacher of learners with disabilities, fighter for the marginalized, and resistor of imposed constraints all contributed to the person I became. When I look at myself and think about who I am, it's complicated; instead of smooth, clear glass, my mirror is pixelated.

My daughter's experience was typical of students with disabilities who are "regarded as intellectually inferior, incompetent, lacking effort, or attempting to cheat or use unfair advantages when requesting accommodations. The phenomenon of being misunderstood ... lead[s] to devaluation and marginalization" (Denhart, 2008, p. 484). I wanted to help transform my students' perspectives on identity so they could find their own sense of purpose in life, understand how their interactions with others affect who they are (Baxter Magolda, 2007). In essence, adult life requires the capacity for self-authorship—the ability to collect, interpret and analyze information and reflect on one's own beliefs in order to form judgments (Baxter Magolda, 1998). As an adult, I had had to incorporate disability into my understanding of myself, and that wasn't easy. I think I related to students with disabilities because of my understanding and empathy for them as they, too, found themselves devalued in an ableist world. We could fight back together, resist the labels.

I have a few strong memories from my years teaching special-education students in this transition class where I came to realize that learning is neither simple nor clearly defined. I remember the day my students read fairytales to a group of second-graders with more enthusiasm and eloquence than they had ever expressed in class. Working in small groups, the high school students had written modern versions of fairytales, solicited illustrations from students at the elementary school, and then published a book. We called it *Turned Around Tales from the Top of the Hill*. It is unclear to me if my students really became better readers and writers based on the assignment. They might or might not have learned what I needed them to learn, the transfer of writing skills, but they did learn how to collaborate, get to know fellow students, and work with elementary school students. However, in education today, there is always the assessment, and this is where the differences of my students became apparent. The beautifully composed fairytales would not count on the state graduation test that required a five-paragraph persuasive essay. I loved the fairytale writing unit because my students enjoyed it and they learned, yet I wasn't the one who decided what kinds of learning mattered. I appreciated my students' pleasure and pride when they saw their stories published in a wonderfully illustrated book because I understood the devastation of failing the test; I had seen, over and over again, my dyslexic daughter's hours of studying not bear fruit on multiple-choice tests.

I remember learning in my modified class who does and does not have power in education. My students were mostly racial minorities, immigrants whose first language was not English, and socio-economically disadvantaged students. My classroom supported the claim of the disproportional presence of minorities in special education. It was clear that there were still inequities within my classroom as well as within the school structure. I had to fight for my students to be moved into general-education and predominantly white classes. I remember one particularly contentious meeting with the assistant principal. One of my students, a white female from a prominent family, was being moved from the modified class to an honors section, a move I believed was inappropriate given her current skill set, while another student, an African-American male who had earned higher grades and achieved more success in my class, was being recommended for placement in the same modified class the following year. He faced additional discrimination based on his race, and I had to argue much more persuasively for his placement based on his work in my class. I was able to insist on his move into the college-prep class, and he was successful. It was the fighter in me that pushed it through; I didn't give up despite the odds against him. My experiences with my own disability gave me an understanding of his situation and the determination I needed to successfully advocate for him.

Cheng (2000) considered the state of racial relations from the lens of mourning/melancholia and grief/grievance. She looked at grief in terms of racial grief, where there are two sides: the "white American identity and its authority" and "the racial other ... [where] racial identity is imaginatively reinforced through the introjection of a lost, never-possible perfection, an inarticulable loss that comes to inform the individual's sense of his or her own subjectivity" (p. xi). These ideas can also be applied to the melancholia of disability. In this melancholia, there are also two sides—the disabled and the non-disabled—with a disabled sense of loss and inability to meet a socially constructed standard of perfection. Disability, like racial grief, "tracks a dynamic of rejection and internalization" (Cheng, 2000, p. xi). Cheng's (2000) theoretical model of identity, while designed to address racial identity, can also be applied to disability. The individual effects of disability on my students' psyches were as important as the fight against social barriers like standardized testing. As a teacher, I understood the melancholia of disability from my own grief over becoming disabled, and just as I fought to resist the view that I was unhealthy, and therefore lacking moral value, I wanted to assist my students in fighting their own devaluation by an ableist school community. I wanted each of them to see a more positive subjectivity than their disability label gave them. I saw their grief at being in a "different" class, and I wanted to turn it into a grievance we could raise and overcome.

The theme of a lack of power and a lack of control permeates my memories whether in the context of being a teacher or a mother or a disabled woman. I've always been attracted to teaching students who struggle, but it's not just from wanting to help; there's also a strong streak of rebellion in the family, of fighting back against oppression. Robert Emmet is a prominent name passed on through the generations, belonging both to my uncle and his father. Robert Emmet was an Irish nationalist who sympathized with Ireland's Catholics and was hanged for treason against the English king. I've always been a fighter, and I think that's part of why I chose to teach the students on the lowest rung of our school ladder. Maybe having a disability has also made me more understanding. As a colleague said,

I think it gives you some empathy for other people. I look at somebody else with a serious disability and I say, Why am I complaining? Look at this person here and what they're dealing with. It helps you put your own life a little bit more in perspective and then to be more empathetic to people, I think. ... Well, I had a couple of students [with diabetes]. And I think knowing you and your situation made me particularly sensitive to those students in the classroom ... watching them a little bit.

As I write my story, I think it's important to expand my readers' comprehension of what it means to live with a disability label and how we can, through empathy, through career choices, through research, support those who live lives that are different from our own. My experiences of being a worker with a disability and working with students with disabilities as a high school teacher reveal how nuanced life with a disability can be. While I needed to fight for my students' placement in general-education classes and for official recognition that they were not less valuable, my own empathy and that of my colleague did not extend to others within our school community. I also faced my own battles as a worker with a disability.

Over time, there have been several models of disability, including the deficit model, the medical model, the social model, and the human rights model (Shakespeare & Watson, 2002), as well as the relational model (Thomas, 2004). Disability frameworks have changed from a focus on impairment, an individual's specific limitation, to a recognition of disability as a state caused by society and present in social interaction. Yet it is clear that "historically, disability has not been taken into consideration when discussing issues of unequal and discriminatory treatment. Disability has been conceptualized as an individual pathology" (Liasidou, 2013, p. 302). The focus is medical; it's on treating the problem with the individual rather than the problem with society. My classroom certainly purported to offer "inclusive education in which students with disabilities are included in the least restrictive environment best suited to their educational needs. However, what that least restrictive environment [was] and how that environment [was] used to meet the individual needs of students with disabilities [was] more ambiguous" (Erevelles, 2011, p. 2158). I may have been successful at meeting the academic needs of my students in some ways, but the discriminatory nature of their separation from general-education students was ableist.

Cheng (2000) asked, "How does an individual go from being a subject of grief to being a subject of grievance? What political gains or losses transpire in the process? ... This transformation from grief to grievance, from suffering injury to speaking out against injury, has always provoked profound questions about the meaning of hurt and its impact" (p. 3). For me, teaching learners with disabilities and speaking out against the discrimination and stigma they faced was a way to move from grief to grievance in my own life. In her work, Cheng referenced Phelan's (1993) rickety bridge. The movement from grief to grievance is similar to crossing the rickety bridge. Cheng (2000) wrote, "It is in the attempt to walk (and live) on the rickety bridge between the self and other—and not the attempt to arrive at one or the other—that we discover real hope" (p. 189). I often feel I am standing in the middle of a rickety bridge, longing for my Self not to be constructed as an Other, wanting to move past grief to grievance where I can assert more control in my resistance. Yet it's hard to find hope. I felt more optimism in arguing for the placement of my students in general-education classes than in asserting control in my own life and leaving my grief behind.

In a way, my move to the insulin pump was a declaration of disability as it meant that my disability was no longer invisible at any time. Today there is no more hiding that I have diabetes when the alarm starts sounding in public. I felt this loss of invisibility most sharply in the workplace. At home or among close friends, my disability has always been present in myriad, very visible ways, but at work, I had hoped it was not noticeable to colleagues and students. What's interesting is the view of a friend regarding my switch to a pump. Her thoughts were much more positive:

These innovations over time did seem to bring a bit more ease to your life and ... it made me feel more confident. It made me feel like this thing was higher tech, sort of making things a little bit more refined for you, you know, more specific, more definite. ... It didn't mean that it was foolproof. Things still went wrong, and you had to deal with it. ... I remember coming out in the morning one day [at your house] and you'd left your book out with all of these minute notations of exactly what you put in your mouth, at exactly what time it was. It just drove home to me the sort of relentlessness of it.

For me, the pump contributes to that sense of relentlessness. Even as I type these words, the alarm is sounding, notifying me that my glucose level is outside my target range. I must stop my work and make adjustments. These interruptions make it difficult for me to see the positive side my friend was able to see because the pump is something I can never get away from, something I can never forget. Disability looms large in my view of my own life.

My experience of living with an insulin pump is typical of many diabetics who make the switch from daily injections to continuous subcutaneous insulin infusion (CSII). On the one hand, I now have more flexibility in what I eat and it's easier to control my blood sugar levels. On the other hand, the insulin pump requires continuous monitoring, increases my fear of technology failures, and makes my diabetes publicly visible (Barnard & Skinner, 2007; Ritholz et al., 2007; Saarinen et al., 2014; Todres et al., 2010). I do believe that the health benefits outweigh the vigilance and visibility burdens, but the pump is one more way that I have both a lack of control and a need for hypersensitive attentiveness to control.

Pump therapy often results from an inability of injections to work well enough to maintain good health so it feels like another failure. I was up to four daily injections with two types of insulin in each injection. That's a lot of complexity. Using an insulin pump is generally thought to improve a diabetic's ability to maintain healthy glucose levels so the person appears to have more "control" and be less "controlled" by the disease, but I'm not sure I agree with this assessment. I may be better equipped to maintain even glucose levels, but with a pump, I lose control of disability disclosure because people can see the pump and hear the alerts. Sometimes it's the little things that become problematic—how to attach the pump to clothing or what the pump bulge looks like. Sometimes I can't feel comfortable or pretty in what I wear because of the pump dangling from my stomach. It's one more element of diabetes that focuses on the body—what it looks like and how it works—and another way to be marked as different. There are also the additional supplies needed to maintain a pump: insertors, reservoirs, set attachments, rechargers, and batteries in addition to the usual insulin and snacks. It's almost like I need an extra suitcase or tote bag everywhere I go. So, while I have more dietary flexibility, my diabetes is now more visible, and I am at the mercy of technology that can fail. With or without an insulin pump, diabetes is still all-consuming in daily life.

One interesting facet of insulin pump therapy is that it forces the diabetic to become more involved in self-care; one can't forget to manage one's diabetes when there is a pump that constantly alerts the user to the need for attention. It also heightens the attention to self-control. Since the fluctuations in one's glucose levels are more immediately visible with a pump, a lack of personal self-control, such as making a poor food choice, becomes more apparent and can add to self-recriminations, guilt, and fear (Todres et al., 2010). It's difficult to even write about pump therapy because of the complexity. It's easier to tell a good story or a bad story, but I know a nuanced story is the reality of disability. The explanation of insulin pump therapy is reflective of the broader narrative of disability.

Deciding what to disclose about one's disability is a significant aspect of being disabled in the workplace. A close friend remembers when I told her about my diabetes:

I remember when you told me [you have diabetes]. My memory is of one of the lunch periods [when] we were having our little lunches together. And it was very matter of fact for you. For me, it was the first time that I was close to somebody who was a juvenile diabetic. My father had adult onset, but you know, it's very different. So, I felt like I had an opportunity to talk. Well, I'm always curious. And so, I remember asking a whole bunch of questions about when you were young and how you were diagnosed, and you were eating ... I think [we talked about it] because we were eating together. You were measuring [food portions]. That was back in the old days when you were like, oh my God, counting everything. I remember we talked about it. I don't think [my understanding] all happened at that conversation, but over the years. Things came out like about pregnancy and talking about birth and what you went through because you were a diabetic. ... All those conversations that would have been shared conversations about these things that everybody goes through, that we would have talked about any way, [but] there was always that other element that was a part of your experience, that was a huge part of your life that was not a part of mine. ... It always seemed like something that was important to know, [in order] to know you.

Diabetes does affect social interactions, which in turn influence my view of myself. When dining out with friends, what I can and cannot eat is always on my mind. I will often eat less healthy meals rather than draw attention to my diabetes. It's easier now that more people have food issues. Not that long ago, I was out to dinner with three other women and as the waiter took our order, one had to ask about the presence of corn in the food as she was allergic, another had to avoid gluten, and the third was lactose-intolerant. My need to count carbs and avoid high-sugar content foods didn't seem so "abnormal" at that moment, yet that wasn't always the case. I used to have to do things like accept the piece of wedding cake but only eat the light cake part and leave the icing on the plate or take an extra-large dose of insulin to combat the higher level of sugar in the food. The social context of disability disclosure, interactions with others, personal goals, and the nature of the specific disability one has all affect disclosure decisions.

As I manage my diabetes with a pump that concentrates my attention on my self-control, I increase my understanding of my body and my diabetes. According to Merriam and Baumgartner (2020), "Embodied or somatic learning is learning through the body. ... Embodied learning is highly intuitive" (p. 90). This learning process has solidified for me the reality that diabetes treatment is not a one-size-fits-all process, just as a disclosure decision is not "a singular event, not a once-and-for-all action but, rather, an ongoing process of continuously, in a variety of settings and contexts, performing and negotiating disability awareness and perceptibility" (Kerschbaum et al., 2017, p. 1). My body is very different from others, and my individualized knowledge of the effects of insulin and food choices make it difficult to explain to others. It's a lifelong journey to comprehend "the uniqueness and complexity of [my] own diabetic pattern and how to make effective adjustments for the productive management of ... an ongoing cycle of active experimentation and feedback" (Todres et al., 2010, p. 1203). The cycle will never end. This acknowledgement makes the burden greater; it's pervasive and exhausting. It diminishes hope and sometimes makes the thought of giving up easy to understand, yet I keep on going.

Disclosure decisions can drive the process of identity development as self-disclosure "clearly falls into the realm of self-determination, where one can learn to know oneself, value oneself, plan to disclose, act, and then experience outcomes and learn from this seminal experience" (Price & Patton, 2003, p. 336). Disability disclosure reflects the modification of one's own subjectivity through repeated decisions of what, when, how, why, and to whom to disclose a disability. The variety of disclosure decisions reflect the relationality and intersectionality of subjectivities of individuals with disabilities just as context and relationships affect these pronouncements (Miller et al., 2017; Samuels, 2002).

Sometimes an individual with a disability can't control their disclosure experiences. If I'm experiencing hypoglycemia and I'm desperate to get sugared food or juice to raise my glucose level, it's obvious my body is disabled. There are other instances where I have more control over disclosure, such as social situations where there is a range of food options. The essential question is whether to pass as normal. Disclosure can lead to skepticism, especially in the workplace, and I never had the option of changing jobs. My diabetes was covered by my health insurance, but if I transferred jobs, my diabetes would be a pre-existing condition not covered by many plans. I also worked in a setting where my union benefits included lifelong health insurance coverage. Since I knew the costs of my diabetes and its complications later in life could be catastrophic, I realized I couldn't retire or change careers until I had put in the required years. These restrictions added further stress to my life.

Stress affects blood glucose levels in diabetics due to hormones released by stressors. Stress can make it more difficult to maintain stable and controlled glucose levels, particularly in type I diabetics in whom stress can cause increased or decreased levels of glucose. My body experiences higher blood glucose measurements when I feel mentally stressed, requiring additional insulin to keep tighter control. Physical body stress, resulting from physical exertion like exercise or the completion of household chores, tends to lower my glucose levels, requiring additional carbohydrates to even out blood glucose levels. Prolonged stress can also be exhausting and debilitating, as can efforts to maintain proper glucose levels. Workplace stress, particularly when supervisors are not supportive, can extend to evenings and weekends. I experienced difficult blood glucose control due to supervisors who were not empathetic and didn't understand the connection between stress and my physical disability.

Individuals with invisible disabilities often decide to disclose when they are anxious that their disabilities will negatively impact their life, when stress or health complications have decreased their ability to pass as normal, and when those around them are supportive. They often choose not to disclose when they fear stigmatization or the response they will receive, when they are concerned they will be treated differently, and when they worry about their loss of independence (Lightner et al., 2012; Kranke et al., 2013). For me, when my diabetes is under control, I can pass as normal. However, when I started using an insulin pump, it identified me as abnormal and I was forced to disclose my disability. Reeve (2002) described "coming out" as disabled as "replacing the dominant medical model public narrative about disability with a social model narrative, as well as overcoming internalised oppression" (p. 494). Because I was "outed" by my pump, however, the disclosure was emotionally painful rather than liberating. I still did not want to accept a disabled identity.

Diabetes distress (DD), or the "emotional burdens, stresses and worries associated with the constant behavioral demands of diabetes self-management," is among "the most important psychosocial concerns in people with diabetes" (Hansen et al., 2018, p. 140). It has been described as a feeling of powerlessness, frustration over illness management, fear of hypoglycemia, anxiety from negative social interactions, responsibility for burdens placed on family and friends, and tension from unresponsive medical professionals (Fisher et al., 2015). Because diabetes distress is context-specific, its connection to the workplace is significant as "reconciling diabetes and work life can be burdensome and ultimately lead to adverse outcomes for working people with diabetes" (Hansen et al., 2018, p. 140). Attempts to manage glucose levels, eat properly, regulate insulin dosage, and maintain physical activity can all suffer depending on the demands of the workplace. A significant contributor to diabetes distress in the workplace is uninformed and unresponsive employers. Ruston et al. (2013) argued that the "complexities of diabetes are not fully understood within many workplaces with employers and managers having little concept of the implications of the disease for their employee or of the effects of the work environment on the employee's ability to manage" (p. 393). This was my experience at work.

Supervisors have a significant power to increase or decrease stress among employees. I remember one supervisor I had who seemed to have a sixth sense for employee stress and always managed to appear and assist at just the right moment. I remember the relief I felt when I saw her in the window of the classroom door with an audio-visual cart on a day that the one I was using failed to work properly. I remember the times she said, “Don’t worry about that. I’ll cover for you,” and the days she stopped by before the first bell or after the last one to check on my health when I wasn’t feeling well or to talk about my family and share stories of her own. She understood that supporting the teachers of her department, whether they had a disability or not, was what led to good morale and camaraderie, productive work practices, and enhanced educational opportunities for students. Unfortunately, she was not typical of workplace supervisors.

At one point, I needed to undergo some medical tests that my doctor had scheduled in the city, and I needed to take the day off. I filled out the paperwork requesting time off and submitted it to the principal. Part of our contract included an allotment of personal days for health reasons. I didn’t think twice about my request until the principal called me into his office. He said I needed a doctor’s note or he wouldn’t approve my personal day. I asked why, and his only response was “I’m allowed by contract to ask for a doctor’s note.” This was not a typical response; my colleagues did not have to supply verification of their visits to the doctor. It was clear from his reaction that my principal felt I was “faking it,” using my disability to secure a day off under false pretenses. This was that same ableist attitude my students experienced when their teachers assumed they were lazy and unmotivated rather than recognizing the effects of their learning disabilities.

I also remember having to head to the nurse’s office at school whenever my blood glucose level rose too high or dropped too low so that the nurse could document in writing what was happening to my body. This gave me an official paper trail in my fight against my principal’s lack of understanding and empathy. A colleague said,

I remember your having to go down to the school nurse. I remember during that period of terrible stress [from the principal], where your numbers were all over the place. You were going down partly documenting it because of what they were doing to you. That schmuck’s behavior was a very frustrating thing to watch. ... [The nurse] would go to the principal afterwards and say something. Not that it made a difference with him.

These events felt like such an invasion of my privacy and forced me to disclose the effects of my disability. Again, I didn’t have control.

The significance of these stories is the effect others have on the health and well-being of an individual with a disability. Here we have not A Tale of Two Cities, but a tale of two supervisors. I could easily rewrite Charles Dickens’ (1859/2003) opening paragraph to explain working with a disability: “It could be the best place to work, it could be the worst place to work, she was a model of wisdom and empathy, he was an icon of misunderstanding and judgment, she believed, he doubted, I hoped, I despaired.” Research has shown that disabled employees experience “more overt and subtle discrimination and more procedural injustice than their non-disabled counter-parts ... and supervisory support [shows] promise in reducing the effects of disability status on workplace attitudes and perceptions” (Snyder et al., 2010, p. 5). While my principal could argue that he had legal justification for requiring a doctor’s note for a personal day, when and to whom he made that demand revealed subtle discrimination. Typical of workers with disabilities, I never requested special accommodations because of anticipated social consequences, and the culture of the work environment played into this. I certainly would have been more likely to request accommodations from my supervisor than from my principal. Workplace culture can create obstacles for workers with disabilities as my principal did, or the culture can support employees with disabilities as my supervisor did (Baldrige & Swift, 2013; Baldrige & Veiga, 2006; Schur et al., 2005, 2009; Snyder et al., 2010).

Stress can also result from the efforts required to maintain control of diabetes. Constant worry about what food I eat, how often I have to test my blood sugar, how I can avoid serious hypoglycemia, what physical activity I can and can't do, and what the long-term consequences of my disability will be all add tremendous stress to my daily life. I remember standing in my classroom, feeling my blood glucose level drop, and reaching for the juice box in my top desk drawer, hoping my students wouldn't think too much about my sipping it while the lesson continued.

And then, when the first juice box failed to prevent my glucose level from falling, I'd grab a second or even a third box, hoping the bell would ring and the class would end so that I would have a few minutes to get things under control. There were times when I would reach into the desk drawer and discover that I had finished my supply of juice boxes, raisins, and other snacks. I'd keep looking at the clock, hoping that I could make it until the bell rang and I could head to a friend's classroom and raid the stash of chocolate she kept in her desk. Today she doesn't know why she started that chocolate drawer and wonders if it was a subconscious reaction to my disability.

Body image is a significant issue with a physical disability. Like many American women, I usually feel fat, but my weight is tied to my insulin use. Fluctuating weight and body image can also contribute to stress and thus affect blood glucose control that then affects my weight. I need insulin to regulate the level of glucose in my blood, but insulin also helps the body store fat, even if I don't want any more stored fat. Insulin works to help the body absorb glucose, but if the body cells absorb too much, it will be converted to fat. Not only is there a lot of pressure to manage diabetes to maintain health, but there is also the added pressure of deciding what to eat and what not to eat and how much exercise is necessary. For me, stress increases the need for insulin as my glucose levels rise. My weight increases as more insulin leads to more absorbed glucose and more fat, and then I feel more stress about the weight gain. It's certainly a vicious cycle.

Workplace attire can exacerbate this stress. I needed acceptable work clothes, but with my fluctuating weight, that wasn't always easy. When my weight increased and I was no longer comfortable in my clothes because they didn't fit or look attractive, I was miserable and my self-esteem plummeted. Those times when I lost weight and felt much more attractive and had clothes that were much trendier and fun to wear didn't last. I couldn't hide in jeans and bulky sweatshirts when I went to work. Again, my diabetes made my life more difficult.

Disability has similarities to gender as an identity marker that is present in the structures of society, in cultural systems, in political policies, and in "the shared human experience of embodiment" (Garland-Thomson, 2002, p. 4). Individuals with disabilities are marked by others as different. The ability/disability difference is an identity marker just like male/female. Individuals with disabilities are often made invisible in society because their individual experiences are not considered part of the norm that is defined by those who are able-bodied (Morris, 1993). Individuals with disabilities "must simultaneously navigate two interrelated territories. One is body management, and the other is social management" (Garland-Thomson, 2014, para. 4). Disability affects how a person is perceived, how that person perceives herself, and how that person manages her body and her social interactions within her daily life. Just as the female gender is not a naturally produced inferior state, neither is disability a natural deficit. Disability is socially constructed in the same way as myths about women are culturally produced (Garland-Thomson, 2002). Disability is one subjectivity that shows "what it is to be human, our relationships with one another, and the experience of embodiment" (Garland-Thomson, 2002, p. 5). Just as feminist theory has argued that "no woman is ever only a woman" (Garland-Thomson, 2002, p. 17), the same is true for individuals with disabilities; they are never just disabled. As I write about who I am, there are both overt and subtle connections between these subjectivities, like the focus on the body that connects disability and gender. I wonder how different this story might be if I were a man. My story talks about my body, my role as a wife and mother, and my career as a teacher, all of which are affected not only by my disability but also by my gender.

Disability resides in the relationships and interactions of various people with different bodies in multiple contexts. It's clear my diabetes has affected my friendships. In a recent conversation with my close friend, we talked about significant experiences in our relationship that were driven by my diabetes. She said,

Well, one big one was when they took you out in an ambulance and [the assistant principal] came and got me. To go over to the hospital to be with you was really scary, I have to tell you. But then, of course, you're chatting away the whole time. You're chatting like nothing has happened. And by the time I got there, where they're sticking you [with needles]. And I nearly passed out from watching them stick you and stick and stick and stick. I do remember that. And then at some point Tom was there, too. I can't even remember at what point Tom got there and for the two of you, it was like this is nothing. And I don't know, it just seems like for me it was such a big deal. That was a very scary thing for me, but also, I felt really good that you wanted me there and that I was a part of that and that the three of us were there and that Tom knew that I was there for you and watching you just take it in stride. It was just like, it was another day in your life. ... Then I think of the time we were going for a walk and you really looked bad. That's the worst I'd ever seen. You were white, drawn, shaking. You looked like you were going to faint. And so we sat down on that bench, and we waited, and we waited. And then the question was, do you call an ambulance at that point? And we did. ... That was the most extreme that I remember; that was really scary for me because we were waiting a long time before you started to feel better ... I had to take the lead from you, but I have to say that was a frightening experience.

It bothers me that my disability has caused moments of fear for a close friend. Who wants to be the friend that scares the living daylight out of those around her? And it's hard for me to hear my friend say, "It was just like, it was another day in your life." That's not the life I want. On the one hand, I don't want my disability to look "like nothing has happened" as it seems to consume me. On the other hand, I long for normality so much that if I can fake it and diminish the disability's presence in the eyes of others, I'll keep doing that.

Friends are a significant part of the social network that supports individuals with disabilities. Research has shown that friendships are generally beneficial in chronic illness management, possibly because relationships with individuals who are not supportive tend to end. Friends provide important emotional support (Gallant et al., 2007), yet there are also challenges to maintaining friendships with a person with a disability. The fear of hypoglycemic episodes not only makes up part of the life of a person with diabetes, but it also affects those around the diabetic, requiring friends to share the burden of disability. The occasional necessity for friends to provide emergency management when a diabetic suffers from hypoglycemia adds stress and anxiety to their lives (Fisher et al., 2015; Frier, 2008; Nefs & Pouwer, 2018). It's difficult enough to shoulder that burden myself, but passing that burden on to others, despite the fact that it may momentarily alleviate it for me, in the long run adds to my own stress and anxiety.

When I read over the words my friend spoke, I am glad I have such caring friends who will stick around despite the difficulties. I also see the differences between my life and a "normal" one. I remember the two incidents described, and while they were frightening for my friend, I didn't feel the same fear in those moments because they were not unusual events for me. It is disconcerting to think that ambulance trips to the emergency room can become commonplace when you have a disability. It's another difference that I'd prefer not to have to experience.

It may be difficult to imagine, but there are times that I forget my disability momentarily, and it can have negative consequences. When my daughter moved to another state, I would make the eight-hour drive to stay with her for a week at a time. It's hard to believe, but on more than one occasion, I was halfway there and remembered that I had forgotten my insulin. One day I realized my mistake and I panicked. I pulled off the highway at the next exit and searched for a drug store on my GPS. It took me quite a while turning left and turning right down unfamiliar roads to find a CVS. And then it was nearly impossible to convince the pharmacist to find my old prescription in the system and, because it was an emergency, process a refill even though I wasn't yet due for one. Sometimes I'd get the insulin covered by my insurance, and other times I'd have to pay the exorbitant cost of the bottle myself because it couldn't be processed through my insurance. And then I'd feel even worse that my mistake was costing me so much money. I'd ask myself, How could you be so stupid as to forget something so important? I started putting signs by the front door before I left on a trip, reminding me to include all my medical supplies, and I started leaving a bottle of insulin at my daughter's house. She recently said, "In some ways, I guess I've had a bottle of insulin in my refrigerator since you started visiting. I don't really think about it being there, but I guess that's a sign of [your diabetes] in our family life." I still find myself amazed at how many times I can forget sensors or pump equipment.

There was even the time I went out for a walk and didn't realize my insulin pump wasn't attached. I had taken a shower, unhooked the pump, and left it on the bathroom windowsill. When I finished showering, I dressed and headed out for a walk, the pump beeping on that windowsill and me oblivious to the sounds. I was lucky that I had a cell phone and that my husband was at home. When I realized what I had done, I was able to call him to ask him to bring me the pump.

Just this weekend I went away with my husband, and as we unpacked our bags in the hotel room, I realized I'd forgotten to pack an extra bottle of insulin. I felt like crying. Trying to figure out if I had enough insulin in my pump and in one extra, almost-empty bottle in my purse, I felt the overwhelming desire to just give up. I often wonder at these lapses. Are they due to my having too much on my mind, like anyone who forgets something when they leave the house? Then I ask myself how I can forget something that is so vital to my staying alive. Is it because I want so much to be more normal and leave the house carefree? Is it because the burden of constantly managing my diabetes has become so exhausting that I fail to realize what I'm forgetting? Is it an unconscious desire to be "normal"? I understand how individuals with disabilities might want to die to stop the constant need to manage their disabilities. Yes, I could have gone home that weekend if I had had to or found a pharmacy that would give me another bottle. Yes, it wasn't really a life-threatening situation. But it was one more straw on the camel's back, and I wondered when it might just break.

What causes this forgetfulness? Is it just normal forgetfulness in the course of daily life, like misplacing your phone or losing your keys? Is it a product of a more complicated life due to a disability that requires constant management and fills one's days with so many specific tasks that some slip through the cracks? Is it a part of some avoidance, of trying to forget the disability that results from a longing to be normal? It's somewhat reassuring that this is not an uncommon problem. It is often due to a disruption in routine, social situations, interruptions in self-care practices, or the demands of a busy life. The most common result of forgetting is additional worrying about the consequences (Brod et al., 2014). No matter the cause it's not just disconcerting; it's also dangerous and adds one more fear to a life filled with anxiety.

Is there any good that comes from my disability? I don't know. It's hard for me to see what others might see. A friend shared,

I think it gave you a very high tolerance for pain, which makes you very strong. ... There've been in a lot of situations in your life which have been really difficult ... you're a bit stoical. ... You have a sense of humor about it. I don't know whether that came first or afterwards, but I think that ... it does make you strong. I think it just makes you empathetic. It makes you the fighter that you are. ... You've been able to take control over your own care and to be able to evaluate that, not to be intimidated in those situations. ... A lot of stuff has happened to you because of the diabetes, but in the context of your family, you've been able to put having a normal family first. I think maybe that's part of the thing that's helped you, the most important thing to you. You have this wonderful marriage. You have these two kids; that's the priority. It's a much greater priority. You have this thing and you're going to deal with it because you have this family and you're not going to let it do anything to them. I think you've had to balance that. There's always been a place of balancing not with Tom because Tom is all in on this, he has to be, but with the kids, you know how much they know, don't know, when to sort of let them know things because you don't want them to be frightened and you're such a strong person in their lives. You are so much a place of strength for them.

Recently I shared this chapter with this true friend. I was moved when she told me that seeing me in vulnerable situations allowed her to be more vulnerable with me. She said she was able to tell me things that she couldn't tell anyone else. Because of our shared vulnerability, she was able to talk about difficult issues with me and that was a gift she cherished. I hadn't realized this. I hadn't ever thought about the subtle ways that my disability had affected my friendships.

When I try to find the silver lining, it's not all that clear, but as I write this story, I'm reminded that I have friends I cherish and a career that's been fulfilling. I don't like to think I've made my friends worry more or given them the sense that they needed to take on additional responsibilities because of my disability. Workplace ableism has angered me and put unnecessary obstacles in my way. Yet my disability hasn't precluded me from developing deep and meaningful relationships; it's just made elements of daily life more challenging, more frustrating, and more complicated.

As I arrive at this place in my story, I'm wondering whether there is anything good to come from all this. Have I felt empowered? Have I satisfied my urge to explain, to be understood? Have I found a sense of immortality in the face of a disabling illness that will ultimately end my life? Have I released the frustration and anger I have felt as a person with a disability? Have I explained my learning process on this journey of disability? Have I used my writing to cope with the enormity and complexity of living every day with disability? (Abrams, 2001). I'm not sure of my answers yet. If it is true that "central to the ability to make sense out of [a disability] loss is the ability to maintain hope, to find some way to change, and to construct a meaningful narrative" (Abrams, 2001, p. 85), do I now have more hope? I don't think so, but I think something has happened through this process of re-storying my life.

Friendships are important because they can provide us with a glimpse into ourselves. We look at a friend and see reflected back the values, the experiences, the emotions we've shared and that have contributed to who we are. My friend sees strength, stoicism, humor, empathy, a fighting spirit, and an ability to prioritize what's important when she looks at my life. It's comforting to know that's what she sees even if I don't always see those same things. It makes me feel I really am more than my disability.

Maybe I'm more empathetic, maybe I'm better able to support my students with disabilities, maybe my daughters have learned from my example, maybe I'm a fighter who won't give up, maybe I'm strong, but maybe I'm not. I don't know exactly what I see when I look in the mirror. I don't know if I've been able to "resist this void, this nonbeing, into which [I have been] thrust" (Rich, 1986/1994, p. 199). I don't know if I've been able to "stand up, demanding to be seen and heard" (p. 199). I just know I'm going to continue to live the rest of my life despite those conditions I didn't choose.

There are arguments for the therapeutic nature of narrative, "the importance of (re)constructing our life narratives so that they are coherent, understandable, and have meaning as we are forced to contend with a never-imagined, unchosen, ongoing, and unrelenting loss of the expected, assumed, dreamed-of, or normative future" (Roos, 2013, p. 230), but I don't want this to be a self-indulgent exercise in "healing." I think it is more about learning, particularly when there is no end, no getting over the loss completely because it is always present. It's an acknowledgement that "the task of re-learning the self and the world is usually arduous and often overwhelming" (Roos, 2013, p. 230) and will last a lifetime. So why bother? What are the benefits? Roos (2013) argued,

Restoration of resilience can take place when one knows fully and intimately what has been lost, and when regulatory reactions such as crying and pain can have their day without censorship or repression. Other benefits may consist of bearing witness, holding memories, healing ... integrating new understandings of the self in relation to the loss, channeling energy resulting from the tension of non-closure into positive, life-affirming pursuits, developing greater compassion and empathic accuracy, and finding life more deeply appreciated in the context of suffering. (p. 230)

I think for me it's about affirming a promise to doggedly continue despite the challenges. It's not so much the bounce-back of resilience as the determined slog through adversity. I do have a clear understanding of what was lost, and I'm still angry about that loss and all its accompanying limitations. Yet I also feel a need to pay it forward. Maybe if I can find the words to tell my story and share what I have learned, my family, my friends, my readers will know what it's like, recognize connections in their own lives, and find the courage to face their own challenges. That's all still left to be seen, but I've tried my best.

CHAPTER 4

Dying from Disability

I wonder how it all got started, this business about seeing your life flash before your eyes while you drown, as if panic, or the act of submergence, could startle time into such compression, crushing decades in the vice of your desperate, final seconds.

After falling off a steamship or being swept away in a rush of floodwaters, wouldn't you hope for a more leisurely review, an invisible hand turning the pages of an album of photographs—you up on a pony or blowing out candles in a conic hat.

How about a short animated film, a slide presentation?
Your life expressed in an essay, or in one model photograph?
Wouldn't any form be better than this sudden flash?

Your whole existence going off in your face
in an eyebrow-singeing explosion of biography—
nothing like the three large volumes you envisioned.

Survivors would have us believe in a brilliance here, some bolt of truth forking across the water, an ultimate Light before all the lights go out, dawning on you with all its megalithic tonnage. But if something does flash before your eyes as you go under, it will probably be a fish,

a quick blur of curved silver darting away, having nothing to do with your life or your death. The tide will take you, or the lake will accept it all as you sink toward the weedy disarray of the bottom, leaving behind what you have already forgotten, the surface, now overrun with the high travel of clouds.

—Billy Collins, “The Art of Drowning”

It did feel a bit like drowning, my near-death experience, although there was no image of my life flashing before my eyes, more of a desire to roll over and go back to sleep, sink into oblivion. As the EMTs revived me on the bedroom floor, I felt disoriented, recognizing indistinct voices and bright lights, staring at the wood beams across the ceiling, feeling the cold, hard floor beneath me. I thought it was a bad dream, and if I just concentrated for a minute, I could expunge the nightmare and drift into a calmer slumber. As I started to become more aware, I recognized I was on my bedroom floor, people were shouting at me, my head hurt, and my body trembled violently. Eventually, I realized I was being loaded onto a stretcher and wheeled to an ambulance; this wasn't the first time that I had headed to a hospital in an ambulance, but this time I didn't know why. I had not been aware when, in the middle of the night, my glucose level dropped to a near-fatal level, my body shaking so convulsively that I fell out of bed, crashing to the floor and cutting my forehead on the bedside table. Fortunately, my husband awakened and called 911. Only later would I think about what could have happened had he not been there: I would have lain on the floor unconscious after the seizure and eventually died. My husband remembered:

I was asleep. There was sort of a really loud thud because you fell out of the bed. You were breathing pretty heavily at one point earlier, but I didn't think anything of it. Obviously once you fell out of the bed, I immediately woke up and thought, What the hell is going on here? You weren't responsive, and quickly I came to the conclusion that this was serious. I kept trying to wake you, and it wasn't working. I needed to do something. I wasn't thinking you were going to die. I wasn't thinking that. I was afraid that there was just something really wrong, and I didn't know what to do. I had to get to people as fast as I could who could help. I called 911. They told me to take the pump off, and I ripped it out. I just remember saying to you, "Stay with me," because at one point, I really did begin to get worried. I just couldn't figure out what was going on. I was trying to describe the situation, and they were just trying to tell me to make sure you were breathing. I wasn't sure how it all got there. I had no idea why you would be completely unresponsive like that. Looking back, I feel stupid that I didn't recognize it was low blood sugar.

It isn't easy writing about death, particularly one's own, but as I've composed this chapter, I've seemed to see the presence of death all around me. My mother had a stroke five months ago. Although she has regained the physical functions she lost temporarily, her dementia has grown worse. It's very painful to watch her lucidity and her life drift away. When I visit her or talk on the phone with her, she cries and says she wants me to take her home. I'm usually able to calm her, but it doesn't last too long. It's heart-wrenching. It's also frightening to think I could end my life as she is ending hers. Is it more frightening that my disability could end my life or that I could end up without the freedom to choose how to die? I'm not sure. Maybe that's why I found it so hard to get through this chapter. On one particularly bad day, I came home after visiting my mother and told my husband if I were facing the same situation, I would take an insulin overdose, turn my near-death experience into practice for my real death experience. Dealing with a chronic illness means constant health challenges, yet it surprised me as I wrote that I could think of a point when it would be too much. Of course, my husband pointed out that if it came to that, I wouldn't be aware enough to take that shot. Disability can hinder independence and so even a choice at the end of life is not freely one's own. Writing about my near-death experience is easier than writing about a future death that could be like my mother's because for me, at the point of my near-death experience, there was no awareness of death approaching. I went to sleep and almost didn't wake up. The fear came later.

My memory of coming to consciousness is still jumbled, more light and noise than human interaction. I had a sense of my husband being there, but the presence of the professionals taking charge and making decisions and controlling what was happening was stronger. As Tom said,

I remember going to make sure the doors were open, running to do that. I remember worrying that if I ran to do that, what was going to happen to you, but I felt like I had to go do that so that they could get in. And I remember the dog also trying to get into the bedroom. I remember putting on the lights so they could see their way through. Once they got there, I didn't feel like things were out of danger, but I felt like there was a little bit more of, okay, we kind of got this. They seemed to figure it out right away. I told them you were a diabetic, and they seemed to be pretty clear about what they needed to do. They gave you a shot of something. They recognized that you were probably having low blood sugar. Looking back, it happened really fast, but I don't remember feeling like it was really fast at that point in time. I just sort of knew something needed to be done.

And the professionals did that something.

I remember lying in the ambulance, my clothes soaked from sweat, my chilled body shaking uncontrollably beneath rough blankets, the EMT talking to me, as I watched the view out the back window. I didn't see my life flash before my eyes. There was no panic that could compress decades into a fleeting glimpse of the past because I had been asleep when the seizure occurred. In the ambulance, I saw the tall evergreen trees in the moonlight along the winding road. It seemed somehow serene, majestic, beautiful. There was an odd disconnection between what was happening to my body and what I was seeing through the small square of glass. I concentrated on those trees, grasping for something hopeful, trying to block out the icy cold and violent shaking of my body that I couldn't control.

A 2017 Kaiser Family Foundation report on attitudes toward death revealed that 92% of Americans recognize their need and their desire to talk about death, yet only 32% have had such a conversation. Ellen Goodman, the founder of The Conversation Project, an organization designed to help people talk about death, said that we "enter into a conspiracy of silence [about death]. Parents don't want to worry their children. Children are reluctant to bring up a subject so intimate and fraught" (Goodman, 2012). I may be talking about death with my husband, but I haven't had that conversation with my daughters, certainly because I don't want to worry them. It's easier to talk about the near-death experience with my husband because I survived; it was a momentary experience with a happy ending, not a slow decline leading to inevitable sadness. What we do talk about in terms of a future death is the preparations and preventive measures to avoid the worst effects. We avoid the most painful parts.

Goodman (2012) argued, "We often comfort ourselves with the notion that doctors are 'in charge' and will make the right decisions," yet for me, a diabetic who has struggled to make my own decisions when doctors do not know the nuances of my body and my diabetes, this seems so wrong. After spending a lifetime opposing the medical model of disability that puts the power in the hands of medical professionals, I find it counterintuitive now to let the doctors decide how I will die. Yet I also recognize there are times when I don't know enough, when my husband does not know enough. I would not have survived that August night if the EMTs and emergency room staff had not taken charge. By its very nature, disability brings about a loss of control over something. As an individual with a disability, I find that there is always this back-and-forth about control. For me, the lack of control, and the fear of losing even more control, has been one of the hardest elements of disability to accept. Personal control and family control are important. Telling the story of one's life can allow a person to assert control so maybe that's what I'm doing now. We may not be able to control the events of our lives, but we can control the meaning we attach to these events in the narratives we compose (Merriam & Baumgartner, 2020; Rossiter & Clark, 2007). We can learn through narratives. I can learn by writing my story and presenting the meaning I've discovered; others can learn from reading my tale.

The lights became bright again in the emergency room, the medical staff again in control, making decisions. Hypothermia occurs when body temperature falls below 95 °F; my temperature was 93 °F and the symptoms were clear: shivering, inability to speak clearly, drowsiness, confusion. The odd sound of my breathing that Tom had heard earlier could have been another sign before I lost consciousness, but we hadn't been aware of the symptoms. He knew my body felt cold, but he had no idea how dangerously low my temperature had dropped. My body was losing heat faster than it was generating it. I was put under a warming blanket to combat the hypothermia. I could hear the motor softly blowing heated air through the inflatable blanket and, very slowly, the shaking subsided. I remember thinking I looked like the Michelin tire man, surrounded by bulging rolls of white polyethylene fabric molded to my body, but it really didn't matter how I looked; it mattered that I wasn't going to die. Tom also felt that sense of relief:

When you left the house, you weren't right. Before the ambulance got there, that was the worst part. I would ask you something, and you weren't responsive. It wasn't like your eyes didn't open. It wasn't like you weren't breathing, but you had no ability to say, "I'm sick, I'm hurt." That was scary. ... When I got to the hospital, you were able to respond a little bit. So, it felt to me like things were okay. I remember standing for a long time, being concerned, [thinking], hey, was this going to impact you in any big way, was there any residual impact of your body temperature falling to 93 degrees. But as the day went on, the nurses in the emergency room seemed that they got this under control.

The significance of my husband's presence was obvious because had he not been there, I would certainly have died. Yet his presence had other significant benefits. Social support is needed if one is to successfully adapt to living with a chronic illness (Khawar et al., 2013), and in this instance, he helped me to better handle the effects—not only the effects of the extreme hypoglycemia but also those of death awareness. This was reiterated in the writing process as I interviewed Tom about what had happened. The interview highlighted his support not only in the moment but also as we went forward. It revealed his anxiety that mirrored mine, and that made the anxiety less burdensome for me because it was shared. Since discussing one's death is not an easy task, death anxiety is often invisible. My near-death experience, my formal research interview with my husband, and the writing process forced that death anxiety into the open. Significantly, it also provided knowledge that was calming and forward-facing. I found out from my husband what had happened when I was present but unaware; that made it a shared experience. It lessened the fear and offered a way to deal with the situation matter-of-factly, just as I have always handled disability. There was comfort in that familiarity.

When I read Goodman's (2015) article about how to talk about dying, I thought about the purpose of my writing. She said we "need to transform the cultural norm from not talking about how we want to live at the end of life to talking about it" (para. 14). She claimed that people need some guidance in order to have death conversations since "everyone seem[s] to have a piercing memory of a good death or a hard death. Some of these stories had been kept below the surface for decades, and yet [are] as deep and vivid as if they'd just happened" (Goodman, 2015, para. 8). My story is a piercing memory, yet until now it has largely been hidden. Is my need to write it down part of a desire to start the conversation? Has my experience forced reality to the surface so I feel the need to share? My daughters will read my dissertation. Will we have the conversation then? Will reading my work lead readers to have that conversation? Will my research make a difference? Maybe, but despite the outcome, the act of writing allows me to wrest control back from the medical professionals who made the life-saving decisions in that moment. I can control the story elements I include, the words I use to describe the event, and maybe avoid the disability paternalism I've rejected.

Once my temperature reached normal and my blood glucose level was controlled, I was moved to a hospital room and treatment became more standard, more of what I was used to from previous glucose problems. There was a doctor determining how much and what kind of insulin to inject, what to eat and when, how often to test blood glucose levels, and how to adjust the insulin accordingly—all things I do for myself every day. And there was friction as I tried to explain what would and wouldn't work, the doctor dismissing my points with "I know best" condescension. But he didn't know best, and my glucose levels fluctuated erratically. When you've lived with diabetes as long as I have, you know your own body and how it reacts; you have to understand it in order to survive. Standard procedures don't always match the nuances of my own body. As usual, it was the nurses who realized I knew what I was talking about, saw the doctor's miscalculations, and pushed for me to restart my pump and take back control.

Tom had ripped the pump from my body when he called 911. I assumed there was a problem with the pump, so I got on the phone to order a new pump. I couldn't leave the hospital until I had a working pump. Tom headed back home to pick it up after it was delivered, along with all the equipment needed to get it functioning. He called my primary-care doctor to describe what had happened and get advice. Finally, with my diabetes under control, I headed home from the hospital. My husband and I started wondering why this had happened, what had gone wrong, and how we could prevent it from reoccurring. We had gotten over the initial shock, but we still needed to process the event and the resulting complications to our lives. Tom decided that it wasn't the right time for business travel; it was fortunate that he had been home that night. When we recently talked about it, he said, "I'd been away for what, three or four weeks prior to that ... it was just luck that I happened to be there ... because chances are this was so bad that, uh, if there was nobody there, you know, ..." and he couldn't finish the sentence. We left it hanging there in an awkward silence. We didn't want to put into words that I could have easily died.

I still feel anger and frustration when I think about the doctor at the hospital. Individuals with disabilities often face paternalism (Coopman, 2003; Dworkin, 1972, 2019; Goodley, 2010; Hahn, 1983, 1986; Ho, 2008; Hubbard, 2004; Kittay, 2011; McKinstry, 1992; Newton et al., 2011; Sandman & Munthe, 2010). Doctors may view disability as a condition to be cured where they have the knowledge and means to apply the corrective treatment. Paternalism is "the interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interest or values of the person being coerced" (Dworkin, 1972, p. 65). Using medical advances like an insulin pump that offer me the ability to manage my disability gives me some measure of self-determination that "provocatively and intuitively attacks the ideology of paternalism" (Charlton, 1998, p. 128). Adult learning is personal, yet it occurs within the social context of adult life (Merriam et al., 2007). Learning to live with disability over my lifetime has been a very personal process, but it has also been influenced by our able-bodied society. As part of insulin pump therapy, I have had to acquire new technological understanding. The old knowledge that I had acquired in juggling several daily insulin injections of multiple types of insulin is no longer useful. I have received information from doctors and medical product consultants, but my learning has been mostly trial-by-error, informal learning. This has made it more difficult. I might be highly motivated and experience-focused like many adults, but the live-or-die consequences provide a different frame within which to view my learning.

The technology gives me more immediate control. This doesn't mean that I don't need professional care, but I do need to be heard and valued for my insight. Fortunately, some of those who might have treated diabetics paternalistically with benevolent intentions in the past now support more patient autonomy (Ho, 2008). Today they advocate for more "active participation from both patient and professional in the decision-making process, and agreement on the decision" (Sandman & Munthe, 2010, p. 652). Even writing about the frustrations of dealing with paternalism provokes my anger. But maybe anger is a way to avoid the really frightening part, the realization that I could easily have died. It's easier to believe I have the wisdom and skills to prevent another similar episode if I focus on what I can do myself.

We attributed the incident to a malfunctioning pump and tried to create a contingency plan for technology failures, all very logical and clinical, no overt emotion. We told ourselves that having been through this once, we now knew how to handle things, how to compensate and avoid dangerous outcomes. Tom said,

So, it was probably a pretty unusual circumstance, but ... we had to think about how to make this work going forward. How often is that going to happen because it did [happen] so that doesn't mean it couldn't again. I remember thinking a lot that I wished I would have been more conscious that the heavier breathing was a sign that there might've been an issue. Now I think I'm more in tune with signs for something like that. I hope ...

Since we couldn't figure out exactly why my blood sugar had dropped so low and caused the seizure, we were terrified that it would happen again.

I was afraid to go to sleep at night, fearing I would not wake up the next morning. I went over in my mind the day before the night it happened. Nothing stood out as unusual. My glucose level was slightly elevated when I went to bed and I awoke once to check my blood and take a corrective dose of insulin, but that was typical. Frequently, I awake during the night, check my glucose level, and either calculate an insulin dose to inject or eat a snack to even out the levels. That night had been no different. There didn't seem to be any answer as to why I had had such a severe hypoglycemic reaction. I test my glucose levels often enough to recognize low-glucose symptoms. The problem is what to do when I'm asleep.

Death anxiety is the dread that results from being aware of death, the depression that comes from understanding the process of dying (Abdel-Khalek, 2005; Awopetu et al., 2017; Lehto & Stein, 2009). According to Khawar et al. (2013), "In chronic diseases, the frequency and intensity of death-related thoughts increase" (p. 75). Death anxiety has been studied in individuals with both terminal (Brown et al., 2015; Hodges & Winstanley, 2012; Neel et al., 2015) and chronic (Gullickson, 1993; Ironside et al., 2003; Öhman et al., 2003; Rahrovi et al., 2018) diseases. So, the key question for me is how one prevents a near-death experience, and its resulting heightened awareness of death, from becoming even more disabling than the disability.

My husband and I had been aware of the possibility of diabetic complications leading to death, but they seemed to occupy some far-off place in the future. I thought I still had a lot of time left to live. As I wrote this chapter's first draft in December 2019, I kept noticing media reports of "those we lost." It was difficult to learn that people like Penny Marshall had died in their 70s from complications due to diabetes. All of a sudden that far-off distant death seemed to be smacking me in the face. I'm already 60, so my 70s is just around the corner. If "the relationship between age and death anxiety is complex and age plays a significant factor in the perception of death anxiety" (Khawar et al., 2013, p. 75), then how can I make sure I don't succumb to death anxiety? And of course, since "education is also related with death anxiety and highly educated individuals [have] higher death anxiety" (Khawar et al., 2013, p. 75), one wonders why in the world I'm writing a dissertation about a disability that can easily lead to early death. How much of the increased stress I felt writing this chapter was due to the stress of dissertation writing and how much was due to increased death anxiety?

The ability to talk about death decisions is "a strong correlate of death distress. ... On the other hand, the extent to which communication occurs may involve the patient's willingness or ability to engage in this dialogue ... [yet] patients' own fear, denial, and distress inhibit their own communication" (Chibnall et al., 2002, p. 336). I wonder how much easier it is to write about death than to talk about it. As I pound away on the keyboard, it's just me; there's no dialogue with others who might feel pain from my disclosures. I am free of the weight of burdening others, until they read my story. I wonder, Will we talk about it then or safely keep our emotions to ourselves, leave the words written on the page but not spoken aloud? Will others find it easier to talk about their own fears because they've read my story, or will they refrain from introspection and just say that's her story, not mine?

I started setting the alarm on my phone for every two to three hours during the night, depending on the glucose level, so I could check and make sure it wasn't dropping precipitously. So much for a good night's sleep. Every time I hear how important a good night's sleep is for staying healthy, I want to punch something. Yeah, I'd love to sleep through the night. Forget about eight hours, even six would be amazing, but that's not my reality. If I make it four hours before my pump alarm goes off signaling low or high blood sugar, or the phone alarm rings on those nights when I'm afraid I won't wake up, I feel like I've accomplished something. And then there's the guilt that I feel because I'm not the only one who is waking up; my husband hears the alarms, too. And when he's traveling, the fear is greater. What if I don't wake up, and he's not there to call 911? Often we spend the night texting or calling. When I wake up, either because the pump alarm goes off or my phone alarm rings, I text him "OK" so he knows I haven't died yet. If he doesn't hear from me, he can call or text to make sure I'm still alive. It's rather stressful; no wonder I don't get a good night's sleep. Tom said,

I never liked being away as much. I don't like it now because of that event. [In the beginning] we were able to use an alert that went to my phone and I was able to check stuff, right? But then we switched to the pump that could work automatically and they didn't have the alarm possibility. ... And so that's when we started the text stuff. I think it also changed your sleeping completely, right? Because now you purposely set an alarm and get up every few hours. Right? So, I mean, I think it's completely changed the way you sleep at this point. Part of the issue is at least if I get an alert, I can do something.

While the phone alerts were helpful, the problem was that Tom was calling constantly because the alarm could go off and I'd still be okay. Disability always seems to leave me facing a double-edged sword.

My diabetes is brittle and fluctuates a lot. The pump alerts are also set to go off before there is actually a significant problem so there is time to fix it. Even though I'm okay, it'll go off multiple times, and usually I just hit the pump, check my glucose level, take more insulin or eat, and go back to sleep. But with Tom receiving an alert, that meant there were constant phone calls as well. It's hard to manage our fears of my dying and an effective way for Tom to know what's going on when he's not around. And of course, there are times when I don't hear the alarm or feel the pump vibration alert. It's too nerve-racking to rely on the alert to increase in volume or automatically shut off the pump when I don't respond to the alert. The technology options are complicated.

Diabetes is a chronic illness that requires self-care in order for individuals to maintain good health and avoid long-term complications. Even in family and social settings, I must check glucose levels multiple times a day, manage insulin pump features, follow a particular diet, and exercise regularly. Researchers have documented the role of family members in providing social support that can help diabetics adhere to their self-care regimens and handle the stress of having a chronic illness (Harvey, 2015; Lyons et al., 1988; Miller & DiMatteo, 2013; Mousavi et al., 2017; Pereira et al., 2008; Rad et al., 2013). According to Miller and DiMatteo (2013), "Diabetes management can be quite complex, requiring lifelong commitment and drastic changes to the patient's lifestyle. ... Social support from family provides patients with practical help and can buffer the stresses" (p. 421). The problem is that while the support I receive from my husband is invaluable, it also increases my stress because of the guilt I feel for disrupting his daily life and creating fear. Not only do I have to awaken several times in the middle of the night to check my glucose levels, but I also worry about waking or texting my husband if my glucose levels are too low or too high. Yet if I don't do this, we will not be warned early enough to prevent a catastrophe. It's an additional layer of disability. Disability brings with it many decisions we don't want to make, many choices between two undesirable options. Family support can feel comforting and encouraging to the individual with a disability, yet it can also create dependence and anxiety in the individual for fear of becoming a burden. I don't want to do this alone, but I also don't want to diminish the quality of life for those I love.

A couple of weeks after my near-death experience, I received a recall notice for the infusion sets that attach my insulin pump to my body through a small cannula and a tube that runs into the insulin reservoir in the pump; they were defective. Large red letters printed across the page blared “URGENT MEDICAL DEVICE RECALL,” followed in much smaller letters with “Potential over-delivery of insulin.” Then there’s the opening line, “Dear Valued Customer: Because the safety of our customers is our top priority, we are voluntarily recalling specific lots of infusion sets used with Medtronic insulin pumps” (Dabbs, 2017), and I’m thinking they already have their public relations spin going. They almost lost this “valued customer”! Next comes the “Explanation of the Issue.” It reads, “Medtronic has become aware of recent reports of potential over-delivery of insulin shortly after an infusion set change. Over-delivery of insulin can cause hypoglycemia and in extreme cases, death” (Dabbs, 2017). It all sounds very technical, just a minor defect, nothing to worry about, just send them back and we will send you new ones. Why not a message that said, “Don’t use our defective product because it could freaking kill you!” I had five boxes of the infusion sets and finally, with this letter, an answer to the question “Why?”

There was some sense of relief knowing that I hadn’t done something wrong, that I hadn’t nearly caused my own death. There was some feeling of hope that maybe with the new sets, I could worry a little less about making it through the night, but truthfully, an experience like this changes you. There’s no going back. The fear is always there now, requiring alarms, middle-of-the-night texts, and the red tube holding a glucose injection in my bedside drawer.

Like family support, technology is a double-edged sword. Insulin pumps are used to maintain proper glucose levels and offer “increased convenience and flexibility, ... the potential for greater dose precision, more reliable insulin action, and relatively quick dosing adjustments for different lifestyle activities” (Zhang et al., 2010, p. 263). While insulin pump technology can improve the quality of life for diabetics, there is also the risk of health complications from too much insulin or not enough (Ross et al., 2015; Zhang et al., 2010). The pump may malfunction, my body’s reaction to the insulin may vary, I may make programming errors, the connection between the pump and my body may become undone or not work correctly, and environmental factors may damage the pump, increasing the possibility of hypoglycemia or hyperglycemia. According to Ross et al. (2015), “Pump malfunction and infusion set failures [have been] the most common adverse events reported” (p. 1018). The question is the level of risk that is acceptable. For the most part, the risk is worth it for me because my diabetes has been more controlled using the pump than it was when I had to take up to four injections a day. I have also been able to detect malfunctions before they become too dangerous. Yet the near-death experience makes it harder to see the risks as acceptable. Again, I feel forced into a choice between two not-so-good options. Just as it’s frustrating to be dependent on others, so too it is difficult to be dependent on technology.

The after effects of this experience spread to those around me, too. It was difficult to acknowledge the changes. It certainly increased our fear. Tom said he had never before thought about diabetes as a disability. As I read disability scholars' work, wrote papers for graduate school about adults with disabilities, completed research on disability topics, and attended conferences, we talked about disability versus disease. What was diabetes? What concerned him now, though, was the change in his perception, how our expectations had to shift. We thought it would be a slow process of dealing with complications, things we thought we could handle step-by-step. Now we had to be more conscious of immediate effects. He said,

Carol, you're my life. ... The fact that diabetes can kill you, without any warning, it's scary. I'm more conscious that something could happen that's very directly related to your blood sugar being high or low. That it's not just okay to eat something or take a shot. Something could happen that is way beyond what happens every day. I don't think I really thought about that. You talk about neuropathy, all the eye doctors you go to and stuff. So, we're aware of the fact that that diabetes can have an effect on things. But the idea that something could malfunction, and diabetes could turn things on a dime, in a way that you aren't able to control, that's different. Every time that something has been bad, other times when we've had to get you to a hospital, there was a time period where you didn't feel well, you were throwing up or your blood sugar was not good, but there was a window [where we could address it]. This happened instantaneously. It was like, Oh, shit. I don't think I realized that before. I hadn't thought about diabetes that way. I know you don't want to wake me up, but to me it's more important. I don't want to wake up in the morning and find out, you know, that like you've passed out or ...

Ohman, Söderberg, and Lundman (2003) claimed that "living with a serious chronic illness means living a life that is hovering between enduring and suffering but also including the process of reformulation of the self" (p. 528). While I have suffered and I have endured, the reformulation of the self is what I find most interesting, especially after I almost died. Just as the moment of diagnosis changed who I was, so too did the near-death experience. Writing this autoethnography is one way to reformulate myself, to appreciate the life I have, to share the insights I have gained in writing my story, to figure out what life might look like in the future. It puts almost dying into perspective when I take a more holistic view of my life.

Part of the process of writing my autoethnography has been figuring out who I am. As a storyteller, I want to capture the emotion of disability in my counter-narrative, yet I also want to report reality. I want to capture the pain, but I don't want to define myself as a victim without any ability to fight back and succeed. I also don't want to create an unrealistic but heartwarming, overcoming-the-odds story. The problem with merely describing contradictions is that it sets up binaries without recognizing complexity. It is important to recognize that "subjectivity is not a static characteristic; it is created by the ever-changing interaction of discourses, institutions and relations" (Danaher et al., 2000, as cited in Reeve, 2002, p. 498). The circumstances within which I am a woman, a wife, a mother, a friend, a teacher, and a researcher affect who I am at any point in time. Reeve (2002) summarized Foucault's description of subjectivity as "dependent on context—people constitute themselves as different subjects ... Therefore, subjectivity is a fluid identity, affected by time and place, culture and society" (p. 498). Yet disability influences all those subjectivities. This autoethnography attempts to describe those selves in relation to disability.

This fear carries over into other aspects of our lives. It's not just about making it through the night. Tom talked about hiking, bike riding, things we like to do, and how they're different now:

I think what happens if we're two miles into something? Right? It's getting dark and your blood sugar goes low and we don't have enough food. You know? So, I've become more aware that this could get more serious way faster than we have the ability to control, mostly because of either equipment not working or just a dumb decision we made, just something we shouldn't have done, but we did it. ... I told you, you're my life. It scares the shit out of me that, that ...

Tom thinks I've always been more aggressive about what I can do, but now it worries him. I see it as one more time I'm losing control. I know we have to be more careful, but disability always seems to be about losing something. The ripples of my near-death experience spread out in many ways, affecting those around me in many different settings. A friend recalled a visit to our home soon after my hospitalization. It was frightening for her. She told me,

The idea that you were waking up to make sure that you were okay, it was just frightening. You are always up in the morning before I am, always. I got up and you weren't up, and I really didn't know what to do. Of all of the times that we've been together that was the most frightening moment for me because then the decision was mine. Always up until then, you were really sort of saying, okay, you have all of these years of experience and you know your body and you make the judgment. Then I had to. I didn't want to bring an ambulance if you didn't need it, but I was about to call. I just thought, I don't care. I'd rather be embarrassed. And at that moment you came out [of your bedroom] and you were fine, but I was ready to call because it was really scary.

It's awful to know that I can cause fear in those I care about. My husband and I have talked about my carrying some kind of alarm all the time, like the one in the commercial where the old lady calls out, "I've fallen, and I can't get up." That's great, nothing like feeling like I'm getting old and death is just around the corner. The problem is that if I'm unconscious, I can't very well press the button. I mean, if I'm conscious, I can call 911, and if I'm unconscious, there isn't anything I can do.

As I write about the effects of my near-death experience, I see that what is so difficult about disability is its overwhelming pervasiveness. There is no getting away from it. All day, every day it's there. And now I even have to be aware of it all night, every night. I know I have a disability when I check and record my glucose levels 15–20 times a day, when the pump alarm sounds, every time I eat something, every time I exert myself physically. It's there when I feel stigmatized and excluded, when others advise me what I should do or tell me what I can't do. I feel it when I long for normalcy and when I feel guilt that I am a burden to others. Sometimes I can feel moments of positivity. I'm pleased when I have a period of particularly good glucose control and reach my desired weight and recognize I look pretty good. I feel a sense of accomplishment knowing I succeeded despite the odds against me when I gave birth to two amazing daughters, when I reached career goals, and when I shared meaningful friendships. I feel less abnormal when I feel loved by my family. Yet despite the flashes of joy and peace, my disability still feels relentless. At this point in my life, after having nearly died, the fear of dying is always lurking in my consciousness; my anger at being disabled is always simmering just below the surface. It's not easy to be optimistic. I want my story to be written on the page so I can read it and then close the cover and put it away, but my disability will never be put away.

So, Billy Collins (1995) asks, “How about a short animated film, a slide presentation? / Your life expressed in an essay, or in one model photograph? / Wouldn’t any form be better than this sudden flash? / Your whole existence going off in your face / in an eyebrow-singeing explosion of biography- / nothing like the three large volumes you envisioned” (33). And here I am creating at least one large volume in an autoethnography. So why autoethnography? Why try for “some bolt of truth ... / an ultimate Light before all the lights go out” (33)? Why willingly submit to the “megalithic tonnage” (33) of my life with disability? Is there an innate desire for immortality, an undeniable yearning to tell my story, a fear of being forgotten, a dread of no one understanding what it’s been like? I’m not really sure, but here I am. The question is, Where do I go from here? When I asked my husband if he sees our future any differently now, he said, “It doesn’t change my day to day view of you or us or the future. It doesn’t. I mean, I don’t walk around feeling like, Oh, no or ... I just love you. What else can I say?” And I love him, too. I think writing this autoethnography is an act of love for my husband, my family, my friends. I’m trying to say that it’s been really hard, but I keep on going, and because I love you, I always will.

In this autoethnography, I’ve tried show how my disability experiences reflect a sociocultural context as I have interacted with my family, my friends, my work colleagues, and the broader society within which I live. I’ve attempted to explain how illness and disability “can force people into narrowly scripted roles and metaphorical representations,” making the person with a disability appear as “a pitiable figure who serves to affirm others’ normalcy and well-being, or as the ‘good patient,’ who must bear up stoically under the weight of suffering” (Garden, 2010, p. 121), all the while rejecting those depictions. If “the ending of an illness narrative is critical to its interpretation: as a story of hope, of triumph over adversity, or of tragic loss” (Garden, 2010, p. 128), then how do I write my ending to reflect what I want my story to say? I don’t want to write a happy ending; there is no cure for diabetes, and I will never live a life that hasn’t been deeply affected by my disability. Yet I also don’t want to turn the last page without hope, without recognition of the many blessings of my life. Maybe I just want my story to offer “meaning, context, and perspective for [my] predicament” (Greenhalgh & Hurwitz, 1999, para.7). I want to share the complexity of my life. I want to figure out what I have learned from that complexity and what that learning can do for me and for others.

Newman (1999) said, “We have no control over our past. We can use it, interpret it, learn from it and even rewrite it but the fact of it mockingly remains” (p. 8). The question then is, What do these images from my past say? Am I disabled? Diabetic? Diseased? Am I determined? Striving? Successful? It’s not as simple as that. I think Newman’s point was to emphasize the complexity of experience so that individuals can interpret their experiences from different perspectives—especially given how our current experiences and learning shape what we recall. Focusing on the physical effects of chronic illness, what one can and can’t do, “does not adequately account for how chronic illness is experienced and needs to be augmented by narrative accounts” (Ironsides et al., 2003, p. 173). This reflects the appeal of telling my story in this autoethnography. Being a diabetic is about more than insulin injections and dietary restrictions; it is about “the possibilities of dwelling in the world in a totally different way” (Ironsides et al., 2003, p. 181) than others, but I want it to be as meaningful of a way. Writing offers me the opportunity to examine the meaning. Can I see various perspectives from these stories of my past? Yes. Will this understanding help me going forward? Maybe. Have I sufficiently dis/entangled the threads of my story, the pieces of who I am? I don’t think so. But this is a start. I have not felt my life is only about enduring and suffering; I think I also have a very strong sense of the need to keep on going, to adapt, to move forward into a future. I might struggle for control of this process, but I don’t let go of it.

As I finish writing my story, we are in the middle of the COVID-19 pandemic. Fear and the possibility of death are all around me. I've read news stories about the challenges people with disabilities face. In a time of self-isolation, what about the people with disabilities who need daily assistance? How intense must their fear be right now? Not only do their disabilities make them more vulnerable, but they also make the care required to avoid the virus more difficult. I think about the shortage of ventilators, the decisions doctors will have to make. I'm an over-60 diabetic. If the choice was an ICU bed and a ventilator for me or for my daughter, there's no question I'd say give it to my daughter. Would I do the same for someone's else's daughter? I'd like to think so, but when does that survival instinct kick in at all costs? I don't know. It's really hard to acknowledge you are on the "let her die" side of the line. How do we decide whose life is more worth living? That's a problem people with disabilities face all the time—the devaluing of their lives.

My mother is in a nursing home, and no visitors are allowed. Even if they were, because of my compromised immune system, it would be impossible for me to visit. I wake up from nightmares that she will die alone. She's not physically ill at the moment, but I can't help thinking that our shelter-in-place will last so long that her death will come. She has dementia, and although I want her to know me when we talk on the phone, I almost wish she would lose more of her understanding of what's happening. The other day the nurse dialed my phone number for her. I told her about my daughters working from home, we talked about the weather, and I explained I couldn't visit until the virus was gone. I told her to ask the nurse to call me every time she wants to talk. I'm not sure she understood. We said goodbye. As she handed the phone back to the nurse, I heard her start to cry. I heard her say she missed us. I was alone with my dog, walking through the neighborhood, and I couldn't stop sobbing.

When she first fell a few years ago and needed full-time care, I had to clean out her apartment. As I went through things she had saved, I cherished great memories until I opened the bottom drawer of her dresser. Inside was a fairly new bathing suit. My mother loved going to the beach. Every summer we would take the long drive to Jones Beach in New York, drag the beach chairs, toys, umbrella, and cooler to the water's edge. After a long day in the sun, swimming in the waves, building sandcastles, eating tuna sandwiches, nectarines, and brownies, we would make the long, hot, sandy ride home. We took vacations to the shore, and we spent days digging for clams at Sherwood Island State Park. As I sat on the floor in my mother's empty apartment, I cried because I knew she would never feel the sand beneath her feet or smell the ocean's saltwater or float on the undulating waves. My mother is a wonderfully kind and caring person whose love for our family has always been a clear, bright, warm presence in my life. And she was strong; she faced adversity and she kept on going. Now, as my tears fall on the keyboard, I only hope she will keep on going until the pandemic ends, and I can hug her again before she dies.

A recent New York Times article asked, "Who will be saved? Who won't?" (Fink, 2020). It talked about the guidelines doctors follow to make treatment decisions in the time of a pandemic. If resources are rationed, will the young and healthy receive them before the old and less healthy despite the fact that "little research has been done to see whether the strategies would save more lives or years of life [or] could paradoxically increase the number of deaths ... protocols involve value judgments as much as medical ones" (Fink, 2020, para. 8–9). In a society that values abled bodies more than disabled ones, that values youth over age, those ethical decisions favor some individuals over others. Those with disabilities and their allies argue that these decisions shouldn't be discriminatory. I want to shout the words of Alice Wong, a woman with a disability—"I deserve the same treatments as any patient. As a disabled person, I've been clawing my way into existence ever since I was born. I will not apologize for my needs'" (Ne'eman, 2020, para. 16)—but I'm not sure I'd be heard even if I shouted.

One of the cruelest aspects of coronavirus is that patients have to suffer alone; family members are forbidden from being by their side in order to prevent the disease from spreading. That is the greatest fear I have right now, that my husband or one of my daughters will get the virus, and I won't be able to be there with them. I'm not as worried about our surviving; it's the solitary struggle that terrifies me. I don't think I would have made it through my life with disability if I had been alone. I don't want anyone to face the struggle to survive by themselves. Maybe that's why I cried when I saw the videos of people in Chicago singing Bon Jovi's "Livin' on a Prayer" as they practiced sheltering in place. That's the way people with disabilities live:

.... Oh, we've got to hold on, ready or not
You live for the fight when it's all that you've got
Woah, we're halfway there
Woah, livin' on a prayer
Take my hand, we'll make it I swear
Woah, livin' on a prayer (Bon Jovi, Child, & Sambora, 1986).

I just want to make it. I want my family to make it. I want my friends to make it. I want people with disabilities and compromised immune systems who are always livin' on a prayer, holding on to what they've got even when it's livin' to fight, to make it. I want them to have someone to hold on to, to have a hand in theirs and know it's going to be all right. I want everyone in my life to make it, just what everyone else wants, too. My lifelong learning has taught me that no matter how hard it is, we have to keep on going.

I just learned that there are seven cases of COVID-19 at my mother's nursing home and the expectation is that the number will increase. In times of crisis, the vulnerable, whether from age or disability, are most at risk. I wish I could change the harshness of reality. I don't know how to keep on going right now.

I don't have anything else to say here. I'm too emotional to reflect on the words I've written. I'm too afraid. You'll have to fill this space with your own words, with your own thoughts and feelings. And then maybe you'll want to share them.

INTERLUDE

“I Know...”

Fear

The possibility of death
all around

As doctors make decisions

Some people are going to be told
they don't matter enough

It's not okay

being deemed less worthy
because I am disabled

Like others

I fear

being passed over
being left out
being forgotten
being deliberately excluded

It's really hard

to acknowledge
you are on the “let her die” side
of the line

Now the fear is magnified
that fear of death

Whose life

is more worth living?

Seven cases

at my mother's nursing home

In times of crisis

the vulnerable are most at risk
the harshness of reality

I called

We talked

She's OK

right now

We said good-bye

I heard her start to cry

I heard her say

she missed us

I was alone

I couldn't stop sobbing

I knew she would never

feel the sand beneath her feet
smell the ocean's saltwater
float on the undulating waves

My mother

was strong
faced adversity

kept on going
I wake up
from nightmares
that her death will come
I only hope
she will keep on going now
so
I can hug her again
before she dies

The greatest fear
I have right now
my husband
or one of my daughters
will get the virus and

I won't be there
The solitary struggle terrifies me
I would not have made it through
my life
with disability
if
I had been alone

I just want to make it
I want my family to make it
I want my friends to make it
I want people with disabilities
and compromised immune systems to make it
I want everyone in my life to make it
What everyone else wants too

My lifelong learning has taught me
No matter how hard it is
We have to keep on going
I don't know how to keep on going
right now

I have
from my forty years
learning to live
with a disability

Gained
problem-solving
resilience
determination
forward-thinking
self-advocacy
not giving up

Because
despite the struggle

Life is still
worth living

What is a good life
 overcome the obstacles of disability
 despite the odds
 find happiness
 share relationships
 learn empathy

Learn
 from the experiences
 of people
 with disabilities

Their lives
 can be good lives

They are worthy

Cope
Keep on going
 despite
 frightening possibilities

My story
 an opportunity to learn
 how
 to keep on going

My story
 is not yet finished

I have
 more chapters to write
 more research to do

My story is not over
 my learning is not done

As always
I will keep on going

CONCLUSION

What Have I Learned? Where Will These Lessons Take Me?

Education is an act of love, and thus an act of courage. (Freire, 1974, p. 34)

Others can learn from my experiences just as I have learned from theirs.

Merriam (2018) explained that adults are always learning, although they may not recognize that learning. As we experience the world around us, we gather information, practice skills, and change attitudes. The meanings we attach to what we learn shape our values and beliefs. Merriam (2018) described aspects of adult education that are evident in my disability experiences. As a person grows, “his or her self-concept moves from that of a dependent personality toward one of a self-directing human being” (p. 85), much like I moved beyond the diagnosis I received during my emerging adulthood to comprehend the complicated reality of a life with disability. My image of myself changed during this process as I had to come to terms with a shift in my identity from able-bodied to disabled. Throughout life, adults “accumulate a growing reservoir of experience, which is a rich resource for learning” (Merriam, 2018, p. 85); as I became more attuned to my own body, my understanding of my disability became deeper than that of the medical professionals who treated me. My social role as an individual with a disability helped me learn to navigate an able-bodied culture, and my perspective on life changed. The more problem-centered focus of my learning, my strong motivation to find out what I needed to solve health problems, and the self-evident reasons behind my quest to learn had to do with the need for knowledge that would keep me alive (Merriam, 2018). My learning was part of my daily life in a way that was less noticeable than going to class or reading or searching online for data; I had to understand how my body would react to food and to activity. According to Merriam (2018), “Learning in adulthood is often more than just adding information. It is also making sense of our experience” (p. 86), and that has been a part of my autoethnographic journey.

When I look back on the past 40 years and reflect on the writing of my narrative, I recognize my learning as self-directed, experiential, embodied, and narrative. While individuals with disabilities are often marginalized and their knowledge undervalued, I can see that the knowledge I have gained from living with a disability is worth sharing.

Alheit (2009), a scholar in biographical research, described biographicity in a way that reflects my feelings before and after my diagnosis when I went from feeling that I controlled my life to understanding that I had lost that control. He said,

As biographical subjects we do indeed have the feeling of being the “organisers” of our life course. Even when things do not run the way we hoped or expected they would, we perform corrections to our life plans under the impression that we do so with personal autonomy. ... [Yet] fate could deal us a blow at any time, making us irrecoverably ill. ... The point is rather that our supposed autonomy of action and autonomous planning is subordinated to “processual structures” in our biography that we can influence to only a very marginal extent. ... What is important is the finding that our basic feeling—that we can act relatively independently over our own biographies—does not necessarily conflict with the fact that the greater part of our biographical activities are either fixed to a large degree or require various “supporters” to initiate them. ... Biographicity means that we can redesign again and again, from scratch, the contours of our life within the specific contexts in which we (have to) spend it, and that we experience these contexts as shapeable and designable. (p. 123)

I had to learn within a new structure after my diagnosis, the structure of a disabled life. I wasn’t going to continue in school much longer, but there was still a lot to learn.

Learning to live with disability has been an ever-present part of my daily life.

Informal learning occurs as we go through the daily tasks of life within the specific context we find ourselves, regardless of whether, for example, we are at work or at home or participating in a social event. There are not specific learning objectives with corresponding activities and assessments. We may not be aware of this learning because it does not take place in a formal educational setting. Informally, organically, and intentionally, we learn as we need to learn, as we respond to the challenges we face day to day. We discover knowledge, we enhance our skills, and we satisfy our curiosity (Marsick & Neaman, 2018; Rogers, 2014; Tough, 2002). Self-directed and experiential learning are types of informal learning.

In a self-directed learning process, “individuals take the initiative, with or without the help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes” (Knowles, 1975, p. 18). Learning to live with a disability has required me to set my own goals, gather information, figure out how to learn what I need to survive, and determine if I’m making progress toward maintaining good health. Part of the disability experience is recognizing the individual nature of disability and having the courage to resist ableist labels and medical paternalism. I have had to learn how my own body works and avoid limiting myself to established treatment adjustments that may not be beneficial to me. Experiential learning acknowledges the need for adults to construct new learning in relation to their previous experiences and highlights the value of those personal experiences adults bring to learning (Brookfield, 1995). My daily experiences have taught me to listen to my own body rather than just rely on the wisdom of medical professionals. Having autonomy as an adult learner isn’t really about learning completely on one’s own; it’s more about making choices regarding one’s learning, a function of self-determination. Garrison (2003) pointed out that in terms of self-management, it is “through a collaborative process of sharing and balancing control between teacher and student, [that] the appropriate balance between educational norms and personal choice [is] ensured” (p. 165). For me the balance has been between medical advice and personal experience.

Understanding one’s own experiences on one’s own terms is what self-directed learning is about. In writing this autoethnography, I have critically reflected on my experiences of learning to live with a disability and shared what I have learned on my journey. Self-determination requires not only acknowledging one’s strengths and weaknesses but also having a true sense of one’s own worth (Ankeny & Lehmann, 2010; Field & Hoffman, 1994). Part of coming to terms with disability is recognizing one’s worth in the face of stigmatization that increases feelings of worthlessness. Key is the acknowledgement that “independence is not about doing everything for yourself but about having control over how help is provided” (Morris, 2001, p. 8). My story has been one of trying to regain and maintain lost control, of learning when to be independent and when to rely on others.

Learning to live with a disability is not something one learns like the multiplication tables before moving on to another topic like grammar rules; rather, disability requires constant learning from the moment of diagnosis to the moment of death. However, there is “diversity both among learners and across situations for the same individual” (Ross-Gordon, 2003, p. 44). Others with diabetes have different learning experiences than I do. My learning experiences can vary depending on whether I am eating out with friends and the knowledge I have acquired regarding food choices is paramount or I’m watching television at home and my activity does not relate directly to my disability. Like embodied learning, self-directed learning is often an informal and invisible element of daily life until we attend to it (Merriam & Baumgartner, 2020, p. 137) as I have been forced to do as an individual with a disability.

Undeniably, my body is at the center of my learning to live with disability.

Lawrence (2012) argued that the body is “a container for stories that each of us hold” (p. 72), and for me, it is also a source of my stories. When I reflect on my learning to live with disability, I recognize the centrality of embodied learning. Embodied learning is experiential and intuitive. It requires acute attention to one’s body as a source of knowledge. This type of learning is not always readily recognized, and it is a difficult process due to the complexity of the body. If we view learning holistically rather than just cognitively, we can clearly see that by increasing our awareness of our bodies, we enhance our understanding of ourselves. We also have the tools to understand the way others’ bodies affect who they are (Freiler, 2008; Kerka, 1999; Lawrence, 2012; Swartz, 2012; Tobin & Tisdell, 2015).

There are two ways I have experienced embodied learning: first, by coming to understand my own body intimately, and second, by recognizing how I am perceived by others and how my social interactions are tied to my disabled body in the same way my gender and my race affect social interactions. As a diabetic, I have had to develop an awareness of my body that is different than others’ awareness of theirs. My embodied learning is also about how my body, in its disabled state, affects my social experiences. My interactions with others are shaped by my disability. My own embodied learning might not be the kind of knowledge that others understand, but gaining an understanding of my own body

and sharing that understanding with others can help me build empathy with individuals with similar bodily experiences. It can also reveal to those without similar experiences what it might be like to live in my type of body. Individuals with disabilities do not choose to have disabilities, but they must deal with the bodies they have and how others react to their bodies. I have reflected on how disability shaped the person I am, I have told my story of living with a body that has a disability, and I have examined how my body defines my interactions and positions me within our society.

In embodied learning, knowledge is gained through attentiveness to the messages the body sends, through the cognitive comprehension of these signals, and through intuition. Changes in the way I feel alert me to what's happening inside of me and demand I pay attention to the messages my body sends. It's not the kind of knowledge that others might understand, but we all experience embodied learning. Sensations that indicate my glucose is rising or falling and my emotional and cognitive reactions to these sensations are like other signals our body sends: the rush of adrenaline we feel as we fearfully walk alone down a dark street, the physical indications of joy we feel when we know we are loved, the heart palpitations and sweaty palms of anxiety. Frequently, we do not recognize embodied learning; learning is not only "a cognitive process, but because for centuries the West has viewed the mind as separate from the body, and because learning has been so connected with formal schooling, the activity is almost always framed from a rational, cognitive perspective" (Merriam, 2018, p. 89). As a diabetic, I have "develop[ed] bodily and spatial awareness, unifying the mind and body in the learning process, and developing awareness of the body's role in socialization" (Merriam & Baumgartner, 2020, p. 237). When an individual understands "one's own body and one's emotional responses [this knowing] can build empathy as it connects individuals through similar bodily experiences" (Merriam & Baumgartner, 2020, p. 237) just as I have found in discussing my autoethnography with a friend who recognized experiences, emotions, and actions similar to mine in her own recovery from cancer. Freiler (2008) noted that "approaching the body is highly personal and private in nature for most individuals" (p. 45), yet I hope that by sharing my experiences of embodiment, I can offer readers some measure of comfort with sharing their embodied learning as they connect to my reflections. By sharing my vulnerability with a friend, I helped my friend see that it was safe to share her own thoughts and feelings. She could risk being vulnerable herself because she knew from reading about my experiences that I would have some comprehension of her experiences. Sharing intimate stories is easier if we believe our stories will be received with care and respect. While there are many facets of my friend's experiences that are different than mine, we share understanding on some level and are empathetic to each other and to those in like situations. The "universal language of the body is something that all human beings share. The body has wisdom and language of its own. Embodied or somatic learning is a way of learning that relies on the body's knowledge" (Lawrence, 2012, p. 1). I have learned the intricacies of my body and my disability, and I can connect with others through my embodied knowledge.

As I have written for an audience, for myself and my family, for friends and readers, I have performed disability.

"To be human is to tell stories" (Clark, 2010, p. 3). We learn when we listen to stories, we learn when we tell stories to others, and we learn by understanding what stories we are a part of (Clark, 2010). My narrative reflects the stories I have heard throughout my life that have shaped the person I am. Writing this narrative allows me to tell my own story, and it places me within the story of disability in our society. My narrative learning has included examining my identity and place in society by sharing my unique perspective on disability, by exploring my emotional responses to disability, by connecting my experiences over time, by reflecting on those experiences, and by expressing my thoughts and feelings (Kerka, 2002; Merriam & Baumgartner, 2020; Rossiter, 2005; Rossiter & Clark, 2007). I hope my story can become a part of the larger story on disability. I recognize that "the process of narrating ... is how learners give meaning to experience" (Clark & Rossiter, 2008, p. 64). Meaning-making is a narrative process (Clark, 2010; Clark & Rossiter, 2008; Merriam & Baumgartner, 2020; Polkinghorne, 1988; Irwin, 1996). The sharing of stories provides a way for individuals to understand the meanings of the stories and encourages them to connect with others through the shared experience. Narratives highlight the social construction of identity (Clark, 2010; Clark & Rossiter, 2008; Frank, 2002).

Self-authorship is part of narrative and part of my research. There are aspects of our lives over which we have control and others over which we do not; as Cohen (2000) noted, “although our lives are partly ... authored by contexts and communities in which we largely had no say, we partake in the authoring process” (p. 299). Individuals with disabilities do not choose to be disabled. They often find themselves in settings over which they have little control in terms of how their needs are met, yet they still have self-authorship possibilities. Clark and Rossiter (2008) argued that “we story our identities in multiple and sometimes contradictory ways; in one context we can see ourselves as the hero of the story, while in another we are someone whose agency is limited” (p. 62). Individuals with disabilities still have the ability to free themselves from the constraints of ableism by authoring their own stories. MacIntyre’s (2007) statement, “I am a part of their story, as they are part of mine. The narrative of any one life is part of an interlocking set of narratives” (p. 218), reflects the co-constructive nature of not only narrative but also identity. The importance of storytelling is clear because “seeing how the other is caught up in a story, people may be better able to understand the stories they themselves are caught up in. ... Dialogue opens when both are willing to become caught up in that other’s story” (Frank, 2002, para. 15). In this way, sharing my story may contribute to others’ self-understanding (Lennon, 2015).

Clark (2001) suggested that “narrative is closely linked to our understanding of ourselves” (p. 87); however, our selves are constantly changing. By compiling my experiences into a coherent story from my diagnosis to my near death, I have worked to make sense of my own life (Rossiter, 1999). Nevertheless, my narrative contains only the pieces of my life that I have chosen to share. My stories “constitute [my] identity [and] enable [me] to manage the complexity of who [I am]. Understanding identity as a narrative construction is another way of conceptualizing personal change” (Clark & Rossiter, 2008, p. 62). My narrative reveals how I have changed as I have experienced disability. Rosenwald and Ochberg (1992) argued,

The stories people tell about themselves are interesting not only for the events and characters they describe but also for something in the construction of the stories themselves. How individuals recount their histories—what they emphasize and omit, their stance as protagonists or victims, the relationship the story establishes between teller and audience—all shape what individuals can claim of their own lives. Personal stories are not merely a way of telling someone (or oneself) about one’s life; they are the means by which identities may be fashioned. (p. 1)

By writing my autoethnography, I have put down on paper an expression of who I am, showing how creating a narrative of one’s life is “the central process of adult development. The life narrative is repeatedly revised and enlarged throughout one’s life to accommodate new insights, events, and perspectives. Developmental change is experienced and assessed through this process of storying and restorying one’s life” (Clark & Rossiter, 2008, pp. 62–63). Including transition points such as receiving my diagnosis, getting married, having children, and coming close to death are also reflections of developmental growth in my life, yet they are not just my moments. Personal narratives also “require an audience, an Other either real or imagined that responds to the narrative in some way; in this sense these narratives are performances of identity, played out in various ways but always shaped by cultural norms” (Clark & Rossiter, 2008, p. 63). In my narrative, I have focused on disability; I have revealed how I have created my identity as an individual with a disability in my life and in my writing.

One of the most important lessons of a life lived with disability is to keep on going and never give up because despite the struggle, life is still worth living.

I woke up this morning to some distressing headlines. Among the patients hospitalized in the ICU with COVID-19, 32% had diabetes (Aubrey, 2020). In one state, 40% of COVID-19 deaths were people with diabetes (Brooks, 2020). Those are not very reassuring statistics. As doctors make triage decisions in hospitals, “some people are going to be told they don’t matter enough” (Fink, 2020). I am aware that the high correlation between diabetes and death from COVID-19 could lead to my being one of those people. As Pulrang (2020) stated, “We understand what scarcity is, and we see the tough choices that emergencies impose. But we are not okay with being deemed less worthy of medical care, simply because we are disabled or chronically ill” (para.7). Like others with disabilities, I am facing the fear of the virus, as people all over the world are, but I’m also facing the additional stress of people with disabilities who fear

being passed over because our lives are deemed less worthy. This is not a new fear as “one of the most fundamental fears people with disabilities have ... [is] the fear of being left out, forgotten, or deliberately excluded. Most of the time we experience this as social exclusion and everyday thoughtless behavior from people who mostly don’t mean it” (Pulrang, 2020), but in the time of a pandemic, that fear is magnified as a legitimate fear of death. The question becomes how I am able to prevent these numbers from triggering panic and increasing my fear to the point where I can’t move forward day to day. Maybe the answer is in what I have gained from my 40 years of learning to live with a disability. According to Pulrang (2020), “Disabled people tend to be creative problem-solvers” (para. 4). They have to be; when they face the barriers of an ableist society, they have to find ways around these obstacles and that enhances problem-solving skills. They “are often resilient in very particular ways. And ... certainly aren’t giving up” (Pulrang, 2020, para. 25). Having experienced significant struggles long before COVID-19 arrived, many people with disabilities have developed coping strategies that others can adopt, including the knowledge that comes from embodied learning. Not giving in to despair is one of those traits. Valuing the life one has is another:

While many disabled people need ongoing medical care, many doctors view life with certain disabilities as unworthy of living. Disabled people who require ongoing ventilator care and other forms of expensive lifelong assistance are used to being asked by medical professionals if they would rather abandon life-sustaining treatment—often with the clear implication that “yes” is the right answer. (Ne’men, 2020, para. 6)

The question becomes what determines a life worth living, what a good life is.

The lives of people with disabilities can be good lives.

Dunn and Brody (2008) described a good life as “one where individuals pursue positive connections to others, cultivate or maintain positive personal qualities, and exercise life regulation qualities” (p. 417). Two factors that contribute to a good life include agency and communion. By looking for ways to overcome the obstacles of disability and maintain well-being despite the odds against easily securing happiness, and by creating strong ties with others, an individual with a disability can maintain a good life despite the circumstances of that disability. Individuals with disabilities are no less interested in finding happiness and sharing meaningful relationships than people without disabilities, so their lives should not be viewed as less worthy. Dunn and Brody’s (2008) “description of the good life portrayed herein is one open to any person who is willing to reflect on his or her current life where connections to others, positive personal qualities, and life regulation issues are concerned” (p. 422). These are evident in my narrative learning. I have reflected on my experiences, acknowledged the importance of my relationships with others, come to understand some traits that have allowed me to keep on going despite setbacks, recognized the need to compensate for my disability, and seen the ways I have become who I am.

Learning empathy is probably the lesson I hope most readers are able to take away from my autoethnography. I see the need for empathy in the challenges faced during this difficult time. I hear teachers talking about how incredibly difficult it is to teach now that their classrooms have moved online as they are no longer in a teaching environment that is comfortable and that matches their strengths. Will they now be more empathetic to students with disabilities who always find that traditional classrooms don’t play to their strengths but rather make them feel like they can’t fit in and measure up? I hear parents lamenting their struggles to assist their children. Will they now be more inclusive of children with disabilities as they gain an inkling of what it is like for parents whose children have serious challenges? I hear people complaining about how hard it is to stay at home. Will they show any more understanding of the obstacles faced by people with disabilities that make it impossible or almost impossible to venture out of their homes? I think there will be a lot of changes in society when the pandemic is over. I hope there will be increased knowledge, more understanding, and greater empathy for others, but I don’t know. I hope in some way, my autoethnography can contribute to a recognition that we can all learn from the experiences of people with disabilities.

In writing this autoethnography, my intention was not to tell readers what to learn from reading my narrative; it’s my story, and others both with disabilities and without disabilities have their own

stories. I had hoped that they might find resonance in my story, connections to their own narratives. Maybe they would see the value in what an individual with a disability learns throughout life and how that learning can translate to other ways of living. Learning to be resilient, determined, and forward-thinking, learning how to problem-solve and self-advocate, and learning how to keep on going despite sometimes terribly frightening possibilities can be applied just as much to dealing with the anxieties and uncertainties of a pandemic as it can to the difficulties of having a disability. The implications of my narrative go beyond the discourse of disability and represent a wider focus on adult learning. I have learned to cope with a disability, and as I watch people struggling to cope with the fear and uncertainty of a pandemic, I offer my autoethnography as an opportunity to learn about how to keep on going, an alternative to vague guidelines, unrelated anecdotes, and conflicting “expert” reports flashing before us on news stations or scrolling by us on social media. There are some connections between a sociocultural understanding of disability and a comprehension of societal and individual relations during a worldwide health crisis.

Individuals with disabilities have experienced living losses, the ones that keep on going.

There are many stories in the news of family members who cannot be by the side of their loved ones who die from COVID-19. They can’t have regular funerals. They can’t go through the rituals of death in the traditional way. LaMotte (2020) wrote that “[t]here is no great gathering of family and friends to honor our mothers, fathers, grandparents, spouses, brothers, sisters, children or friends so suddenly and cruelly ripped from our lives. There is no wake, no shiva” (para. 2). This complicates the grief as rituals enable people to heal. People are also grieving the loss of their way of life, of opportunities that had been on the horizon, of celebrations of life’s momentous occasions. These losses are nonfinite and ambiguous, much like the loss one feels when diagnosed with a disability. These losses are significant as they

lack the clarity and definition of a single point like a death. ... And that lack of clarity can make it hard to move forward. As the pandemic has evolved, people have had to confront a series of losses: The loss of a sense of safety, of social connections and personal freedoms, of jobs and financial security. Going forward, people will experience new losses we can’t yet predict. (Weir, 2020, para. 8)

Individuals with disabilities have already learned how to cope with chronic sorrow. They have knowledge to share. Those grieving from their losses during the pandemic can learn from individuals with disabilities who have found ways to cope and live good lives despite the grief of significant loss.

As “life narratives are retrospective, always in process, unfolding” (Merriam & Baumgartner, 2020, p. 264), my story is not yet finished. I have more chapters to write, more research to do. In deciding to use the split-page format, I chose to write the story segment at the top of the page; I then reflected and analyzed that part of the story on the bottom of the page. There are many facets of the subtext that can be expanded with further research and writing. I might explore in more depth the presence of longing in individuals with disabilities, how the medicalized view of individuals with disabilities affects relationships, the overlap of disease and disability, the role of ambiguous and nonfinite loss in chronic grief, the effects of courtesy stigma, and comparisons of the embodied nature of gender and disability. While these topics, along with many others, are touched upon in this dissertation, there is ample room to dig deeper and explore further. I was able to discuss this dissertation with friends, family members, and those offering editorial advice. However, I was unable to include all these perspectives in my work. While I made many changes to the content, I haven’t yet expanded the analysis. This opportunity for future writing and reflection is part of what makes my autoethnography a work in progress. Writing an autoethnography is a complicated task, and I have only managed to present part of my story. My story is not over; my learning is not done. As always, I will keep on going.

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CAROL ROGERS-SHAW VITA

EDUCATION

Doctor of Philosophy (August 2020) in Lifelong Learning and Adult Education, The Pennsylvania State University, University Park, Pennsylvania.
Master of Science (May 1989) in Education, Fordham University, New York, New York.
Master of Arts (May 1985) in English, Fordham University, Bronx, New York.
Bachelor of Arts (May 1981, *magna cum laude*) in English, Fordham University, Bronx, New York.

ACADEMIC EMPLOYMENT

Graduate Teaching Assistant and Instructor of Record, Department of Learning and Performance Systems, The Pennsylvania State University, August 2016–May 2018.
Research Assistant to Dr. Davin Carr-Chellman, Department of Learning and Performance Systems and Department of Leadership and Counseling, The Pennsylvania State University and University of Idaho, May 2016–May 2019.
Teacher, English, Summit High School, Summit, New Jersey, September 1988–June 2014.
Teacher, English, Loyola High School, New York, New York, September 1984–June 1988.
Teacher, Saint Agnes Elementary School, Brooklyn, New York, September 1982–June 1984.

PUBLICATIONS

Rogers-Shaw, C. (2017). Adult learners with disabilities: Overcoming invisibility and exclusion. In A. B. Knox, S. C. O. Conceição, & L. G. Martin (Eds.), *Mapping the field of adult and continuing education: An international compendium, 1* (pp. 83–86). Sterling, VA: Stylus Publishing.

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