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**HEALING FROM DRY BONES: CREATIVE EXPRESSION  
AND ADULT LEARNING IN DIABETES CARE**

A Thesis in

Adult Education

by

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## ABSTRACT

Because of the complexity and individuality of people, the nature of knowing and teaching in patient education cannot be reduced to “the kinds of recipes as used in the physical sciences” (William, 2002, p. 54). Neither can we assume that the recipe we are using is working for all, or even, at all. As health care educators, we need to be open to explore and to meet the needs of the patient learners. This is not going to happen in one way, or a “right” way. Alternative (creative) ways of knowing lead to other, multi-dimensional methods of inquiry to understand the teaching and learning process in patient education.

The primary purpose of this action research study was to understand how adults make meaning of and experience diabetes, and to use multiple ways of knowing in the integration of diabetes care. The two research questions which formed the basis of this study were: “How do adults make meaning of their Type 1 diabetes?” and “What are the ways in which adults with diabetes could engage in creative expression to find greater meaning?” The action research was informed by a constructive postmodern and feminist poststructural perspective, where there is not one overriding, great Truth, but many *truths* as defined and experienced by the learners themselves (Foucault, 1980; St. Pierre, 2000; Tisdell, 1998). As they incorporate creative ways of knowing into their understanding of “their shifting selves,” learners experience opportunities for growth and development of their own identity and meaning.

The qualitative model which informed this study was an action research design, held with a group of seven women (eight, including myself), who had insulin-dependent

diabetes for ten years or more. In addition to an initial planning stage using one-on-one interviews, the action research included three group intervention and reflection meetings, and one final reflection session as a conclusion (five meetings total). During the initial planning phase, participants discussed two primary questions in a narrative style of interviewing: (a) Tell me about your diagnosis, and (b) What types of activities do you enjoy outside of work? Based upon the results of these questions, the intervention (the action or implementation of the plan) included the body as a way of knowing through the use of meditation and understanding how one felt about having diabetes, forming those feelings into a simple image, and using that image to create metaphor and words to describe the experience of diabetes. Transforming those metaphors and images into photographs, participants expressed what they “knew” about diabetes on multiple levels.

Although participants initially could not express what having diabetes was like during the initial interviewing process and planning stage, after going through the action research process, participants could clearly communicate the experience of diabetes using the metaphor they created during the sessions. Paying attention to all aspects of knowing within the mind-body-spirit is important not only to those with diabetes, but the field of adult education as a whole. Following the work of many who write in adult education about the multiple ways adults construct knowledge, this research expands the understanding of how adults with diabetes come to learn, feel and know about their experience, and for others to learn how to use multiple modalities in teaching and learning. By using the body to *process* knowledge, and imagery as its *product*, we can help students understand more about themselves (and ourselves) than using a rational, linear approach alone.

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## ACKNOWLEDGEMENTS

You think you can avoid pain, but actually you can't. If you do, you just get sicker, or you feel more pain. But if you can speak it, if you can write it, if you can paint it, it is very healing – Alice Walker

This dissertation was born in my spirit the day I received the diagnosis of diabetes. As a pre-adolescent girl, I had no way of expressing my anxiety and frustration about giving injections and having fluctuating blood sugars. Through writing about the experience, I felt a great release of energy, and for many years I wanted to publish a book to help other people with diabetes understand that they were not alone. At that time, I did not have the structure, the knowledge, or the education to know how to create a narrative that would reflect not only my feelings, but those of others who have been in similar situations. I didn't know how to speak it, to paint it, or to mold the depth and breadth of the experience into being.

Finding my way through the doctoral program at Penn State Harrisburg has been a wonderful discovery of my own learning style and a challenge to find my sense of self in adult education. All of the professors, Daniele Flannery, Ed Taylor, Patricia Cranton and Libby Tisdell have had a powerful influence on the forming of my identities as an educator and a person with diabetes. Daniele was one of the first educators to recognize my thinking creatively and metaphorically as strengths, and valued these ways of knowing as a gift. She helped center my ideas, my passion, my drive. Daniele is like the purple of the moon, the one filled with compassion and wisdom. Ed has the heart and spirit of a great educator, caring about students as individuals and encouraging each to succeed. Through his example, Ed taught me how to write articles and literature reviews

with scholarly fervor. Because of his energy and desire for continual growth, he represents the green of pine and forest, wanting to explore and searching to know more.

Patricia and I learned more about each other through writing e-mails of personal experiences and reflecting on photographs. We did not need to say much through words, but her life and authenticity spoke sweetly and softly. She travels in my heart and body throughout life as an empathetic spirit, touched by a loved one's struggle with the complications of diabetes. Patricia is midnight blue, the inner peace of the sea and wonder of the ocean.

Libby was my inspiration and my encouragement to complete. She helped me reflect and understand aspects of spirituality and culture, introduced me to the Dances for Universal Peace, and overall encouraged me to grow not only academically, but personally and holistically. We share the love of so many things: the zest for life filled with art and spirit, the fun of talking philosophically and creatively, and the challenge of interpreting meanings and symbols in movies. Libby has provided the structure that I needed to my otherwise fluid writing style. Like turquoise, she represents the soulful sky of feminine mystique and direction.

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To all those who have diabetes, I hope you have the opportunity to read this dissertation and to find your own place where you learn to live with your disease and become integrated with all of its struggles. When you find that path, when you feel that pain between life and death, when you know you are going to survive, thank the higher power and look within yourself to find the strength to endure.



## CHAPTER 1

### INTRODUCTION AND PURPOSE

*There is no cure.* Those are the words I remembered when I was diagnosed with insulin-dependent diabetes at age 12. Upon my initial release from the hospital, friends and teachers would ask what it was like to give myself shots and what foods I was “allowed” to eat. I didn’t want to talk about my diabetes. My disease was something I would have rather ignored. Nearly 20 years after my diagnosis, a friend asked a different question. She wanted to know how I *felt* about having diabetes. My feelings were distant, but I managed to say that taking shots was like brushing your teeth -- you get used to it. That wasn’t true. I wasn’t “used to it” at all. In fact, I barely understood my own feelings about having diabetes.

That week, Central Pennsylvania was preparing for a February blizzard, and my son and I decided to stay at a friend’s house. Having nothing to do but watch the snow, I went to the computer that faced the window and looked outside. As the storm intensified, the question grew until it seemed as though the snow itself was asking, “How do you feel about your diabetes?” My fingers touched the keyboard, and began to write:

*Tonight I hear a new voice. I see healing in the white flakes sailing past the window. I sense peace, a covering, a moment when the world stops to watch the forgiveness of heaven. Through the clouds, the sky brings healing.*

*I ask myself about my feelings about diabetes, and my first reaction is to fly far away. I don’t want to answer. You might say I am angry or afraid, but those words are not enough to explain how I feel.*

*I feel alone, walking in a dark place, a dungeon, with skeletons around me. There are candles on the wall, and I take them to light my way, but all I see are dead*

*skulls and bones. I walk through them, hoping to get out of the tunnel, but I find that the cave ends, and all I can do is turn back, or sit down with the rest of them and wait my turn. This is what diabetes feels like.*

*It is the waiting that is the worst part, the anticipation of what is going to happen. The shots, the syringes, the sore fingers are so insignificant compared to the unknown. One unit of insulin could either bring healing or death. I don't know when I go to bed at night whether I will have an insulin reaction by morning, or whether with certainty I will wake up to treat it.*

*My eyes twitch, and I wonder if something is really wrong, or whether I just have a little dust in them. When I see spider veins in my eyes, does that mean that another blood vessel has broken, or is this a normal result of laser surgery? I am always anxious, because I am wondering what is going to happen next. I walk through the valley of bones and wonder whether I will get out.*

I went downstairs for a hot raspberry tea. Sitting at the kitchen table, reflecting on what I was feeling, I noticed a book, *Jesus in Blue Jeans* (Jones, 1997). Although I am not particularly religious or exclusively Christian, the title intrigued me, and I thumbed through a few pages. One, two, and my eyes settled on the sentence, “Any of us can look into our past and find a valley of dead, dried out bones” (p. 130). My soul shook as I continued reading this passage from Ezekiel 37:

*The hand of Yahweh was on me; he carried me away by the spirit of Yahweh and set me down in the middle of a Valley full of bones. He made me walk up and down and all around them. There were vast quantities of these bones on the floor of the Valley; and they were completely dry.*

*He said to me, “Can these bones live?” I said, “Only you know, Lord.” He said, “Say, Dry Bones, hear the word of Yahweh.” The Lord says this to the bones: I am now going to make breath enter you, and you will live. I shall make flesh grow on you. I shall cover you with skin and give you breath, and you will live, and you will know I am Yahweh.*

*There was a noise, a clattering sound; it was the bones coming together. And as I looked, they were covered with flesh, yet there was no breath. He said to me, “Say to the breath, Come from the four winds, breath; breathe on these dead, so that they come to life.” The breath entered them; they came to life and stood up on their feet, a great, immense army.*

This was the prophetic response to my dry bones, a moment of healing, a releasing of the silence. I asked Yahweh, *What would diabetes look like if you put flesh and muscle on my dry bones and helped them to breathe and live?* I *did* believe the dry bones could live. I *knew* the bones which were haunting me could lead to a new perspective, a different relationship with my diabetes. This was the hope I needed. *Help the dry bones in this Valley of diabetes rise up into a great immense army. Help me, Yahweh.*

### Background of the Study

This metaphor of dry bones continues to represent my feelings, and my hope and healing, of having diabetes. Writing about this experience touched many ways of knowing about the experience of having a chronic illness: emotional, somatic, metaphorical, spiritual. I felt the presence of a greater power, actively listening to my *fears* and my *feelings* about diabetes rather than asking the mechanical questions of, “Do you notice any changes in your feet, do you have any problems with swelling, and are your blood sugars under control?” *Dry Bones* was the initial source of inspiration for this dissertation and further study into ways of knowing about diabetes and the creative aspect of holistic care.

During my years of having insulin-dependent diabetes, I have listened (more or less) to the advice of physicians and tried to understand how to improve my diabetes care and lessen complications. During that time, it seemed like an integral part of the treatment plan was missing ... my thoughts and feelings as the patient. From this insider patient perspective, diabetes care is different than when it is viewed from a distance. It takes courage to inject a needle under the skin four or five times a day, or to start an insulin pump. It requires persistence to handle a disease that is relentless. It takes

understanding to put yourself in the place of a patient who crawls on the kitchen floor while trying to get a cup of juice, trembling in sweat and fuzziness. From a distance, the decisions about medical care and diabetes treatment look different than when they are up close and personal. Until there is a cure for diabetes, we need to continue to search for the best advances in medical care and listen to the experiences of patients so that people with diabetes can not only manage their disease, but integrate it into their lives. It is not enough for me to be told what diabetes is and how to treat it. I need to know what it *means* to have diabetes.

As a patient advocate on the council of the Diabetes Center at the Penn State Milton S. Hershey Medical Center (Pennsylvania), I and the others in the group have begun to look at diabetes from many angles. On this council, there are patients, scientists, physicians and administrators who are collaborating to redesign diabetes care. Being part of this advisory committee has helped us pool our resources of both technology and human empathy, ideas and plans, to create a patient-focused diabetes center. In order to become patient-focused, however, we need to understand how the patient comes to know and learn about having diabetes in more than a rational way. This desire to understand meaning and integrate *all* ways of knowing in diabetes care is the background behind the work of this research in adult education.

#### Purpose and Research Questions

The overall focus of the field of adult education is how adults create and construct meaning in many contexts, and how to educate adults in light of how they learn (Merriam & Caffarella, 1999). The area of patient education is one of the many contexts of adult education. Particularly related to the area of diabetes care, patients are often “students”

who learn from their physicians and diabetes educators about the management of their disease. Much of the traditional medical approach to diabetes care primarily comes from a cognitive-behavioral perspective (for example, Berkel, Poston, Reeves, & Forey, 2005; Bodenheimer, 2003; Fox & Kilvert, 2003; Gottlieb, 2004; Graves & Miller, 2003; Hall, Joseph, & Schwartz-Barcott, 2002). One underlying assumption of this approach is that adherence improves care, and that this compliance objectively measures the extent to which patients' behavior relates to medical advice (Lutfey, 2005). Following dietary requirements according to the standards of the diabetic food plan, adjusting insulin to meet food intake, and exercising religiously to control blood sugar are the three main goals in this approach (American Diabetes Association, 2003a). Typically, the plan is determined by the doctor and/or dietitian, and the patient is expected to follow, comply and adhere to the treatment. If patients resist this rational, scientific model of diabetes in the context of clinical treatment, they are considered to be acting irrationally by not protecting their health and best interests.

The primary purpose of this research was to understand the experience of diabetes and to explore creative and alternative ways that adults find meaning in their diabetes to complement and supplement the traditional medical model. Through a narrative approach in initial interviews and three stages of action research (Connelly & Clandinin, 1990; Kemmis & McTaggart, 1988) with eight individuals who are insulin-dependent, we explored multiple ways of finding meaning and "knowing" about diabetes. Following the work of many who write in adult education about the multiple ways adults construct knowledge (for instance, Belenky, Clinchy, Goldberger, & Tarule, 1986; Dirkx, 2001; Somerville, 2004; Yorks & Kasl, 2002), we created metaphors from the body and

photographs of images that described the experience of diabetes. Several participants also used pottery, writing, and beading to express their experience of having diabetes. Although there were nearly an infinite number of ways we could have explored creativity and meaning making, these were the particular medium through which our experience was expressed.

The two research questions which formed the basis of this study were: “How do adults make meaning of their Type 1 diabetes?” and “What are the ways in which adults with diabetes could engage in creative expression to find greater meaning and wellness?” In the practice of adult education, another question which this study answered was “How can educators and clinicians incorporate alternative ways of knowing into their practice?” The primary focus was to understand how adults made meaning of their disease, and to use creative ways of knowing in the integration of diabetes care.

This study was grounded in adult education in primarily two ways. First, exploring creative ways of knowing opens up opportunities for adults with diabetes to understand how they come to learn, feel and know about their diabetes care. Second, as patient education in a health care setting is a form of adult education, practitioners and patients may benefit from carrying the results of this study into their context and medical practice. Before we can begin to use creative modalities in diabetes care, we need to begin by understanding the experiences of the patients themselves. The patients can speak to us and give us rich information about the use of creative expression and meaning-making.

This research was also a response to the lack of attention to the creative dimensions of knowing and to the lack of research in both the adult education and the

patient education literature surrounding meaning-making and chronic illnesses such as diabetes. It was also a personal adventure into understanding how the experience of having diabetes has affected my perceptions of life, and using creative ways to find greater healing for myself in the unique role of both researcher and insider. Later in the chapter, I return to explain more about the general design of the study; first, it is important to understand the rationale and significance of the research to adult and patient education.

### Rationale and Significance of the Study

There has been some discussion in adult education about alternative ways of knowing, and what such ways of knowing offer to our understanding of how adults come to know and learn (for example, Dirkx, 2001; Donoho, 2005; English & Gillen, 2000; hooks, 2003; Lawrence, 2005). Some health educators have moved from the cognitive-behavioral perspective into narrative forms of making meaning related to health and illness (Angen, 2000; Bailey & Tilley, 2002; Casey & Long, 2002; Wright-St. Clair, 2003), but only in recent years have educational researchers stepped out of the traditional theoretical “comfort zones” to find alternative ways of processing knowledge.

Because of the complexity and individuality of people, the nature of knowing and teaching in health settings cannot be reduced to “the kinds of recipes as used in the physical sciences” (William, 2002, p. 54). Neither can we assume that the recipe we are using is working for all, or even, at all. As educators, we need to be open to explore and to meet the needs of the learners. This is not going to happen in one way, or a “right” way. Multiple ways of knowing begin to inform the practice of adult education and make way for multi-dimensional methods of inquiry into understanding the teaching and

learning process in patient education. Prior to this study, these types of ways of knowing have not been researched with those who have a chronic illness and, specifically, diabetes in the adult education literature.

At this point, research on multiple perspectives of diabetes care and treatment is quite limited. The lack of research on diabetes is disproportionate to the magnitude of the problems (McDonald, Tilley & Havstad, 1999). Since diabetes is the fourth or fifth leading cause of death in most developed countries, it is certain to be one of the most challenging health problems in the 21st century (*International Diabetes Foundation*, 2005). Diabetes care becomes an even greater health issue because most patients are still resisting or being labeled as “non-compliant” to their care. In other words, they are not exhibiting “good” behavior. Lo (1999) indicated that from one-third to three-quarters of people with diabetes are not adhering to their diabetes regime, despite the fact that the disease, and its many complications, is life-threatening.

Even though people with diabetes are at risk for complications and are not adhering to the diabetes plan, the way people come to know and learn about their chronic illness has not been researched. Much of the medical and nursing research has centered on behavioral compliance and a rational approach to diabetes care (Brown, Harris, Webster-Bogaert, Wetmore, Faulds & Stewart, 2002; Kyngas & Hentinen, 1995; Rapley & Fruin, 1999; Thorne, Harris, Mahoney, Con & McGuinness, 2004). In one study, compliance was defined as a “situation in which the patient’s behaviour corresponds with the clinical instructions given” (Sackett & Haynes, as cited in Kyngas & Hentinen, 1995, p. 730). This behavioral approach is one way to ensure conformity to the bio-medical model (Koch, Kralik & Sonnack, 1999), but it does not address or engage multiple ways



of knowing and learning about diabetes, nor does it help patients find *meaning* in the experience of having diabetes.

The search for *meaning* may be difficult to quantify; however, “the meaning patients attribute to an illness does seem to affect how they rate their overall health, and these perceptions may influence treatment effectiveness, psychological symptoms, coping and somatic outcomes” (McFarland, Rhoades, Campbell & Finch, 2001, p. 250). These are important questions, and significant to the great number of people with diabetes and those who provide care and education for them.

#### Theoretical/Philosophical Framework

Adult learning theories are characterized as falling generally into one of four dominant paradigms: behaviorist, humanist, cognitivist, or liberatory/emancipatory (Amstutz, 1999; Elias & Merriam, 2005). The first three theoretical paradigms have been described as “meeting the needs of mainstream economic, academic, and social programs and goals” (Welton, as cited in Amstutz, p. 19), with the fourth, emancipatory paradigm, challenging these dominant views of the knowledge production process. In behaviorism, the assumption is that people learn through positive and negative reinforcement, where positive behavior is rewarded and negative actions are punished (Skinner, as cited in Merriam & Caffarella, 1999; Watson, 1930). Humanists go beyond behavioral change to effect changes in values, attitudes and beliefs to reach for self-direction and self-actualization (Knowles, 1980; Rogers, 1961). Cognitivists, such as Lewin (1951) and Piaget (1995), seek to develop the skills and tools necessary to learn better, or to “learn how to learn” (Merriam & Caffarella, p. 364).

A key difference between the first three of these theoretical perspectives (behaviorism, humanism and cognitivism) is on the locus of learning. Whereas the behaviorist focuses on external stimuli, the cognitivist looks internally to the mental and psychological processes that contribute to learning, and the humanist attends to the personal affective and cognitive needs. Although humanism does attend to the affective dimensions of learning, it generally excludes the social context of learning and is limited in its application to diverse groups (Amstutz, 1999). In addition, humanist psychologists rely heavily upon cognitive talk therapy for evaluation and empowerment of themselves (Elias & Merriam, 2005). The humanist and behaviorist theories to learning are the primary approaches used in traditional medical care for the treatment of chronic illness.

The fourth paradigm of learning theories discussed by Amstutz (1999) is liberatory or emancipatory in its orientation. This group of interrelated theories in adult education challenges this behaviorist idea of what is “good” and “bad” behavior, and the humanist ideal of “equality for all,” primarily based on the assumption that each individual is equally situated in our culture and has equal opportunity and equal access to resources. The liberatory/emancipatory perspective includes the interrelated discourses of resistance/constructive postmodernism and feminist poststructuralism, which serve as the major theoretical grounding of this study (Foucault, 1988, 1980, 1972; St. Pierre, 2000; Tisdell, 1998).

There are many commonalities between resistance/constructive postmodernism and feminist poststructuralism. Both of these discourses examine the sociocultural and structural influences (such as power relations based on race, gender, class, physical ability, sexual orientation) that affect the individual. They both challenge the dominant

culture in deconstructing and questioning what has typically been valued in the construction of knowledge (Foucault, 1980). They also focus on enabling the ways people can reconstruct their identity through the development of voice, by examining the positionality and power of the teacher and the students, and differences in the cultural identities of the students and their access to power (Elias & Merriam, 2005; Merriam & Caffarella, 1999; Tisdell, 2003).

Not all versions of constructive postmodernism are necessarily feminist in the sense of focusing on gender. Several reasons that this study is informed by feminist poststructuralism as well as constructive postmodernism are that feminist scholars have given attention to ways of knowing that include listening to an inner voice and the voice of experience, making connections to others and attending to relationship, and claiming the subjective sense of self through intuition and feeling (Belenky et al., 1986). Until the publication of Belenky et al.'s work in 1986, relational ways of knowing had been silenced in a culture of rational analysis, objective reasoning, and scientific thought, which are traits usually attributed to a masculine identity. Belenky et al. did not state that connected and relational knowing is gender-specific, but they believe it may be gender-related as a predominantly female orientation.

The space created by attending to connection, relationship, the subjective self and multiple ways of knowing with the publication of Belenky et al.'s work, though not poststructural in its orientation, opened space for the *affective* dimensions of learning. Many feminist writers since that time (English, 2005; Lather, 1991; St. Pierre, 2000; Tisdell, 1998) have drawn from the work of Belenky et al. and combined it with other feminist and poststructural influences that examine how social forces and power relations

based on race, gender, sexual orientation, affect the construction of knowledge, and one's identity, which is why feminist poststructuralism is included as a philosophical framework for this study.

Within both the feminist poststructural and the postmodern perspectives, there is not one overriding, great Truth, but many *truths* as defined and experienced by the learners themselves. In this regard, "what can be known is not absolute, but relative" (McCulloch, as cited in Collet, 1999, p. 4). There is space for the examination of multiple truths and differing realities, and room for *all* voices to be heard, not just those in a position of power. Foucault (as cited in St. Pierre, 2002) said, "I believe too much in truth not to suppose that there are different truths and different ways of speaking the truth" (p. 28). As learners exercise their own sense of "truth," learners experience opportunities for growth and development of their own identity. In this regard, beliefs about self and truth do not remain static, but are shaped and shift over time.

Attention to the affective dimension of learning, the identity of self as shifting, and the deconstruction of evidence allow for alternative ways toward knowledge construction. Multiple ways of knowing are discussed in this dissertation, and include: (a) the affective (Dirkx, 2001; Palmer, 1990; Yorks & Kasl, 2002), (b) the spiritual (Balducci & Meyer, 2001; English, Fenwick & Parsons, 2003; Tisdell, 2003a); (c) the imaginal and/or symbolic (Clark, 1997; Dirkx, 2001; Tisdell, 2005); (d) somatic (Beaudoin, 1999; Somerville, 2004); and (e) the artistic or creative (Lawrence, 2005; Olson, 2005; Wuthnow, 2001). Each of these areas will be described in detail in the review of the literature (see Chapter Two).

By engaging with the problems and issues raised by postmodernity, adult educators may find the interpretive frameworks and conceptual resources helpful in reflecting on current patient care (Edwards & Usher, 2000). By taking a constructive postmodern view, fresh forms of knowing offer a more holistic and inclusive view of patient education. Traditional medical models and behavioral components are not enough to help patients find meaning, although this does not imply that they have no place. The challenges of postmodernity invite different questions, as the ones posed in this study, and suggest new approaches to learning in its wide variety of forms.

From this philosophical perspective, we add layers of depth, meaning and hope to the dry bones of diabetes care in this study and offer somatic, imaginative, intuitive, and creative dimensions to traditional ways of understanding. By researching these ways of knowing, more patients with diabetes may find meaning and healing within their chronic illness. This allows patients to give voice to their creativity and other aspects of their being, and may account for the many ways that people come to know and learn.

### Overview of Research Methods and Design

This study used a qualitative design to complement the purposes and philosophical perspectives of the research. In qualitative research, one assumption about the world is that there are multiple realities and perspectives, illuminated by the view of the participant. The process requires flexible, changing strategies, and the results are specific (non-generalizable) to a particular context. Because qualitative research makes use of a smaller, purposeful sample of participants, rather than a large, randomized number of subjects, sample selection has a profound effect on the quality of the research (Coyne, 1997). Categories such as age, gender, status, position in an organization or their

interests may serve as starting points to determine who would match the aims of the study. Instead of standing as a detached observer, the researcher also becomes immersed in the study with the participants (McMillan & Schumacher, 2001) and places a “substantial emphasis on how participants in a study make sense or meaning of a situation” (Creswell & Miller, 1997, p. 37). Specifically, the two interrelated qualitative models which informed this study were narrative inquiry through the use of unstructured interviewing and action research with a group of eight participants.

The primary purpose of narrative inquiry is to create a process in which we give an account of the multiple levels of experiences through the use of experience and story. As cited in Patton (2002), Bochner notes, “Narrative analysis honors individuals’ stories as data” (p. 116). The sense of the whole is built from many data sources with a focus on the significant, concrete events of life that create powerful narratives (Connelly & Clandinin, 1990).

A narrative approach to interviewing was used during the first stage (the planning stage) of action research, where I interviewed and collected the narratives of ten participants (including myself) to explore the meaning making process of diabetes. Two of the participants withdrew after the initial interviews, leaving eight participants to complete the study. The question to begin the narrative included, “Tell me about your diagnosis,” from which participants were free to elaborate in whatever direction they chose. During these interviews, I listened for responses that specifically related to feelings about diabetes, difficulties that patients experienced, how they made meaning of living with a chronic illness, and images that participants may have used to describe diabetes. An additional question which I asked during the course of the interview was,

“What kinds of activities do you enjoy, outside of responsibilities in the home, diabetes, work and family?” The responses to this question became the data from which the action research process was based.

Action research is another form of qualitative inquiry, but its purpose is not only to listen to the narratives and voices of others, but also to take action. It is different from narrative inquiry in that it is meant to improve a social situation; for example, the relationship between patient and doctor in health care. Through a cyclical phase of planning, action, observing, and reflecting, participants explored the use of creative expression to find alternative ways of learning and making meaning of their diabetes. In addition to the initial one-on-one narrative interviews, the action research process included three group intervention and reflection meetings, and one final reflection session as a conclusion (five meetings total). The cyclical interventions of acting and reflecting focused on the use of photography and images to help participants find new pathways to a greater understanding, knowing, and potential healing, of diabetes.

#### Assumptions and Limitations of the Study

As a researcher who views the process of meaning making and creative expression from a constructive postmodern perspective, I have identified several assumptions and limitations of the study.

##### *Assumptions*

1. Learning is not only a rational, cognitive process but also an emotional, experiential and creative one. Likewise, the rational or biomedical perspective is not enough to understand the experiences of living with diabetes. There are

multiple ways of knowing, in addition to the rational perspective, that need to be understood in the context of diabetes care.

2. Those selected in the purposeful sample wanted to contribute and participate in the goals and research of this study. They were able, and had the freedom, to express their own views, feelings, and thoughts.
3. Creativity is a powerful and wonderful way in which to tap into aspects of the imagination, symbolism, somatic responses, and emotion.
4. As participants reflected and engaged in creative expression, they had the opportunity to bring their feelings and thoughts into the open. In this space, there was the possibility of greater healing and wholeness.
5. Images have the power to change the relationship participants had with diabetes, which also brings an opportunity for healing.

#### *Limitations*

1. The purposeful sample included participants from the Penn State Milton S. Hershey Medical Center. Although the Penn State Diabetes Center is one of the most progressive centers on the East Coast, the demographics of the area include a population of primarily Caucasian, mid- to upper-level class, Christian, and heterosexual individuals. With the exception of one participant who was bi-racial, the participants in the study reflected the dominant culture.
2. In qualitative research, the results are not generalizable, although it is up to the reader to determine whether the results can be applied to a particular population. Whether the results would be similar to patients with Type 2



diabetes or other chronic illnesses is unknown, but could be the result of additional research.

3. Although there are multiple interviews and sessions conducted over a period of five months, this study did not determine whether using creative, alternative ways of making meaning resulted in a longitudinal shift in thoughts, feelings and related behaviors.
4. As a white American woman, I am shaped and limited by the cultural norms and manners of self- and creative-expression familiar to me and my culture.

Additionally, I assumed that there are ways that adults can find meaning, even if that meaning changes or at times becomes elusive. There are still those who have not learned to live well with their disease and, by conducting further insider inquiry, perhaps researchers will be able to discover ways to assist those individuals and help them find meaning through their disease. As one who has insulin-dependent diabetes and as a researcher passionate about this topic, my ambition was to provide more insider research that helps to respond to some of these issues in finding ways to help others find hope in their illness.

#### Definitions of Terms

In order to interpret the research and create a common understanding, it is important to briefly define some of the medical terminology and to place the adult education concepts in the context of this dissertation.

#### *Type 1 Diabetes*

In Type 1 diabetes, patients have a total lack of insulin and require multiple daily injections. Some patients use an insulin pump and others use traditional syringe and vial

injections. They are also at a greater risk of having a low blood sugar and long-term complications. This type of diabetes cannot be prevented through diet or exercise, and may also be referred to as IDDM (Insulin Dependent Diabetes Mellitus) or “juvenile diabetes” (*WebMD Health*, 2003).

### *Type 2 Diabetes*

In Type 2, or NIDDM (Non-Insulin Dependent Diabetes Mellitus), patients cannot use insulin efficiently, but the pancreas does produce a limited amount of insulin. They have infrequent low blood sugars, and their diabetes can be managed by oral medications and attention to improving nutrition and exercise. Unlike Type 1, this type of diabetes can often be prevented or delayed by following a healthy lifestyle (*WebMD Health*, 2003). Shiu and Wong (2002) state that “the two forms of diabetes have a different aetiology” (p. 162).

### *HbA<sub>1C</sub> or A1C (Abbreviated)*

HbA<sub>1C</sub> is a measurement of blood glucose regulation over time. Whereas a blood glucose test gives a one-time, or momentary, glimpse of a patient’s blood sugar, an HbA<sub>1C</sub> measures the patient’s average blood glucose over a three-month period. In diabetes, HbA<sub>1C</sub> levels predict the risk of complications (Snieder, Sawtell, Ross, Walker, Spector & Leslie, 2001). Patients with higher HbA<sub>1C</sub> levels had more difficulty coping with diabetes and had an increased expectancy of recurrent illness (McFarland, Rhoades, Campbell & Finch, 2001). Conversely, patients who reported an active coping style were found to have better HbA<sub>1C</sub> values (Rose, Fliege, Hildebrandt, Schirop & Klapp, 2002).

### *Healing*

Healing is different from coping or managing diabetes. Where coping is a state of “tolerating, minimizing, accepting or ignoring things that cannot be mastered” (Richardson & Poole, as cited in Kralik, Koch, Price & Howard, 2004, p. 260) and “the cognitive process whereby people learn to tolerate the effects of illness” (O’Neill & Morrow, 2001), this does not necessarily lead to healing. Making meaning through healing goes beyond just existing, or “dealing with” the disease. For purposes of this study, healing is a transformational process, an adaptive ideal of living with an illness, and finding a purpose in chronic illness, even if a cure is not possible.

### *Meaning Making*

Several studies referred to making meaning in a chronic illness experience as a search for understanding and assists individuals in finding a sense of purpose in their lives (Dirksen, 1995). Making meaning also assists individuals to regain a “sense of mastery and well-being over an otherwise chaotic and disordered environment” (Bard, as cited in Dirksen, 1995, p. 629) and “changes in self awareness” (p. 631). From the literature and for purposes of the literature review, meaning making was defined as a search for understanding, a sense of purpose, and healing from diabetes. In alignment with the constructive postmodern perspective, making *meaning* of illness is different than finding *truth*. Where truth is a single, transcendent, and objective understanding of reality (Bailey & Tilley, 2002), the idea of creating meaning comes from a personal understanding with multiple realities.

## Organization of the Study

This study was an exploration into the lives and stories of eight women who have lived with insulin-dependent diabetes for at least ten years. Chapter Two contains reviews of literature in the following areas: (a) the theoretical/philosophical framework; (b) chronic illness and meaning-making in the adult education literature; (c) insulin-dependent diabetes and management from the medical literature, and (d) multiple ways of knowing from the adult education and arts therapy literature. Chapter Three of the study provides a detailed description and rationale for the methodology used in this dissertation. Chapter Four summarizes the findings of the initial narrative interviews, and the findings and photographs of the creative, action research process are described in Chapter Five. Chapter Six summarizes the findings of the final interviews, and Chapter Seven revisits the process and the findings in relation to the philosophical framework and research literature, discusses implications for adult and medical education, and recommends areas for further research.

## CHAPTER 2

### REVIEW OF THE LITERATURE

The purpose of this chapter is to review the literature related to the primary research questions: “How do adults make meaning of their Type 1 diabetes?” and “What are the ways in which adults with diabetes could engage in creative expression to find greater meaning and wellness?” To that end, the first section describes the philosophical underpinnings of constructive postmodernism as the conceptual framework, specifically in the deconstruction of traditional patient education and the recreation of alternatives to holistic diabetes care. In relating this to adult education, one area discussed is the gap in clinicians’ preparation to understand their patients as learners or themselves as teachers (Lightburn & Beck-Black, 2001). The doctor, unless an insider with diabetes as well, understands the diagnosis and the treatment plan, but will not need to ever inject a needle under his or her skin four or five times a day. S/he will not need to be attached to an insulin pump 24 hours or day, or s/he will not pass out on the kitchen floor while trying to get a cup of juice. The perspectives of both the physician (as teacher) and the patient (as learner) are needed in order to gain a more complete and holistic picture of the experience of living with diabetes.

The second section contains a review of the literature from both adult education and health education that relates to meaning-making and how adults may find meaning in chronic illness. Because the adult education and medical literature come from different disciplines, each body of literature is reviewed separately. The adult education and psychological literature explains the themes of the use of narratives for new

understandings, the construction of new individual and social identities, the search for meaning in paradox, and the need for a holistic perspective.

The third section focuses on the health education and medical literature that centers on meaning making and diabetes specifically. The themes discussed in this section include the current treatment in diabetes care, the physician's position of power, shifts in self-identity for the patient, and the emotional impact of diabetes on the self. From my philosophical view, both reviews of meaning-making center on the *patient's* perspective, rather than that of the clinician, the family, or other's view of the illness experience. Ravenscroft (2005) stressed that that the patient's perspective is needed, for "without the inclusion of the affected individual's perspective, it is possible that the information [from the provider's perspective] is incomplete or misleading" (p. 502).

To offer a more holistic view of meaning making, the final section describes multiple ways of knowing from the adult education and arts therapy literature. The content in the review summarizes the affective way of knowing and related paths in the adult education literature which include: (a) the spiritual, (b) the use of the imagination, symbols and metaphors, (c) somatic or experience of the body, and (d) the artistic and creative. These ways of knowing create opportunities for expression of what it means to have diabetes in ways that have not been researched. The arts therapy literature provides models for the use of creative expression in finding meaning and healing to be used in this action research study. In this area, the literature reviewed includes artistic expression as a way of knowing, the healing arts in practice, and creative self-expression for those with chronic illness. In summary, these four sections in this chapter describe the philosophical framework, the review of meaning making and illness, a review of

meaning making and diabetes care, and a review of multiple ways of knowing in the adult education and arts therapy literature related to creative expression.

#### Theoretical/Philosophical Framework:

##### Constructive Postmodernism and Multiple Ways of Knowing

Adult education has various purposes, defined through the philosophical lens from which it is viewed. Those purposes include the desire to “acquire some type of knowledge, information or skill” (Merriam & Caffarella, 1999, p. 47), or other purposes such as encouraging the growth and development of individuals, assisting people in resolving practical issues of adult life, and providing opportunities to foster change (Caffarella, 2002). Patient education in a health care setting is a form of adult education, and this section explores the theoretical framework of constructive postmodernism from which this study emerges. This will be explained following a look at the philosophical groundings of traditional approaches to patient education.

##### *Philosophies of Traditional Patient Education and Adult Education*

“Although learning can be defined in a variety of ways, most definitions include the concepts found in behavioral change and experience” (Merriam & Caffarella, 1999, p. 249). In fact, one definition is that “learning can be thought of as a process by which behavior changes as a result of experiences” (Maples & Webster, as cited in Merriam & Caffarella, p. 250). Most of the patient education has been based on prescribing behavioral changes, and has centered on the doctor’s expertise and evidence-based knowledge in improving behavior and metabolic control (Bissell, May, & Noyce, 2004; Lerman, 2005; “Young Adults,” 2004). In the traditional medical model, behavioral changes and adherence to treatment are essential for improving the prognosis in chronic

illness and clinicians counsel patients on how to improve adherence regarding their diet, exercise, and insulin regimens, and in keeping their appointments (Lerman, 2005; Rhee, Slocum, Ziemer, Culler, Cook, El-Kelli, et al., 2005). Self-help books, marketed through the American Diabetes Association, also emphasize changing patient behavior. Sample titles include: *101 Tips for Behavior Change in Diabetes Education* (Funnell, Anderson, Burkhart, Gillard & Nwankwo, 2003); *Diabetes – A Practical Guide To Managing your Health* (Rodgers & Walker, 2005); *Diabetes A to Z* (American Diabetes Association, 2003b); *Dr. Bernstein's Diabetes Solution* (Bernstein, 2003) and *Diabetes for Dummies* (Rubin, 1999).

#### *Assumptions in the Traditional Medical Model*

The traditional medical approach to patient care in diabetes shares the underlying assumption that adherence improves care, and that this adherence objectively measures the extent to which patients' behavior relates to medical advice (Lutfey, 2005).

Following dietary requirements according to the standards of the diabetic food plan, adjusting insulin to meet food intake, and exercising religiously to control blood sugar are the three main goals in this approach. Typically, the plan is determined by the doctor, and the patient is expected to follow, comply and adhere to the treatment.

In the 1990s, the results of the Diabetes Control and Complications Trial (DCCT) were published, placing an even greater emphasis on controlling blood glucose and adhering to the treatment plan. The trial demonstrated a lesser risk for chronic complications of diabetes, such as retinopathy, kidney disease, heart disease and neuropathy when intensive control was used. The results of the DCCT “forever changed the philosophy of diabetes treatment, mandating that meticulous glycemic control be the



therapeutic goal” (Skyler, 1997, p. 648). The plan for patients was to frequently measure blood glucose levels and take actions based upon the results. Led by the results of the DCCT, many doctors followed these clinical guidelines and accepted the scientific validity of them (Basina & Kraemer, 2002). Now, there was evidence that patients who carefully followed their treatment plan would reduce their risk for complications. Along with this scientific finding comes the binary division of compliance and non-compliance. Those who followed their plan were “good,” and those who did not were “bad.”

### *Connections to Adult Education*

The use of objectives, learning by reinforcement, and behavioral modification in learning exemplify the behavioral approach to education. Three traditional roots in behaviorism include (a) materialism, entailing some type of determinism to explain behavior and basing reality on what is external, factual, and observable; (b) scientific realism, preferring the hard data of science over the soft data of religion, art and the humanities; and (c) positivism, knowing through scientific observation and the measurement of facts (Elias & Merriam, 2005).

Through the philosophical view of behaviorism in adult education, the role of the teacher is to provide knowledge to the student in order to change the student’s behavior. In this way, learning can occur. Objectives are set for the student to reach, and the behaviors are reinforced if the objectives are met. In patient education, much the same phenomenon occurs when medical professionals provide scientific evidence to the patients in order to improve glycemic control. Objectives to reach the desired number are set, and the patient is expected to bring those blood sugar results to the next appointment so that the doctor may determine whether the objective has been reached. Learning

objectives maintain that “learning outcomes could be measured objectively and precisely, thus revealing how much progress has been made on the part of the learner” (Elias & Merriam, 2005, p. 94).

There is also a humanistic orientation implied in the approach to patient education. Humanists believe that people can control their own destiny, that people want to become better or strive for a better world, and that their behaviors are a consequence of their personal choices from an individualistic perspective (Merriam & Caffarella, 1999). The humanist philosophy (such as Knowles, as cited in Tisdell & Taylor, 2000) has an individual and psychological worldview, where there is little recognition of difference between learners and the student has the role of self-teacher. This view is also found in diabetes education, where it is assumed that patients have the ability to shape their destiny through compliance and adherence. A humanist trend in diabetes care is to become more collaborative by involving patients and families in the educational process, but the doctor still controls the process (Blaylock, 2000).

#### *Constructive Postmodern and Feminist Poststructural Perspectives*

Two interconnected perspectives that offer a more creative and holistic approach to adult education and to patient education for diabetes care are constructive postmodernism, informed by the works of Foucault (1988, 1980, 1972) and the closely related feminist poststructuralist view (St. Pierre, 2000; Tisdell, 1998). Postmodernism is used to explain nearly everything that is not considered “modern,” or in the worldview of the Enlightenment. Unlike the modern world, which is characterized by the rational, scientific and industrial view, the postmodern perspective is more fluid, complex and adaptive (Wheatley, 2001).

There are several paths of postmodernism, including deconstructive postmodernism, which is also called literary, philosophical, or “ludic” postmodernism (Ebert, 1996). Deconstructivists believe that the idea of reality itself is “strictly a fiction, a construction of the imagination” (Inbody, 1995, p. 532). Everything is contested, and the focus is on a play on words. Derrida (as cited in St. Pierre, 2000) claims that we can never know what something means. This kind of mind and word game makes it difficult for any kind of change to occur, much less issues related to diabetes care, and ludic postmodernism does not reflect the philosophical underpinning of this research.

In contrast, the constructive postmodernist places little value in deconstructing categories until there is nothingness, but makes way for deconstruction of former ways of thinking in order to bring reconstruct new perspectives. In the constructive space, the modern and postmodern live in moments of dynamic tension (Edwards & Usher, 2000). Here, scientific evidence and research play on the same ground as questioning of assumptions and recreating ways of knowledge. This philosophical view combines the imaginative process needed to create hypotheses with the muscle behind scientific research. It deconstructs evidence to allow room for multiple ways of knowing, and both the rational perspective and alternative ways of knowing are valued. It is important to note that, because of the various discourses of postmodernism, and to distinguish deconstructive from constructive postmodernism, many adult educators avoid the term postmodernism and refer instead to poststructuralism (Chapman, 2003; St. Pierre, 2000; Tisdell, 1998). The term “poststructural” as opposed to “postmodern” makes social structures visible, and avoids the confusion between those versions of postmodernism that focus only on deconstruction. For our purposes here, constructive postmodernism is

roughly equivalent to resistance postmodernism and poststructuralism (Lather, 1991; Mann & Huffman, 2005; St. Pierre, 2000).

With these remarks in mind, closely related to constructive postmodernism, then, is feminist poststructuralism (Blundell, 1992; Mann & Huffman, 2005; Phillips, 2002; St. Pierre, 2000; Stone, 1999; Tisdell, 1998), which explores the structures of the system and positionality of the participants within the system. Although Foucault and feminism have not always been seen as compatible, they are similar in their attention to power, ongoing construction of knowledge and discourse (English, 2006). Feminist poststructuralists explore issues of positionality regarding the way that people are “positioned” relative to the dominant culture, which connects to whose voices are heard, and whether there are certain minorities (such as women, certain ethnic groups, or patients of the lower class) represented in the research. Stone (1999) addressed this idea of positionality clearly: “Who one is matters and in educational research this matter plays out in who is researched, by whom, and in what ways” (p. 328). This brings into question not only who is researched, but also the methods of recruitment practices for the research, the theoretical underpinnings of the physicians, and the purpose of those who are funding the research. A feminist poststructuralist would address issues of power in race, gender and class relations, as well as issues in how knowledge is constructed, challenge the dominant biomedical structure of diabetes, and help patients understand the multiple differences they carry with them as people with a chronic illness.

As stated earlier in Chapter One, this study is not focused on gender, but is informed by feminist poststructuralism because feminist scholars have given attention to affective ways of knowing (Belenky et al., 1986; English, 2005; Lather, 1991; St. Pierre,

2000; Tisdell, 1998). Although not postmodernists or poststructuralists, Belenky et al. challenge rational analysis, objective reasoning, and scientific thought, which are traits usually attributed to a masculine identity. Insights from feminists such as Belenky et al. called into question the exclusive focus on rationality as a way of knowing. The space created by attending to connection, relationship, and the subjective self opened space for affective and multiple dimensions of learning.

A simplification of these three different, but related, postmodern perspectives can be described using a metaphor of a cardboard box. The deconstructive postmodernist would deny the existence of the box and say, “What box? The box is not a box.” The constructive postmodernist would recognize the existence of the box and ask “What could we do differently with it,” with the feminist poststructuralist also asking, “Yes, and *whose* box is this?” The philosophical underpinnings of the postmodern perspective are listed below, and they include: (a) the recognition of fluid, shifting and multiple identities of “self;” (b) construction of knowledge; (c) power relations and voice; (d) deconstruction of binary categories; and (e) differing views about “truth” and certainty.

#### *Fluid, Shifting and Multiple Identities*

The self is not seen as unified and integrated, but as fluid and ever-changing. As Gergen (cited in Merriam & Caffarella, 1999) argues, “Under postmodern conditions, persons exist in a state of continuous construction and reconstruction ... Each reality of the self gives way to reflexive questioning, irony and ultimately the playful probing of yet another reality” (p. 357). There are many potential selves and stories to narrate in a sea of possibilities (Dirkx, 2001; West, 1996). Sheared (1999) refers to the self navigating this sea of “polyrhythmic realities.”

The addition of a chronic illness can be one of these identities from which patients view themselves, but the illness is only part of the whole person. Also, this identity with disease can shift from the foreground to the background, and allows for the possibility of change to occur over time. This is different from a behavioral view, which would view the process as linear, or “the step-by-step” approach to change. Multiple changes are occurring within individuals simultaneously. Viewing identities as fluid, multiple, and unstable presents more possibilities for the understanding of differences within individuals, and allows for multiple understandings of what is “true” and “real” (Mann & Huffman, 2005). Constructive postmodernists would deconstruct the established identity of patient and reconstruct a new understanding as a person with multiple and intersecting levels of identity. Feminist poststructuralists would be additionally concerned with how those identities (race, gender, sexual orientation, class, for example) are positioned within the dominant culture, and how social structures shape identity. Both constructive postmodernists and feminist poststructuralists would discuss these identities as constantly shifting. The more we are “conscious of how structural systems of privilege and oppression inform our identity and behavior, the more we have capacity to act to change our behavior ... thus shifting our identity” (Tisdell, 2001, p. 275).

### *Construction of Knowledge*

Postmodernity is characterized by a questioning of the scientific method, or any *one* method, a denial of the universal truth and technical reason, and of “objectivity and value-neutrality in the making of knowledge claims” (Edwards & Usher, 2000, p. 37). In a postmodern way, the source of knowledge and the transference of knowledge are questioned in order to reconstruct new relationships with ourselves and our experiences.

Knowledge is not limited to a text or medical diagnosis, but is found in many ways, a few being the body, imagination, emotions, relationship, and the space of connection between these that allows for alternative ways of constructing knowledge.

Knowledge is not only objective and rational, but is open to the engagement of the somatic, imaginative, intuitive, and creative. In this way, the understanding of disease is both an objective measure of science and a human experience filled with emotion (Ironside, Scheckel, Wessels, Bailey & Seeley, 2003; Wright-St. Clair, 2003). If diabetes were recognized only as a measure of blood glucose, then the experience of having a low blood sugar, the worry about complications, and the metaphor of dry bones would have no meaning. But the experience of having diabetes does have meaning to those who *know* the experience of these things, and it is often in the body, the imagination, the emotions, where knowledge about having diabetes is constructed.

These affective ways of making meaning have been silenced in a culture of rational analysis, objective reasoning, and scientific thought, which are traits usually attributed to a masculine identity. The traditional way of “viewing ‘authority’ emphasizes a mode of rational argument and excludes other, more diverse ways of knowing” (Flannery & Hayes, 2001, p. 35). From a constructive postmodern and feminist poststructural perspective, the traditional view is challenged by raising the questions of who constructs knowledge and how that knowledge is transferred. The presentation of knowledge is not excluded to one group or one view; rather, it is made available to all learners in multiple ways. The space created by attending to connection, relationship, the subjective self and multi-dimensional ways of knowing open space for the *affective* dimensions of learning.

### *Power Relations and Voice*

Traditionally, patients have not often had a voice in the ways in which they were able to communicate with their doctors and medical team. They have been locked out without a key to the medical terminology, objective descriptions, and the classification of these, typically in a language within a reductionistic biomedical model (Koch, Kralik & Sonnack, 1999). Many medical decisions are made by doctors and their medical power to determine what is or is not in the best interest of the patient. The patient's perspective typically is not authorized or attended to in this interaction (Nair, Dolovich, Ciliska & Lee, 2005). From a postmodern view, the insider's perspective of the patient needs to be included and, in fact, is central to this process (Hartrick, 1998).

From both a constructive postmodern and feminist poststructural view of patient education, a focus is on discovering the ways that patients find meaning and construct knowledge. Another emphasis is on developing a collaborative relationship between the doctor and patient to find ways of treating diabetes that meet the need of the patient. Additionally, the feminist poststructuralist would also say that there cannot be a truly *collaborative* relationship because of the differences in the economical and educational positionalities of the doctor. Most postmodernists would agree that one voice -- one ontology, one epistemology, one code of values -- need not prevail for all. There is room for a chorus of voices. Here, the door is opened to the multiplicity of traditions and voices of which we are a part and to an emergent dialogue with unlimited creative potential (Gergen, 2001).



### *Deconstruction of Binary Categories*

Postmodernists and poststructuralists challenge such categories of patient/doctor, right/wrong, rational/affective, science/experience, or normal/abnormal (specifically Foucault, 1972) and deconstruct the way that knowledge has been determined by the medical field. Descartes exemplified this binary categorization through his thinking of either/or in Cartesian dichotomies and his mind/body separation (Hemphill, 2001). In constructive postmodernism, the binary categories are deconstructed and recombined in order to form new possibilities of relationship. From this view, the mind/body relationship is nondualistic and acausal; so that even to speak of mind and body is misleading. Mind and body both enfold and interpenetrate each other (Wade, 1996). There is an emphasis on the body-spirit-mind connection, rather than a separation; or a relationship between rationality and affective domains of knowledge (Tisdell, 1998).

In the medical setting, this would mean paying attention to the psychosocial aspects of having diabetes, highlighting the value of the emotion and the imagination to help patients find healing, and rediscovering ways of thinking (cognitive) and feeling (affective) about diabetes. There would be an appreciation of both scientific research to find a biomedical *cure* for diabetes, and the affective experiences that contribute to the *healing* process for those who have the disease. One participant said, “If you give me medicine, you’re treating 30 percent of my disease; if you could treat my heart [emotions], you could have treated 70 percent” (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 160). Constructive postmodernism is not about the fragment of either/or and the separation of mind/body categories, but the connections in both/and, which creates space for all types of ways of knowing and learning.

*Truth and Uncertainty*

Constructive postmodernism and feminist poststructuralism also have underpinnings that relate to the social construction of reality, the exploration of subjective experiences, and questioning of “truth” (Phillips, 2002). To many postmodernists, there is not one overriding Truth, but multiple truths, each determined by both individual and social realities (Foucault, 1988). Some may believe there is one Truth, but that we can not know or understand it in this lifetime. In constructive postmodernism, both statements are possible, and “true.” Feminist poststructuralists would be concerned with who was researched in the trial. They would raise questions such as, “What racial groups and ethnicities (and genders, sexual orientations, classes) were represented? Who defined the success of the study? What was the socioeconomic status of the participants? Who was funding the study? Who will benefit from the study? What was the race and gender of the participants?” In other words, “Whose truth was heard?” Although a constructive postmodernist would be aware of whose voice was represented, the focus would be not be on social change, but the reconstruction of the study’s results to improve the lives of the individual participants.

By engaging with the problems and issues raised by postmodernity, adult educators may find the interpretive frameworks and conceptual resources helpful in reflecting on current patient care (Edwards & Usher, 2000). By taking a constructive postmodern view, fresh forms of knowing will allow for a more holistic and inclusive view of patient education. Traditional medical models and behavioral components are no longer enough, although this does not imply that they have no place. The challenges of

postmodernity invite different questions and suggest new approaches to learning in its wide variety of forms.

From these philosophical perspectives, the construction of knowledge is not only rational, but also somatic, imaginative, intuitive, and creative. By including additional ways of knowing, more patients with diabetes may find meaning and healing within their chronic illness. This allows patients to give voice to their creativity and other aspects of their being, and may account for ways that many people come to know and learn, and the way they make meaning of an illness.

### Meaning Making and Chronic Illness

The initial impetus behind this literature review on meaning making and chronic illness was the lack of research on the ways in which chronic illness was discussed in adult education and/or patient education classrooms. Although there was literature surrounding the inclusion of race and gender in higher education, there were few, if any, studies regarding chronic illness. In fact, two educational databases, Proquest Psychology Journals and Wilson, matched only two articles (Baumgartner, 2002; Jackson, 2006) that talked about adult education and illness at all. Like those of a marginalized race, sexual orientation, or gender, those with a chronic disease cannot leave their identity of illness at the door. Chronic illness is a part of who they are. One of the first movements toward an understanding of identity surrounding chronic illness was to explore the ways in which adults, in general, make meaning of their chronic illness, and how they cope with their disease. How do they find a purpose in their illness? Cassel (1982) stated that, “personal meaning is a fundamental dimension of

personhood, and there can be no understanding of human illness or suffering without taking it into account” (p. 641).

The number of people with chronic illness is increasing. Nearly half of Americans have at least one chronic disease, everything from allergies to heart disease. That translates into 125 million people among a population of 276 million. Considering the success of medical advancements and the aging of the population, the number of individuals with a chronic illness is expected to reach 157 million by 2020 (*Associated Press*, 2000). This means that nearly all of us have, or know someone who has, an illness that is incurable. Unlike an acute illness that involves a temporary treatment plan with hope of recovery, a chronic illness requires an “ongoing process of adjustment to the situation” (Youngkhill & McCormick, 2002, p. 237). When faced with a chronic illness, whether for ourselves or those close to us, we will ask questions about how to make sense of our disease. Milstrey-Wells (2000), both a physician and a patient with multiple chronic illness, said:

Any health condition that’s ongoing, that’s limiting in any way, that’s painful or fatiguing, requires an understanding of not only the condition, but of who we are and how we’re going to deal with it. (p. 4)

By looking at the literature on meaning-making and illness, we can begin to understand how adults co-exist and make sense of their disease.

#### *Overview of Types of Studies and Definitions*

There were 25 studies included in this review of the research on meaning making and chronic illness. An underlying theme in this literature review of the studies on

meaning making and chronic illness was that all of the studies were qualitative in nature. The researchers adopted an insider perspective, or a way of understanding the participant's view of the chronic illness experience. Because of this focus on the individual perspective, all of the articles with a methodology section used actual quotes, field notes and narratives of those with chronic illness in the empirical research. Qualitative research was the common form of research because it best captured participants' lived experience (Narayanasamy, 2002). Daaleman, Kuckelman-Cobb and Frey (2001) selected a qualitative research method "in order to gain a richer and more complete description" (p. 1504). Others chose a form of qualitative study to "illuminate factors that are absent in the [quantitative and correlational] existing literature" (Lyons, Jacobson, Prescott, & Oswalt, 2002, p. 8) and to exemplify the "meaning of human phenomena while understanding the meaning of the lived experience" (Sturge-Jacobs, 2002, p. 21).

In order to study chronic illness, the researcher needs to define the context in which it is used. Two studies defined chronic illness as an "altered health state that will not be cured by a surgical procedure or a short course of medical therapy" (Narayanasamy, 2002, p. 1464) and a "disease or injury that lasted more than six months and has caused an individual to significantly alter his or her day-to-day activities" (Ironside et al., 2003, p. 172). Other studies implied that chronic illness was a type of life-threatening illness that had no cure (Allcroft, 2003; Angen, 2000).

Others did not provide a definition, but used specific examples of illnesses for research in their study. The examples included forms of cancer (Allcroft, 2003; Angen, 2000; Lyons et al., 2002), chronic lung disease (Bailey & Tilley, 2002), AIDS/HIV

(Baumgartner, 2002; Bedell, 2000; Hall, 2001), psychiatric issues (Boydell, Gladstone & Crawford, 2002; Casey & Long, 2002), rheumatoid arthritis (Brown & Williams, 1995; Neill, 2002), type 1 and type 2 diabetes (Koch et al., 1999; Paterson et al., 1999), chronic myocardial infarction (Svedlund, Danielson & Norberg, 2001), multiple sclerosis (Wright-St. Clair, 2003), and fibromyalgia (Sturge-Jacobs, 2002). Other researchers studied chronic illness in general, without reference to a specific disease or condition. For purposes of this dissertation, the definition of chronic illness was synthesized from the literature. Chronic illness is defined as an incurable disease or injury that has caused a change in the way an individual views or experiences day-to-day activities.

#### *Findings of the Studies*

Although finding meaning from chronic illness can be a difficult road, many individuals in the research found meaning in their lives. Finding meaning in long-term illness has been associated with successful coping, adaptation and recovery (Allcroft, 2003). With the exception of some participants (Koch et al., 1999; Svedlund et al., 2001), most of the experiences in the research were positive ones, filled with rich narrative. One woman diagnosed with HIV/AIDS said that her disease gave her a way to make a difference and said “everything happens for a reason” (Baumgartner, 2002, ¶ 30).

Since narrative analysis involves the “examination of participant stories identified in interview data” (Bailey & Tilley, 2002, p. 575), it would make sense that the purposes of most studies were to understand the lived experiences of those with chronic illness and how meaning could be made from that experience. Brown and Williams (1995) added that people make meaning in terms of their life experiences, expressed in narratives. Youngkhill and McCormick (2002) refer to this as listening to individual’s life stories.

Five themes emerged from the data and the narratives of the research. They include: (a) using narratives for new understandings, (b) constructing new individual and social identities, (c) finding meaning in paradox, (d) searching for a holistic perspective, and (e) restructuring the meaning of illness as a transformational experience.

#### *Using Narratives for New Understandings*

Much of the literature supported that the use of narrative, or telling stories, is the primary way adults make meaning of their illness (Angen, 2000; Bailey & Tilley, 2002; Casey & Long, 2002; Wright-St. Clair, 2003). As cited in Wright-St. Clair, “The use of personal narrative and storytelling have been explored as ways of making sense of things, managing the everyday world, and reconstructing a life for those who live with a longterm illness” (p. 47).

The qualitative researchers who analyze stories realized the importance of telling stories as a meaning-making strategy (Bailey & Tilley, 2002). In the story of one man suffering from lung disease (Bailey & Tilley), his going to the store was now a difficult chore. As a young boy, he ran to the store, but now, “ah if I **walk** a block that that plays me right out” (p. 577). From this narrative, it is found that making meaning of illness requires a new understanding of living with disease. For another patient, being ill required a “whole new way of looking at myself” (Ironsides et al., 2003, p. 178).

Because of illness, there is a change in priorities. One man with AIDS said that the main motive for change was that a lot of things he used to think were important no longer had value. They “didn’t matter. Being successful at work. Being able to press 20 more times at the gym. Being at this party. Didn’t matter. You know, it seemed very superficial, silly” (Bedell, 2000, p. 202). Participants in a different story agreed that

living with a chronic illness taught them about being human and about what matters in life (Ironsides et al., 2003).

Finding meaning required an understanding of being both healthy and being ill (Ironsides et al., 2003; Kralik, 2002). In earlier research, Loveys (as cited in Kralik, 2002) identified a “process of transition to the ‘at risk’ role of people living with chronic illness which is defined as a perplexing state of neither being sick nor well” (p. 152). Those with HIV/AIDS found that this was a tentative and uncertain place (Bedell, 2000). Uncertainty also came through in the way those with chronic illness understood symptoms. As one woman with rheumatoid arthritis said, “Any aches and pains you get, you think, what’s happening now?” (Brown & Williams, 1995, p. 699).

In some stories, participants used metaphors, analogies, or other symbols to describe their illness. “People often use metaphors when it is hard to depict the subjective meaning of things in everyday words” (Wright-St. Clair, 2003, p. 46). Participants with AIDS referred to their disease as a dragon, a pet (Baumgartner, 2002), and a partner (Baumgartner; Wright-St. Clair). Other metaphors included a specimen (Ironsides et al., 2003), an aggressor, a savior, a guest, an adversary, the crew of the Marie Celeste, or a big, black monster with huge teeth (Wright-St. Clair). Another shared that maintaining a balance in living with illness is like sailing a small boat (Kralik, 2002).

Women commonly disclosed how their “reflective attempts to articulate the meaning of their experiences brought about new understandings of their illness and their everyday world with multiple sclerosis” (Wright-St. Clair, 2003, p. 50). The use of story was a powerful way to construct meaning for those with chronic illness. McAdams said,



“If you want to know me then you must know my story, for my story defines who I am”  
(as cited in Casey & Long, 2002, p. 603).

*Constructing New Social and Individual Identities*

A constructivist orientation “asserts that the fundamental quality and motivation of being human is the effort to interpret experience and to seek the purpose and find significance in events” (Allcroft, 2003, p. 4). According to this, the constructivist research techniques enable a researcher and a participant to observe the participant’s process of meaning making. Fife’s process model diagram (as cited in Allcroft, 2003) supposed that the diagnosis of a chronic illness produced a coping response. The response then “triggers construction on two connected dimensions: self meanings and contextual meanings” (p. 9). The construction of self concerns a construction of a new, individual identity, where the construction of context involves the social world around the person with a chronic illness.

For many participants, social interaction and support was an important part of making meaning (Baumgartner, 2002; Boydell et al., 2002; Brown & Williams, 1995; Casey & Long, 2002; King, Cathers, Brown, Specht, Willoughby, Polgar, et al., 2003; Lyons et al., 2002; Narayanasamy, 2002). Getting involved in the HIV community gave one participant a “lot of strength” and helped her realize she was “worth fighting for” (Baumgartner, 2002, ¶ 58). For some, volunteering and investing in relationships were ways in which they could construct meaning by helping others with HIV/AIDS (Hall, 2001).

Another study of making meaning in HIV (Bedell, 2000) found that being able to lean on other people nearby, or a phone call away, was comforting. One man said, “A

day does not go by that I don't talk with these people [family and friends]. And I talk very openly. And try to listen as well" (p. 200). Those with a psychiatric disability said that friendships were important, and friends made them feel warm and comfortable. (Boydell et al., 2002). Sherwood (as cited in Narayanasamy, 2002) suggested that talking with others helps those with a chronic illness connect to others who understand them.

Support groups were also an outlet to share feelings and to "unburden on each other" (Bedell, 2000, p. 200). For those with diabetes, it also was a source of obtaining information of managing disease (Koch et al., 1999). In the case of diabetes, however, there were societal limitations because of the adjustments needed in eating arrangements. Since most social events involve food, the participants with diabetes felt left out (Koch et al., 1999).

Participants also found meaning by reflecting on their individual purposes for life, rather than on the larger social context. In Daaleman et al.'s study (2001), "Meaning making was the contextualization of medical conditions within a life scheme" (p. 1507). These participants reflected on their purpose in life and personal philosophies as an important part of making meaning.

In a few studies (Lyons et al., 2002; Narayanasamy, 2002), meaning making included a spiritual awareness of needing someone or something greater than themselves to see them through. For this context, spiritual awareness meant reflecting on a personal faith or a belief in God or a Divine Power, and praying for an intervention.

Narayanasamy pointed out that the literature on spirituality and chronic illness is scarce.

For some participants, finding a purpose meant asking questions and seeking answers (Allcroft, 2003; Koch et al., 1999). Allcroft continued that

In much the same way as a scientist, it appears that people diagnosed with a variety of life-threatening illness have an inherent tendency to ask questions, generate theories as alternative answers to those questions, and develop hypotheses to those tentative answers. (p. 11)

Participants found a purpose by reflecting on and constructing meaning from both an individual and social context.

### *Finding Meaning in Paradox*

Although the word, *paradox*, was not used in each study, participants used multiple examples of paradox in their narratives. Researchers may have used the word dialectic (Neill, 2002), quandary (Angen, 2000) or balance between (Paterson, 2001). Those who spoke of their experiences of living with chronic illness in Angen's study gave "evidence of negotiating numerous contradictory pathways on the journey to healing" (p. 6). They felt that the threat of illness gave them both physical and psychological limitations while also bringing a freedom or a sense of permission to make changes in their lives. They felt a sense of being blessed to have lived another day. One patient (Daaleman et al., 2001) described her condition as a paradox between feeling "blessed and yet healed, even though I suffer with the condition" (p. 1507).

In a few studies (Angen, 2000; Kralik, 2002; Neill, 2002; Svedlund et al., 2001), people's stories of living well with chronic illness involved both taking responsibility for the illness and not feeling shamed or despondent because of it. Those with illness needed to take an active role in finding meaning, while still retaining a sense that they are not to blame for causing the disease.

Another paradox was that those who once had a disease that was considered *acute* now had a *chronic* condition due to improved treatment techniques. There was a shift from thinking about “When am I going to die?” to “What am I going to do for a living?” (Bedell, 2000, p. 201).

People with illness needed to make sense of both internal processes as well as external, i.e. family, culture, medical doctors (Casey & Long, 2002). In the case of psychiatric illnesses, it was the paradox between the voices inside and outside of the head. In other illnesses, it was the paradox between the not wanting to take medication but having to. There was a tension between the inside and the outside world, and this caused a conflict in making meaning.

One metastudy (Paterson, 2001) provided the Shifting Perspectives Model of Chronic Illness. The model shows living with chronic illness as an “ongoing, continually shifting process in which people experience a complex dialectic between themselves and their ‘world’” (¶ 7). From this perspective, the experience of chronic illness is either in the foreground or in the background. When illness is in the foreground, individuals focus on, and may be absorbed by, their sickness. At times when wellness is in the foreground, participants can try to understand their disease. Their self, not their disease, becomes the source of identity. These shifting perspectives between *ill* and *well* helped adults make meaning of their chronic illness. In a later study, Paterson (2003) interviewed a participant about the experience of living with a chronic disease and applied the model. Although the patient agreed that the model was reflective of her experience living with MS, there were also times when both were equally present. She describes this as “living in the orange,” where illness represents red and wellness represents yellow, and “I am

likely to be a blend of things” (p. 990). This addition to the model illustrated the importance of including patients with illness in the research process.

In another example of living in paradox, Boydell et al. (2002) said there is a “dynamic interplay” between friendship being necessary to good mental health, and good mental health being necessary for establishing friendship (p. 126). In the same study, there was the question of whether to tell or to not tell others about their disability. Telling may result in rejection, but withholding information may result in tension.

Two authors (Ironside et al., 2003; Wright-St. Clair, 2003) made the distinction of disease as an *objective measure* of change and illness in the *human experience* of illness. The paradox existed in the subjective and objective, as well as the disease and illness. Dunn said, “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (as cited in Angen, 2000, p. 4). The holistic model emerged from this type of systems perspective.

#### *Searching for a Holistic Perspective*

The biomedical approach is not enough to understand the experiences of chronic illness (Brown & Williams, 1995; Ironside et al., 2003). Biomedicine insists that suffering is without meaning, and unnecessary, because

pain can be technically eliminated. Symptoms are divorced from the person who has them and the situations that surround them, secularized as mechanical mishaps, and so stripped of their stories, the spiritual ramifications and missing pieces of history that make meaning. (as cited in Angen, 2000, p. 9)

Angen continued that biomedicine has employed scientific methods to alleviate the suffering of illness and to make life longer, but “growing numbers of people . . . are

searching for ways to take an active role in their own healing processes, recognizing the need to engage their own healing resources” (p. 4). Other researchers (Ironsides et al., 2003; Koch et al., 1999; Lyons et al., 2002) added that focusing on functional recovery is not adequate enough to describe the way in which chronic illness is experienced.

In contrast to the biomedical approach, all participants of one study (Daaleman et al., 2001) talked about having a worldview as well as an individual view that incorporated mind, body and spirit. One participant identified this as “a sense of life that’s so much larger, and because of connectedness, it’s not just alone, that you’re part of something much larger” (p. 1508).

An example of a holistic model used in health care settings is the conceptual framework of the Health-Related Spirituality Model (Daaleman et al., 2001). This framework described changes in the functional status of those with illness and the paths that the person takes to understand the meaning of life to become a healthy person “at peace with myself” (p. 1509). According to this framework, the main way in which participants made meaning was to accept the reality of their life events. All participants in Daaleman’s study described their life experiences in comprehensive and holistic terms, not limited to their medical status. This global perspective was captured by one participant as “that kind of harmonious blending with the entire” (p. 1507).

### *Restructuring the Meaning of Illness as Transformational*

Baumgartner (2002) said that the nature of learning in chronic illness is transformational. Using Mezirow’s transformational theory, beginning with a disorienting dilemma, Baumgartner believed that critical reflection on this event is the “lynchpin of the transformational experience” (¶ 4). Kralik (2002) also recognized that

participants experienced a disorienting dilemma or, in this case, an extraordinary event that caused great turmoil and stress in their diagnosis. One participant noted:

It doesn't seem to happen the way we'd think it would. Our day of diagnosis seems to take us by great surprise, no matter how long or obvious the road to that point has been. I recall just how quickly it all happened, and how just a few words changed my life forever. (p. 149)

Through reflective processes and taking action to cope with their illness, participants were able to move on with their lives in a position of "ordinariness" (p. 149). Embedded in this process of learning to live with a chronic illness is the implication that transformation represents "the adaptive ideal of living with a chronic illness" (Paterson et al., 1999).

Some individuals lived with chronic illness by participating in meaningful occupation through textile arts (Reynolds, 2003a). This helped them maintain their self-esteem, restore identity, and led to a turning point (King et al., 2003), or transformation, in their lives. According to Corbin and Strauss (as cited in Reynolds), "A balance between preserving continuity (of former interests) . . . and embarking on change was apparent in the narratives, supporting the view on identity reconstruction" (p. 125).

Hall (2001) said there are three stages in constructing meaning from chronic illness, which included: (a) experiencing suffering, (b) containing suffering, and (c) transforming suffering. Dealing with loss of autonomy and a loss of self was an aspect of all three stages. As participants confronted their suffering through self-reflection, they experienced transformational experiences and were able to heal and find a purpose in their illness.

Those with diabetes referred to the transformational process as a “hatching out of your shell” and an ongoing series of steps toward “coming to terms with me as a diabetic and me as the person I wish to be” (Paterson et al., 1999, p. 791). Emerging from their study, Paterson et al. provided a Model of Transformation. In this model, there is a decision to identify and work with the challenge of having a chronic illness. From there, the individual creates a new understanding of the disease through transformation to help make meaning and purpose of the self and identity within chronic illness.

As a result of the perspective transformation, participants found an enormous amount of purpose and a reflection on what was important, whether that be an increased awareness of nature, of appreciation for the human condition, or a sense of gratitude to be alive. Sword (as cited in Kralik, 2002) added that reflection and inquiry is a transformational process to interpret and make meaning of experiences. One individual with cancer explained her transformational experience as she realized that, “One day, I looked up at the sky and suddenly felt this immense gratitude” (Angen, 2000, p. 6). Another participant with AIDS explained, “I have a new vision of myself, a new dream for my life” (Hall, 2001, p. 51).

In the theory of Health as Expanding Consciousness (as cited in Neill, 2002), Newman revealed that health and illness are not separate, but a unitary context of a whole. She states that an event, like the diagnosis of an illness, provides the conditions for individuals to see differently. *Self-transcendence*, defined as the acceptance of hardships, and *transformation*, defined as the process of living with chronic illness, resulted in “new ways of being and doing in living” with the challenges of illness (p. 30).



This transformational experience was not comfortable. It caused struggles (Kralik, 2002) as “your emotions all over the place as you strive to adjust . . . you learn to get some control of your illness and the way you perceive it” (p. 150). Some moved through this transformation by making different choices and living within the boundaries that illness had imposed upon them (Kralik; Lyons et al., 2002). One woman with multiple sclerosis said, “My life is so different now” (p. 151). Another expressed that “Growing and learning is never a bad thing in our lives. But with an illness we must grow into an entirely different pattern than what our roots started” (p. 152).

#### *Summary and Discussion of Findings*

In summary, participants made meaning by telling their stories of illness. Some narratives included the use of metaphor, and some contained the elements of paradox. Social interaction and relationships with friends, families and others with the disease was a way to make connections and to better adapt to the illness.

There were three primary models that assisted in understanding the way adults made meaning: (a) Shifting Perspectives (Paterson, 2001), (b) Health-Related Spirituality (Daaleman et al., 2001), and (c) Model of Transformation (Paterson et al., 1999). In addition, the theory of Health as Expanding Consciousness (Neill, 2002) provided an example of ways to restructure the meaning of chronic illness.

Many participants perceived their illness from a holistic perspective, which meant their diseases affected not just their physical world, but their mental and spiritual selves as well. The biomedical approach to disease did not assist in making meaning. For the individuals in this study, the majority found a sense of peace and acceptance in living with their chronic disease.

As a result of these findings, making meaning is expressed primarily through telling stories of experiences with illness. Although the use of narrative has been a common thread throughout the review of literature, few studies explained *how* adults made meaning through the telling of these stories. Is it the telling of the story itself, or the critical reflection of it, that helps adults find meaning in their illness? What about the stories that people do not, or cannot, tell? These questions led to these areas of discussion.

#### *Researcher and Research Methods*

Beginning with the researcher, to what extent does he or she influence the meaning making process in the narrative analysis? Only a few studies (Baumgartner, 2002; Brown & Williams, 1995; Casey & Long, 2002) recognized the researcher's role of power in the interviewing and interpretation of data, but no others in the review directly addressed the researcher's influence. Baumgartner said she had an influence, but did not address how. Casey and Long asked "To what extent is the story modified in the research interview and subsequent analysis, interpretation and retelling?" (p. 610). As a strength, the researchers did recognize the limitations of their purposeful samples and did not try to make broad generalizations about the findings.

From the studies, approximately 75% of the participants were white women of the middle class, who were educated and could respond in English. Thorne and Paterson (2000) stated that, "The vast majority of insider research in chronic illness has included participants who are able to talk coherently, [and] who are well educated" (p. 11). Although the extent to which these factors influence meaning making is not discussed in the literature, the research on those of a minority status is limited. Another demographic

not included in the research is the ways in which the age of the participants influenced the meaning making process of chronic illness.

If the studies were more inclusive of other ethnic identities and socio-cultural dynamics, perhaps other forms of making meaning would have emerged. Only a few studies (Daaleman et al., 2001; Narayanasamy, 2002) addressed the spiritual component of making meaning. There are many forms of spiritual expression, including the use of art, writing, music, songs, or other creative avenues for expression. Even in the study of Reynolds (2003a), where white women found meaning in their creative artwork, the primary reason they found meaning was that it gave them a sense of meaningful occupation. Not one study used artistic expression alone as a way to make meaning.

An additional area for discussion is the way in which the interviews were conducted. With the exception of a few studies (Baumgartner, 2002; Daaleman et al., 2001), most of the studies were a single, often retrospective, snapshot of an interview. Had the research consisted of multiple interviews over periods of time, the researchers may have developed alternative findings. Additional longitudinal or action research studies would assist in understanding chronic illness as patterns, rather than as moments, in time.

#### *Considerations in Meaning Making Process*

Looking at the meaning making process, some researchers focused on chronic illness in general, and others involved specific diseases. Even in the stories of those with the same disease, such as HIV/AIDS, participants related to their condition in different ways. Some viewed HIV as a dragon, and some called it a partner. The images of these two metaphors suggest different ways in which the participants made meaning, even

though the medical diagnosis of the disease was the same. It would be informative to further explore how the meaning making process of chronic illnesses is similar and how the process in individual diseases is different. Thorne and Paterson (2000) commented that:

The commonalities and variations within chronic illness experience make it apparent that neither a disease-specific nor a generic approach alone creates an understanding of the phenomenon of what it is like to live with a chronic condition. (p. 9)

As the research suggested, this will not be achieved by looking at disease from only a biomedical perspective, but also through the holistic understanding of illness.

One study mentioned that certain illnesses were overlooked in the research. Thorne and Paterson (2000) did not include psychiatric illnesses in their research because this illness was considered a disease of the mind, not the body. The distinction would lead to the assumption that there is a separation between the body and mind. Therefore, diseases like diabetes would also be either a condition of either the body or the mind, but not both. If this were true, daily injections of insulin or life-threatening hypoglycemic events would affect only the physical body, but not the psychological realm. What about fibromyalgia, of which there is no known cause nor cure? Would it be classified as a disease of the mind or the body, and how would the two be distinguished from each other? Based upon two decades of insider research, Thorne and Paterson stated there is clearly a lack of research in the relationship between spirit-body-mind in chronic illness. This research will add to the body of literature in adult education regarding meaning making through multiple ways of knowing.

## Meaning Making and Diabetes

The previous section of the literature review summarized the research on meaning making and chronic illness in general. This section focuses on meaning making within the health and medical education regarding the specific chronic illness of diabetes. It explores what is missing from current medical practice in order to help patients find meaning, not compliance, in their diabetes care. Where compliance is a term defined by medical professionals, and professionals and patients understand the experience of illness from different worlds, meaning comes from the patient's perspective. The meaning of diabetes in people's lives is understood to be linked to the experience and management of the disease process (Hartrick, 1998).

The professional's models of treatment and priorities of care focus on the causes and origins of diseases (etiology), diagnosis, pathophysiology and treatment, while patients' explanatory models are more focused on consequences and influences on daily life (Hornsten, Sandstrom & Lundman, 2004). The differences between patients and professionals in their understandings often result in conflicting expectations and perspectives of care (Nair, Dolovich, Ciliska & Lee, 2005). It has not been determined whether "treatment adherence and metabolic control hold the same significance for people living with diabetes as they do for health care practitioners" (Hartrick, 1998, p. 78).

In taking a postmodern and poststructural perspective, the issue of the power and positionality of the physician is an important one. It is also necessary to explore the positionality of the patient and his or her relationship to the dominant culture in relationship to gender, race and other cultural identities. Research from the American

Diabetes Association (2005) shows that a relatively equal number of men and women in the United States over the age of 20 have diabetes, with approximately 8.7 percent of women (or 9.3 million) and 8.6 percent of men having the disease. The National Institute of Diabetes (1995) also confirmed that diabetes strikes both white men and white women nearly equally, yet there is a higher rate (two to four times) of prevalence in diabetes among African American, Hispanic/Latino, American Indian, and Asian/Pacific Islander cultures than white cultures. Most people, both men and women with diabetes, try to make meaning of their disease and experience an “ongoing process of adjustment to the situation” (Youngkhill & McCormick, 2002, p. 237). *How* diabetes affects people in the meaning making, coping and adjustment process has not been addressed. This review explores the connection others have made in their experiences of living with chronic illness, and reviews the themes that emerged in the health education literature on meaning making and diabetes through a constructive postmodern and feminist poststructural lens.

There are 27 studies included in this review of the research on diabetes and meaning making: 17 of the researchers used a form of qualitative research in compiling the data for the study; nine conducted quantitative research; and one used both quantitative and qualitative methods (Tak-Ying Shiu & Yee-Man Wong, 2002). The patient participants in the qualitative studies were purposeful samples of individuals with a variety of chronic illnesses including diabetes, or diabetes only (both Type 1 and Type 2). Thirty-four had Type 1, 14 had Type 2, and the majority did not specify whether they had Type 1 or Type 2, but simply had “diabetes.” Three of the articles included both men and women in the research, whereas the rest of the participants in this review were either women, or simply specified as “patients,” without specifying gender. From a

constructive postmodern view, this type of generalization is problematic in that an individual should not be lumped into a category of “patient,” without respect to differences in patients’ identities.

### *Findings of the Studies*

Even though it may be difficult to quantify, “the meaning patients attribute to an illness does seem to affect how they rate their overall health, and these perceptions may influence treatment effectiveness, psychological symptoms, coping and somatic outcomes” (McFarland, Rhoades, Campbell & Finch, 2001, p. 250). Four major themes emerged from the health education literature of meaning making and diabetes, including: (a) the cognitive treatment for patient care and diabetes is inadequate, (b) the medical professional has a position of power in patient care; (c) a patient with diabetes experiences shifts in self-identity, and (d) diabetes has an emotional (affective), psychological impact on the self. Other minor themes emerged, which related to (a) the somatic symptoms of diabetes, (b) diabetes as a socially constructed illness, and (c) other factors of influence, such as the patient’s socio-economic status and education, feelings of marginalization, gender, and degree of self-efficacy.

### *Inadequacy of Cognitive Treatment Alone*

Most of the research suggested that the cognitive approach to treatment for people with Type 1 diabetes is not adequate (Chan & Molassiotis, 1998; Hartrick, 1998; Koch, Kralik & Sonnack, 1999; Kralik, 2002; Kralik, Koch, Price & Howard, 2004; McDonald, Tilley & Havstad, 1999; Rose, Fliege, Hildebrandt, Schirop & Klapp, 2002; Skinner, Cradock, Arundel & Graham, 2003). Rose et al. made the clear statement that “pure,

cognitive knowledge of treatment appears to have limited significance under routine conditions” (p. 40-41).

“The prescriptive and perhaps oppressive nature of self-management, as being the adherence to prescribed medical treatment plans, has little meaning for people living with illness” (Kralik, Koch, Price & Howard, 2004, p. 265). In this same article, Thorne and Paterson suggested that health professionals may complicate the learning process with rigid ideas about managing chronic illness. When patients inform their doctors with problems of adherence, many doctors assume:

their patients simply lack knowledge or motivation. They launch into lengthy technical explanations, explaining the pathophysiology of hypertension or motivate their patients through the use of scare tactics, although neither of these techniques have [sic] been proved [sic] to be effective. (Lo, 1999, p. 422)

Kralik et al. (2004) contended that self-management of chronic illness can be both a structure and a process. It does not work to have patients as passive subjects, absorbing the information; instead, patients must be engaged in the dynamic and active process of learning and exploring the boundaries of chronic illness. “Self management of chronic illness was more than ‘doing’ but was entwined with a sense of ‘being’ and ‘becoming’” (Kralik et al., 2004, p. 265).

In one quantitative study (Chan & Molassiotis, 1998), the researchers concluded that there is no association between diabetes knowledge, or the cognitive aspect of knowing, and compliance. In other words, there “was a gap between what the patients were taught and what they were doing” (p. 431). They documented that poor control and non-compliance account for problems in one-third to three-quarters of diabetic patients



(Hernandez, as cited in Chan & Molassiotis), and that only seven percent of diabetic patients were fully adhering to the regimen. Some participants pointed out that if people with diabetes did not follow the regimen, they were viewed as “cheating” and/or not complying with treatment (Hartrick, 1998). It meant that they were somehow in the wrong. “In essence, it felt as if the diabetes regimen was valued more than they were as people” (p. 84).

In addition to a cognitive approach, participants expressed an approach that reflected respect of them as “intelligent consumers of health care information, and a recognition of some aspects of the context of their lives beyond their chronic illness” (Thorne, Harris, Mahoney, Con & McGuinness, 2004, p. 301). Similarly, patients felt antagonized by communication styles that seemed to discount their feelings about disease management or over-emphasized the relevance of scientific and rational evidence for decisions related to living well with diabetes. Chan and Molassiotis (1998) said that providing knowledge about diabetes is only “one step in the process of facilitating patient participation and compliance. It is essential to understand the individual’s belief and attitude, motives, demands or priorities” in order to understand how to help the patient (p. 437).

#### *Patient/Doctor Positionality in Care*

Although much of the research addressed the issue of compliance (Brown, Harris, Webster-Bogaert, Wetmore, Faulds & Stewart, 2002; Kyngas & Hentinen, 1995; Rapley & Fruin, 1999; Thorne, Harris, Mahoney, Con & McGuinness, 2004), compliance is not enough to find meaning or healing. In one study, compliance was defined as a “situation in which the patient’s behaviour corresponds with the clinical instructions given”

(Sackett & Haynes, as cited in Kyngas & Hentinen, 1995, p. 730). This is an issue of power between doctor and patient, and compliance is a way to ensure conformity with to the bio-medical model (Koch, Kralik & Sonnack, 1999). People with diabetes should receive medical care from a physician-coordinated team (American Diabetes Association, 2002). Such teams include physicians, nurses, dietitians, and mental health professionals with expertise and a special interest in diabetes. “When a health care professional is engaged with the patient in problem-solving and care management, there is a feeling of teamwork, of investment in supporting positive outcomes, and of enthusiasm for working together to create the best decisions possible” (Thorne, Harris, Mahoney, Con & McGuinness, 2004, p. 301). According to the American Diabetes Association (2002), it is essential in this integrated team approach that individuals with diabetes assume an active role in their care.

This dual process approach deconstructs the concept of patients as passive victims of medicine, and emphasizes the need to actively involve individuals in the learning process (Skinner, Cradock, Arundel & Graham, 2003). Through a collaborative approach, the patient is acknowledged as a primary player in their diabetes care. Although the medical team is critical to the initial knowledge and ongoing management of care, they are not responsible for the day to day blood testing, nutritional decision-making, and glucose problem-solving that surrounds each minute of the life of the person with diabetes. In fact, “outsider models of diabetes care that invest time and effort in motivating clients to adhere to diabetes regimens and strive toward glycemic control have been relatively unsuccessful” (Kurtz & Rosenstock, as cited in Hartrick, 1998, p. 86).

In taking a constructive postmodern and feminist poststructural view, the patient is central to his or her diabetes care, and it is not entirely in the position of the doctor to make these types of decisions concerning compliance. This is not to undermine the importance or impact of medical advice, but rather to highlight the complexity of having diabetes and to realize the experiences and emotions of the patient. Ultimately, it is the patient who needs to find healing and internal meaning, not the medical team.

“People claimed the empowering process of taking responsibility for living well with illness by questioning the direction of their health care and making choices about every fact of their health care” (Kralik, Koch, Price & Howard, 2004, p. 266). In another study by Kralik (2002), the women challenged information and knowledge, and appraised what was acceptable to their lives. This sometimes earned them the label of being noncompliant with medical treatments. On the contrary, they said, they had found life. “This sense of making choices to enable them to live well with illness could only be achieved once women had the opportunity to resolve the poignancy of the illness experience” (p. 151).

Some patients seemed to adapt well to having diabetes, whereas others worried about the future deterioration of their condition, found difficulty with self-care routines that do not fit their lifestyle, and wondered how to cope with their disease (Hartrick, 1998; Kralik, Brown & Koch, 2001; Kyngas & Hentinen, 1995). Some felt that self-care routines do not have any useful meaning and, there is very little known about the “personal meaning of self-care or the perceived impact of this chronic disease” (Kyngas & Hentinen, 1995, p. 734). According to Anderson (as cited in Kyngas & Hentinen), the personal meaning of having diabetes is strongly related to the patient’s self-care and to

the degree of psychological and social adaptation to the disease. Anderson and Hernandez (as cited in Hartrick, 1998) argued that “practitioners’ perspectives, and the diabetes care that emerges from them, fail to address aspects that are meaningful to people with diabetes” (p. 76).

Health care professionals have a powerful influence on the meaning of diabetes, and they may not be aware of their effects (Hartrick, 1998). Hartrick reported that some of the most powerful forces within the health care establishment were the messages and ways of talking about diabetes. The philosophical underpinnings of the educator’s beliefs about diabetes care influence the theories that may be used, (i.e. affective, behavioral, cognitive, humanist), and the content and style of any educational material, education, and language (Skinner, Cradock, Arundel & Graham, 2003).

Participants described that when doctors used the label, *diabetic*, it “led to generalizations being made that detracted from the recognition of the individuals’ uniqueness” (Hartrick, 1998, p. 83). Another patient reported, “You were just dehumanized; you were just a pincushion to regulate,” and “If he had any idea about me and my type of person, I don’t think he could have put me in a category of the type of person that would stop taking insulin” (p. 83). The participants in this study described a strong underlying message that health professionals know what is best for the patient. Another patient said, “You know the doctor is right and all will be well if you don’t struggle ...” (Kralik, Brown & Koch, 2001, p. 598).

Research in adults and adolescents with diabetes has consistently demonstrated that individuals hold a diverse set of beliefs about their illness, and that these beliefs are “robust and proximal determinants of patient’s emotional well-being and self-care

behavior” (Skinner, Craddock, Arundel & Graham, 2003, p. 76). These beliefs do not necessarily fit the medical model. To help patients find meaning of their diabetes, it will be helpful to deconstruct the binary categories of medical/personal, compliant/non-compliant, and doctor/patient in order to find a more holistic view of diabetes care that encompasses multiple angles of the spectrums.

### *Shifting Identities around Illness*

The quality of life experiences for people with chronic illness are multiple and varied. Positive experiences with illness could bring greater self-awareness, with a “re-ordering of priorities and a sense of living for today” (Dirksen, 1995, p. 631). People may make meaning by reflecting on why their diabetes occurred and its impact on their identity. Shifts in self-identity, when living with chronic illness and the struggle for self-preservation, involved “an ongoing process of negotiation and verbal accounting or storytelling” (Kralik, Koch, Price & Howard, 2004, p. 262). Shifts or disruptions in identity may be influenced by a variety of life experiences, but the interpretation of living with diabetes makes its impact in a new way. Living with diabetes is an ongoing process of reinterpretation of that illness (Kralik, Brown & Koch, 2001). One participant from this study reflected that “I am in a whole new place now, one I used to know nothing about. It is so amazing how quickly life changes” (p. 599).

In one narrative of chronic illness (Kralik, Koch, Price & Howard, 2004) the participant said, “I could do anything I wanted to without even thinking about it” and it was important to not “give up on things, but replace them with something else” (p. 263). Another patient said, “Don’t let your chronic illness dominate your life, but try to combine it in your life” (p. 264). At times, living with diabetes was a crisis, and at other

times it was smooth sailing. This required a shift in perspective and identification with the illness experience.

From a feminist perspective, Kralik (2002) addressed the shifting identities of women who needed to care for their disease while connecting with their social and family content. Some were mothers and working women employed full-time in the workforce, who needed to manage multiple responsibilities. Kralik found two major themes with these women, *extraordinariness and ordinariness*. The research revealed that women living with illness were involved in an “ongoing process of movement between extraordinariness and ordinariness” (p. 147). This meant that the women experienced an “extraordinary” period of transition toward incorporating the chronic illness in their lives and, over time, some may make the transition to incorporating chronic illness in their lives. One woman said:

I still want to be the old me desperately, and yet I know I can't. Trying to find the new me is hard ... nothing is familiar, everything I knew about myself has changed. (Kralik, 2002, p. 149)

Ordinariness was about finding a place for illness to fit into their lives. They achieved this by “taking calculated risks, surrendering security, making choices and forcing boundaries that illness had imposed upon their lives” (Kralik, 2002, p. 151). This involved the reconstruction of multiple and shifting identities of their selves, such as partner, mother, worker and student, to be enriching and fulfilling to their lives. They had reconstructed their identities through living with chronic illness, and now added the additional identity of patient to the whole of self. One participant described this well:

Then comes the time to move on. It's like a rebirth. All the knowledge you had about yourself, feelings, dreams, etc. go through a rather radical shake-up. You are a new person; the illness has made you stronger in some respects. Your focus is now on yourself and maintaining a fragile health balance. (Kralik, 2002, p. 151)

Participants described diabetes as something they lived with every minute of the day (Hartrick, 1998), and it influenced their identity, their life structure, life choices, and priorities. In describing the meaning of diabetes, these participants used metaphors such as “the envelope of diabetes, the walls of diabetes, unknown terrain, a cloud looming, a ball and chain that you drag around, and a noose around your neck” (p. 81). A physician called having diabetes “a life sentence” (Brown, Harris, Webster-Bogaert, Wetmore, Faulds & Stewart, 2002, p. 346).

Although having diabetes was a negative experience in these stories, to some it was at least reassuring that they had a name for a diagnosis. “A diagnosis meant that the illness was validated by medical science and was then perceived by others to be real” (Kralik, Brown & Koch, 2001, p. 595). A medical diagnosis of diabetes appears to be shrouded in personal meaning, and Kleinman (as cited in Kralik, Brown & Koch) stated that “meaning arrives with a vengeance together with the diagnosis” (p. 596). Patients receiving a diabetes diagnosis must absorb information and adopt a new lifestyle almost immediately (Koch, Kralik & Sonnack, 1999). The diagnosis is the beginning of a new understanding of an identity with chronic illness and a lifetime of shifting expectations as patients move through the illness experience. The shaping and reshaping of sense is “always in progress and that it is the active involvement of the actor-in-the-world that creates the personal sense” (Teekman, 2000, p. 1128).

Another study spoke of illness as reshaping the female body (Kralik, Koch & Telford, 2001) and as acknowledging the changing, or shifting, perceptions of self. Women described “fearing the change in the familiar self and often compared themselves in illness with their previous self” (Kralik, Koch & Telford, 2001, p. 182). It seemed as though illness intruded on every aspect of their lives, and only those with diabetes were/are able to describe what it is like to live with the shifting identity of chronic illness (Koch, Kralik & Sonnack, 1999).

#### *Affective Knowledge of Diabetes*

The treatment of diabetes necessitates both behavioral and psychological adjustments (Hartrick, 1998; Kyngas & Hentinen, 1995; Nair, Dolovich, Ciliska & Lee, 2005; Rose, Fliege, Hildebrandt, Schirop & Klapp, 2002). Behavioral changes involve nutritional modifications and blood glucose monitoring, but the psychological stress of living with diabetes may demand even greater adjustments. This relationship between psychological stress and diabetes is more complex than previously believed (Lo, 1999, p. 422). For example, “patients with diabetes report more concern about possible future diabetes-related complications than concern about taking insulin injections or the limitations in lifestyle” (McFarland, Rhoads, Campbell & Finch, 2001, p. 250).

Indeed, diabetes carries many emotions with it, including anxiety, stress, denial, depression, loneliness, embarrassment, isolation, and worry. In this paper, the process of finding meaning and healing through these emotions is called “the affective ways of knowing.” One participant with Type 1 diabetes summed up this emotional struggle:

Insulin is very potent. Immediately after injection, it suppresses blood glucose, if it slips too low, it's much lower than 'optimal' . . . the best is, of course, to stand



in the middle of a spring balance. But it's impossible, isn't it? I'm anxious, worry about late complications. It's like a running enemy. I fight with it every day. (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 158)

Another said having diabetes and experiencing hypoglycemia is "difficult to tolerate which no outsiders could understand" (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 158). The overall feelings within this study of 13 participants was that they felt that the thought of the future with diabetes was "fearful and disturbed," and two of the participants who were blind as a result of retinopathy were worried about the end of life that denoted a "slow and miserable process of dying" (p. 158).

Metaphors such as "a silent invader, worse than cancer, and invader of every important organ" (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 158) described diabetes as more than a biological disease. Another participant said, "If you give me medicine, you're treating 30 percent of my disease; if you could treat my heart [emotions], you could have treated 70 percent" (p. 160). Doctors, patients, and close friends or family need to understand the emotions involved with having diabetes. One study attributed the stress of diabetes from family members, labeling this type of stress as expressed emotion relating to criticism and emotional overinvolvement (Koenigsberg, Klausner, Pelino, Rosnick & Campbell, 1993). This type of psychological stress accounted for 19% of the variance in HbA<sub>1C</sub> levels.

To reduce stress and anxiety, McFarland, Rhoades, Campbell & Finch (2001) recommended that clinicians ask about the meaning patients attribute to having diabetes. For example, after inquiring about the chief complaint, the clinician could ask, "How does that affect you?" They also recommend asking a follow-up question that elicits

more meaning that the patient ascribed to the problem. It could be phrased, “What in particular about that problem concerns (bothers, troubles) you the most?” (p. 253). Then the clinician can plan with the patient what can be done to lessen the stress associated with the problem. These questions relate to an affective way of making meaning by opening a dialogue about the *feelings* associated with having diabetes. If physicians and patients do not recognize the psychological, emotional and affective aspects of having diabetes, patients may miss appointments, resist disclosure about diabetes to some health care professionals, or be unable to initiate diabetes self-management processes (Nair, Dolovich, Ciliska & Lee, 2005). Indeed, diabetes affects both the physical body and the psychological, and both must be recognized in a holistic healing process.

#### *Additional Minor but Important Themes*

The major findings of the studies were those noted above. In addition to the above themes, there were other factors found in the literature which may affect the meaning making and healing process. Those included: (a) somatic symptoms; (b) social constructs of meaning; (c) the socio-economic status and education of patients; (d) feelings of marginalization as a person with diabetes; (e) gender; and (f) the degree of self-efficacy.

*Somatic knowledge of diabetes.* Chronic illness, such as diabetes, is a constant process that includes being vigilant of bodily responses, carefully planning daily activities around those responses, and learning new strategies (Kralik, Koch, Price & Howard, 2004). Women used the somatic symptoms of their body, subjective feelings and their ability to follow daily tasks as a measure of health and as a guide for recovery (Kralik, Koch & Telford, 2001).

Women described their bodies as “alien” and a source of “pain, discomfort, and inconvenience,” and for some a source of embarrassment (Kralik, Koch & Telford, 2001). Self-esteem and self-image were influenced by the way women perceived that others experienced their bodies. Changes in body appearance also created problems, when “the prospect of finding a partner and commencing a relationship was daunting because women were faced with concerns of when to tell a new partner they have a chronic illness” (Kralik, Koch & Telford, 2001, p. 185).

Women’s health and well-being are embodied experiences which include embodiments across generations within and across cultures (Green, Thompson & Griffiths, 2002). Having diabetes is an embodied experience, which requires attention to the somatic changes through hypo- (low) and hyper- (high) glycemia, changes in eyesight, feet and kidney function, and pain through insulin injections and blood glucose tests. For some, the experience of diabetes is interpreted by paying attention to shifts and changes in the body (Kralik, Koch & Telford, 2001).

*Social constructs of meaning.* For those with diabetes, social support serves as a source of protection, or buffer, against the harmful effects of both men and women living with the disease (Dunkle-Schetter, Holahan, Grigger, as cited in O’Neill & Morrow, 2001; Lo, 1999). Findings also suggested that connecting women with others with similar symptoms and remaining positive can promote self-esteem (O’Neill & Morrow). Self management is not a linear, consistent process; rather, it is grounded in the personal and social context of people’s lives (Kralik, Koch, Price & Howard, 2004).

In one study of women (Kralik, Koch & Telford, 2001), the participants found meaning in writing as pen-pals to each other. One participant said, “Their stories have

become a part of me . . . That other women have expressed how it has been for them and how they have coped despite the hurdles of chronic illness . . . is somehow healing to me” (p. 181). In this study, the meaning of diabetes was understood through interaction with others in a social situation.

*Socio-economic status and education.* It has been suggested that higher education and socio-economic status improve quality of life in diabetes (Cheng, Tsui, Hanley & Zinman, 1999). This was confirmed by Chan and Molassiotis (1998), who stated that patients with a “higher educational level were more knowledgeable on diabetes” (p. 436) and by O’Neill and Morrow (2001), who believed that “socio-economic status and education appear to be positively associated with the use of coping strategies” (p. 264). For those where literacy is an issue, perhaps providing oral instructions or audio-tapes may be a beginning step in a strategy to help some patients find meaning (O’Neill & Morrow, 2001). Although higher socio-economic status and education may lead to greater knowledge of diabetes, knowledge alone does not lead to meaning making and better management of the disease.

*Feelings of marginalization.* The feeling of oppression, or marginalization, may also affect the openness and the treatment of diabetes. Some may choose whether to disclose (if obvious markers are absent) their condition to others (Kralik, Koch, Price & Howard, 2004). Some feel that living with a chronic illness means feeling different from others, and that it is not “normal” to be ill (Kralik, 2002; Kralick, Koch & Telford, 2001).

*No studies on gender differences.* None of the studies compared the differences or similarities in the meaning making process of men and women. In some studies, women were studied exclusively (Koch, Kralik & Sonnack, 1999; Kralik, 2002; Kralik,

Koch & Telford, 2001; O'Neill & Morrow, 2001). In Koch, Kralik & Sonnack, the women felt that diabetes was always present and always central in their thoughts, decisions and plans in their daily lives. They said, "you never get rid of diabetes" (p. 718). One researcher (Kralik) questioned the assumption by health care professionals that women would "automatically" tolerate the symptoms of illness, and the side effects of medication juggling and treatments. Other researchers (O'Neill & Morrow) concluded that there is a difference in symptom perceptions of both genders, but "the extent to which men and women perceive and respond to symptoms differently needs more attention" (p. 263). In the Fitzgerald study (as cited in Koch, Kralik & Sonnack), the researchers surveyed 1,201 patients with diabetes and researchers found that there were many similarities in the reactions of men and women to a diagnosis of diabetes. However, the differences were not noted, and this may also be an area for further consideration.

*Positive influences of self-efficacy.* Chronic illness research demonstrated that clients with self-efficacy have better self-management, more effective coping and fewer hospital admissions (Edwards, Scherer & Bruce, as cited in Tak-Ying Shiu & Yee-Man Wong, 2002). "It is therefore worthwhile to consider whether the patient training program, for instance, should routinely include the goal of enhancing beliefs in self-efficacy in their interventions particularly in light of the fact that positive experiences in this area have already been reported" (p. 40-41). In some cases, self-efficacy meant being assertive about the need for appointments or information from their physicians (Nair, Dolovich, Ciliska & Lee, 2005) and being able to carry out tasks designed to

control symptoms and avoid both acute and chronic complications (Bandura, as cited in Rapley & Fruin, 1999).

Following Bandura, most researchers have treated self-efficacy as a specific or behavior-specific construct; however, “when applied to the self-management of complex chronic illness health-care regimens, self-efficacy theory must account for initial and ongoing phases of a multitask self-management regimen” (Rapley & Fruin, 1999, p. 210). The patients’ beliefs in self-efficacy may help them overcome barriers of the disease and improve blood glucose. A feminist poststructuralist, however, may challenge the behaviorist and self-management programs in order to “carry out their self-management tasks” and to “follow a self-care regimen” to control their diabetes (Rapley & Fruin, 1999, p. 211) in favor of a more holistic, patient-centered approach. The extent to which self-efficacy affects meaning making was not explored.

### *Discussion*

Managing a chronic illness is not a linear, consistent process. It never goes away and, by definition, there is no cure. In the case of diabetes, many factors influence blood sugars, including the patient’s feelings about the disease, exercise levels, amount of insulin, number of carbohydrates, and, in fact, a near infinite number of possibilities. This cannot be managed by using only cognitive methods of treatment. Only seven percent of the diabetic patients adhered to all aspects of the regimen (Chan & Molassiotis, 1998). That means that 93% of all people with diabetes are finding a gap between what they know and to what they adhere. Education alone rarely is sufficient to ensure patient adherence (Gordon & Duffy, 1998). Perhaps the focus is not so much on knowledge, or even lack of knowledge, but the problem may lie in the strict adherence

regimen itself. The rational and biomedical perspective is only the beginning to understanding treatments for diabetes. There is a greater depth to the *process* of diabetes care in which these studies only lightly tapped.

It is interesting to note that a few studies showed relatively low correlations between clinical measure of disease activity (HbA1c) and patients' perspectives of well-being and meaning-making (Guyatt, Feeny & Patrick and Mackeigan & Pathak, as cited in Burroughs, Desikan, Waterman, Gilin, & McGill, 2004). Most of these studies took on an approach to wellness, rather than focusing on diabetes as an illness. In other words, in a search for meaning, the patient asks, "How do I become well?" rather than "How do I manage my disease?" These are very different questions, and there is little research regarding the "real" or practical ways in which patients become well, or find meaning, with their diabetes.

It has been difficult to generate a body of research to extend an understanding of other treatment possibilities beyond the biomedical model, and even more difficult to find any description beyond generalizations of how patients have found meaning of their diabetes. These generalizations and the lack of a practical model are discussed in the next section.

#### *Lack of a Practical Model*

From a constructive postmodern perspective, as a researcher, I wanted to begin to reconstruct a useful way of reframing current practice to incorporate multiple ways of knowing. From this view, it is important to provide responses to the patient's question, "How do I become well?" None of the studies, with the exceptions of Kralik, Koch, Price & Howard (2004) and Hartrick (1998) gave any practical guidance or deeper

questioning as to how the care of people with diabetes could be improved. Kralik (2002) said that some women make a transition to incorporating chronic illness into their lives over time, but she did not research *how*. Rose, Fliege, Hildebrandt, Schirop & Klapp (2002) stated that those “with an active coping style were more optimistic” (p. 10), but there was no teaching model of this, or an explanation of what this looks like in practice. Sappington & Kelley (1996) thought it was important to understand the perspective of the patient, and said that a professional nurse can provide holistic care by being aware of the individual’s uniqueness. Although this may be a beginning, it does not go deep enough to help patients or practitioners understand *how* to see the perspective of the patient.

Hartrick (1998) gave four considerations for holistic practice: (a) acknowledge and attend to the particulars of people’s experience by presenting diabetes information within the context of the person’s life, (b) support and assist people in finding meaning of diabetes, (c) teach to both the acquisition of knowledge and the discovery of personal meaning, and (d) ask questions to think about “what knowledge do clients bring?” or “how does my professional knowledge complement the patients’ knowledge,” and “how can I evolve my care to incorporate both forms of knowledge?” (p. 85-86). Although these questions lead to a more inclusive and holistic practice, there are still questions relating to understanding *how* professionals can help to discover meaning. Kralik, Koch & Telford (2001) used a process of writing to bring a new sense of clarity to the illness experience, but it was the only process discussed in the literature to create a sense of meaning. Again, it was not discussed *how* the process was designed.

After reviewing the literature, the question remains as to what kinds of creative and innovative ways there are in order to make meaning of diabetes. In modifying the



questions posed in Kralik, Koch, Price & Howard (2004), which were directed to participants with chronic arthritis, a researcher could begin this study of people with Type 1 diabetes. Those research questions might include: (a) what were your experiences of seeking medical help; (b) what was it like when you received a diagnosis; (c) what implications did you think diabetes would have for your life; (d) how did you perceive that the people around you handled or reacted to your diagnosis; (e) how do you live with diabetes; (f) what are the sorts of things that help you to live with diabetes; (g) could you share an experience that you will never forget because it best describes what it means to live with diabetes; (h) what was important for you before diabetes and what is important for you now; and (i) what advice would you give to a friend who has just been diagnosed with Type 1 diabetes? In addition, another question related to meaning might be, “Can you identify some of the things you do or experience that make you feel well?” (Koch, Kralik & Sonnack, 1999, p. 714).

It is interesting that in each of these studies, the participants identified the doctor or medical professional as the expert, but not themselves. In finding meaning through diabetes, perhaps the category of patient/doctor should be deconstructed, with the patient as expert and the medical professional as the support system and coach. The dynamic interplay between the two, in other words, the *relationship*, is what becomes central to diabetes care.

#### *Lack of Diverse Populations*

In this literature review, with the exception of the Chinese population, there were no minorities explicitly represented in the studies. More research needs to be conducted as to why minorities are not part of these studies. Perhaps socio-economic factors or the

recruitment tools themselves inadvertently seek to exclude minority groups. If they are not recruited, they cannot be studied. “Further research examining the similarities and differences . . . of care perception across cultures would be of value” (Nair, Dolovich, Ciliska & Lee, 2005, p. 120). In relating this to gender, an understanding of the significance of experiences about diabetes across different cultures can contribute to the ways in which the female body and experiences are seen and interpreted, both by women themselves and by professionals who invest in the medical management of women’s bodies (Oudshoorn, as cited in Green, Thompson & Griffiths, 2002). How illness is perceived is culturally constructed and has meaning, and these meanings have implications for a more healthy lifestyle with diabetes (Liburd, Namageyo-Funa, Jack, & Gregg, 2004).

#### *Affective Influences*

Lastly, from 13 participants who were asked to list something that, if present, might help reduce their fears and worries, seven (five Type 1 and two Type 2) identified “psychological counseling” and seeing “nurses and doctors who have diabetes themselves” (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 160). With the exception of expressions of metaphors and pen-pal relationships, no other forms of creative meaning-making were mentioned in this study. The research indicated a more compliance-centered approach, rather than patient-centered, where the patient is able to express him or herself in the diabetes care. There is a lack of research using the imagination, symbol, or creative expression in order to make meaning of feelings about diabetes.

In future research, further consideration of the relevance of personal meaning for holistic diabetes care is required (Hartrick, 1998). Hartrick believes that a greater

understanding of what it means to live with diabetes can serve to “inform and expand the existing perspectives of diabetes and perhaps contribute to the development of more holistic models of diabetes care” (p. 77). In addition to researching affective ways in which adults make meaning of diabetes, it is also important to teach different philosophical principles and educational practices to diabetes professionals and educators. The philosophical underpinnings of the educator’s beliefs about diabetes care were recognized as important because the beliefs influence the theories that may be used (i.e., affective, behavioral, cognitive, humanist), and the content and style of any educational material or education (Skinner, Cradock, Arundel & Graham, 2003).

If educators have been taught in a behavioral approach to medicine, then they do not know any other way to help patients. If educators are to reach patients on an individual level, then they cannot employ one overarching philosophy to meet the needs of all patients. This allows for a more holistic model of diabetes care, but more research needs to be completed as to how this actually looks in practice.

### *Conclusions*

The perceived impact of Type 1 diabetes and the degree of stress associated with having diabetes affect both mental and physical health. The more positive the meaning attached to the illness, the more positive the mental and physical health. “Higher HbA<sub>1C</sub> levels and a history of depression are associated with a more negative meaning being attributed to illness” (McFarland, Rhoades, Campbell & Finch, 2001, p. 250). That is one of the reasons why is important for patients to find meaning in their chronic illness. “The tension between caring for diabetes and caring for self was often fueled by the lack of

acknowledgment of the personal meaning diabetes and the diabetes regimen had in their lives” (Hartrick, 1998, p. 85).

The purpose of this section of the literature review on meaning making and diabetes was to explore the medical journals, both quantitative and qualitative research, to summarize and discuss ways in which adults with Type 1 diabetes could make meaning of their illness. In taking a constructive postmodern lens, the primary theme which emerged was the discussion that the cognitive approach is not enough in order for patients to heal and find meaning of their disease. A more holistic approach is needed for treatment. Kralik, Koch, Price & Howard (2004) summarized that the strategies for developing better health may lie with “understanding what it important for individuals living with illness so that a holistic approach (that is inclusive of biomedical understandings) lays the framework rather than the segmented bio-medical model and particular disease categorization” (p. 265).

Some also could not find meaning in their relationships between the familiar and their new identity as a patient with a chronic illness (Kralik, Brown & Koch, 2001). Although the fact that diabetes was a significant event in people’s lives, the studies did not address specifically how adults came to find healing from their disease. This was the focus of my research and, perhaps, a greater purpose for my life: to collect the narratives and creative expressions of adults with Type 1 diabetes in order to discover how they begin to experience and make meaning of their chronic illness. In this approach, it is important to have the experiences of the patient both heard and regarded as legitimate knowledge. Since much of chronic illness self-management literature is from the perspective of health professionals (Hill, 1995, as cited in Kralik, Koch, Price & Howard,

2004; Kralik, 2002), it is time to research and hear from those whom chronic illness affects: those who have Type 1 diabetes.

Medicine has a problem-solving agenda and deals with objective, observable facts. This focused activity means there is a potential to ignore subjective experiences, and particularly those of marginalized groups relating to ethnicity, class and gender. The emotional response to illness may be just as significant as the biomedical treatment and diagnosis, particularly when it comes to a life-changing, chronic illness, such as diabetes. By sharing in further research in taking an insider approach, I anticipate that the findings of affective and creative ways of making meaning will add to this literature base. They will help both the practice of medicine and the healing process of many men and women who have not found hope for their Type 1 diabetes in the biomedical perspective alone.

#### Multiple Ways of Knowing in Education and the Healing Arts

The earlier sections of this literature review focused on the theoretical framework of the study and the meaning making process of individuals with a chronic illness and/or diabetes. The final section of this literature review describes the multiple ways adults come to know, learn, and make meaning from the literature in both adult education and in the healing arts, which can contribute to how adults might continue to make meaning of their diabetes.

#### *Adult Education and Multiple Forms of Knowledge*

In the adult education literature, there has been some discussion about alternative ways of knowing, and what such ways of knowing offer to our understanding of how adults come to know and learn (Armstrong, 2005; Dirks, 2001; Donoho, 2005; English & Gillen, 2000; hooks, 2003; Lawrence, 2005; Noble, 2005; Olson, 2005; Sullivan, 2005;

Tisdell, 2003a). In exploring these ways of knowing, the first question on which such educators focus, either implicitly or explicitly, is “What constitutes knowledge?” From a critical epistemology, Habermas (as cited in Kincheloe, 1991) bases knowledge on three forms: the technical (technically useful knowledge), the practical (information which allows people to be understood), and the emancipatory (freedom from forces). As a critique, Habermas does not mention alternative or creative knowledge, and Yang (2003) stated that most of the critical paradigm tends to fall within the realm of instrumental rationality. From a holistic theory of learning, Yang proposes three other facets of knowledge: explicit (knowledge of rationality and the mind), implicit (knowledge of experience and the body), and emancipatory (knowledge of meaning and the heart). From a constructive postmodern perspective, Yang’s holistic theory of knowledge is more consistent with the ways that adults come to learn, as Yang examines the relationships and connections between knowledge and allows for an array of ways of knowing, such as somatic and affective.

An article by Yorks & Kasl (2006) stated that “many educators grasp intuitively that practices tapping into expressive ways of knowing are useful but that they typically do not have a clear notion about how these activities are linked to learning” (p. 44). Researchers have only begun to explore the ways that the human system processes information, and educators have just ventured into the landscape of incorporating these ways of knowing into their classes. Perhaps there is a fear that expressive ways of learning is not “real” learning. There is a tendency to “juxtapose didactic pedagogical strategies against expressive modes, as if they were mutually exclusive” (Yorks & Kasl, p. 44). From a constructive postmodern view, alternative ways of knowing are not in

conflict with the cognitive, rational model. Rather, *all* ways of knowing are invited into a holistic learning experience. When we open up intellectual space to incorporate multi-dimensional ways of knowing, as expressed through “metaphor, dance, poetry, visual art, or dramatic expression, we draw on the affective, somatic, and spiritual domains.

Participants can more fully express what they know” (Lawrence, 2005, p. 4)

Although the various sections below appear to be linear and separate, they resemble more of a textured pattern, each overlapping and intersecting with each other. These alternative and creative ways of knowing begin to inform the practice of adult education and make way for other methods of inquiry into understanding the teaching and learning process.

### *Affective*

Several adult educators have addressed the affective component in learning (Armstrong, 2005; Donoho, 2005; Dirkx, 2001; English & Gillen, 2000; hooks, 2003; Lawrence, 2005; Noble, 2005; Olson, 2005; Sullivan, 2005; Tisdell, 2003a; Yorks & Kasl, 2002). Michelson (as cited in Yorks & Kasl) observed that “the cerebral, the objective, the universal, are seen as superior to the subjective and particularly . . . [in order] to have power over experience” (p. 184), but many of us perceive emotional and affective ways of learning as also important to the learning experience. Belenky et al. (1986) also emphasize the importance of learning through connection, relationship and the significance of affectivity in learning. A supportive climate, a caring teacher and students who have respect for each other as individuals, or a teacher who involves the whole person in the learning experience bring an affective dimension to teaching. We teach the whole person, who is “connected with the earth as a living system, with the

community, and with the transcendent” (Sinnott, 2001, p. 246). In medical education, paying attention to the way that a patient feels about having diabetes, in addition to how he or she is treated for physical symptoms, places value on the affective domain of learning.

In this interaction of relationship and connection, the whole person and situation is more than the sum of its parts. To pay attention to the affective domains (emotions or intuition, for example) allows us to learn more about a person than by relying upon our cognitive functioning alone. To learn as a whole person, we must “listen for the whispers from our hearts and the messages from our bodies. Of course we involve our minds, but we avoid concluding that thought and thinking are the beginning and end of learning” (Apps, 1996, p. 2). Our emotions, and our imaginative thoughts of them, assist in the meaning-making process and the ways we interpret and experience ourselves (Campbell, Chodorow, Denzin & Jaggar, as cited in Dirkx, 2001). These affective and expressive processes can facilitate meaningful learning (Yorks & Kasl, 2006).

### *Spiritual*

In the spiritual, or transcendent, dimension there is an awareness of some higher power or non-rational, connective and unseen force that extends beyond the consciousness (Balducci & Meyer, 2001; Elkins et al., as cited by English, Fenwick & Parsons, 2003; Palmer, 1998; Wheeler, Ampadu & Wangari, 2002). Spirituality is also related to a sense of wholeness and healing, meaning-making, a move to a greater authenticity, and a way that people construct knowledge through unconscious and symbolic processes which may also be cultural (Tisdell & Tolliver, 2001). Spirituality could include aspects of religious practice, but not necessarily. Religion refers to the



beliefs and rituals followed by a community of people, where spirituality concerns the quest for meaning-making and fulfillment, and it permeates all human activities and experiences.

Spirituality is about an “awareness and honoring of wholeness and the interconnectedness of all things through the mystery of what many [refer to] as the Life-force, God, higher power, higher self, cosmic energy, Buddha nature, or Great Spirit” (Tisdell, 2003, p. 28). Because it is not based in just a religious practice, spirituality may be found in a number of places, including music, art, poetry, and nature. For some, the spirit may be experienced in a synagogue, near a waterfall, or at a serendipitous moment on the way to the grocery store. They are not necessarily found in a church, but through art forms such as music, art, image, symbol, and ritual (Tisdell, 2003). These kinds of spiritual events are often unplanned, and happen by surprise (Palmer, 1990; Tisdell & Tolliver, 2001).

Spiritual forces have also been described as a primary drive leading to “bonding with community in ways that alleviate psychological suffering” (Wheeler, Ampadu, & Wangari, 2002, p. 73). An example of how one can *know* through the spirit in community is through reflection of one’s own personal stories of religion and spirituality (Flannery & Hayes, 2001). As a result of her participation in a spiritual group, Flannery became aware of her images of God, her ways of thinking about spirituality, and the lived practices which she followed. Her spirituality was centered on an idea that she had to be strong and “live up to the soldier image” (p. 30), and she wanted to unlearn and relearn her ideas about spirituality that seemed masculine to open up opportunities for multiple ways of knowing. Our sense of spirituality has a profound impact on our lives, as it

affects our self-awareness, our sense of interconnectedness, and the ways we learn and make meaning in our lives (Tisdell, 2003).

### *Imaginal and Symbolic*

With the exception of Dirkx (2001), who said that learning is fundamentally an emotional, imaginative connection with the self and the social world, there is limited research on symbolic or imaginal learning in adult education. Parks (as cited in Tisdell, 2005) talked about the role of the imagination in spiritual experience. She explained that when there is some type of conscious or unconscious conflict, one pauses or moves away from consciously dealing with it. There is some type of image or insight where the conflict is removed and recast, a repatterning, and then an interpretation or testimony about the experience. This is not a new idea, as the cycle of birth, death, and rebirth leading to transformation has also been expressed in Paleolithic art and in the myths and religions across all cultures (Clark, 1997). In relating the concept of recasting and repatterning to adult education, it also sounds similar to change theory (Lewin, 1951), which relates to unfreezing, freezing, and refreezing; transformative theory (Mezirow, 1991), involving the process of working through a disorienting dilemma; or the process of untying a knot, being at loose ends, and reconnecting (Apps, 1996). In using the creative process of imagination, however, the inclusion of the *image* or *symbol* is central to the repatterning and interpretation of the experience.

Others who draw upon the imagination as a way of knowing call upon it as a window to the unconscious; a gateway to the unconscious and our emotional, feeling selves; and *seeing* rather than just *looking* (Azara & Green, 1995; Bleakley, Farrow, Gould & Marshall, 2003; Dirkx, 2001). For some individuals and cultural groups who

have been oppressed through race, illness, gender, or sexual orientation (for instance), they can begin to explore, re-create and express their cultural identity in positive ways through the use of creative expression and symbol making. This incorporates knowing on another level and can be referred to as “reclaiming one’s sacred face” (Abalos, as cited in Tisdell & Tolliver, 2001, p. 14). This ties cultural meanings and symbolic meanings to understand aspects of identity in deep and sacred ways. Symbols and images can help learners connect the conscious and unconscious worlds of knowing.

### *Somatic*

Somatic, or embodied knowing, is knowledge centered in experience that involves the senses, perception, and the connection of the mind and body (Matthews, as cited in Kerka, 2002). Placing the body at the center of subjectivity and learning allows different questions to be raised about self, the individual in relation to others, and in relationship to the culture at large (Brockman, 2001; Kerka, 2002; Morris & Beckett, 2004). Marshall (as cited in Somerville, 2004) expressed a concern that attention has been placed on the theoretical body, and little to lived experiences and data.

Issues arising from the somatic approach include the following: (a) recognition of the body as a source of knowledge; (b) empowerment and resistance to the dominant culture, where learners begin to question the dominant culture and sources of knowledge; and (c) a means of developing empathy and respecting diversity (Kerka, 2002). We must go where our bodies take us. Awareness of our bodies and the sharing of our somatic responses opens up the opportunities for alternative ideas about knowing and learning (Bach, Kennedy & Michelson, 1999; Barlas, 2001; Beaudoin, 1999; Gustafson, 1999; Todd, 2001). Somerville (2004) talks about the experience of the lived body, and the

particular attention which is given to the body during episodes of illness. Diabetes, in particular, is a condition under which the body necessitates its presence. The patient comes to *know* his or her body through the dizziness of hypoglycemia, the exhaustion and lethargy of hyperglycemia, and the feeling that things are “just not right” in the body. Knowing is not a disembodied part of the self, but an integrated part of it. The senses, feelings, emotions, cognition, and learning are carried in the body and its relationship to other people.

### *Artistic and Creative*

Educators can bring techniques from journaling to making collage to photography into a collaboration with patients who otherwise might never have acknowledged being creative themselves. “Narrative and expressive arts techniques allow us in a myriad of ways to tap into this ongoing creative meaning-making process in all our lives” (Caldwell, 2005, p. 173). Knowledge can be found in music and vocal sounds (Bolman & Deal, 1995; Reading, 2004; Williams & Taylor, 2004), writing (Dangel & Guyton, 2003), and many forms of art and creative expression (Palmer, 1990; Reynolds, 2003b; for example). By using art and creativity to tap into the spiritual, the imagination, and the somatic, people can reconstruct their belief structures and begin to make new meaning.

The commonality between these ways of knowing is that a certain degree of creativity and imagination is needed in order to learn. Palmer (1990) said, “In creative action, our desire is not to solve or succeed or survive, but to give birth to something new” (p. 9). In helping patients with diabetes, “unrestrained creativity” is needed in “matching the therapeutic regimen, in particular, the insulin distribution, to the lifestyle of the patient. This becomes particularly important for patients with chaotic schedules,

unpredictable varying work shifts, changing time zones, and intermittent bursts of physical activity” (Skyler, 1997, p. 649). By remaining flexible and open to alternative and creative ways of knowing, there is an opportunity for greater healing, creation of relationships, and meeting of spirit through community. Even if a cure for diabetes is not within reach, healing from a chronic illness is always possible (Byock, as cited in Balducci & Meyer, 2001) by engaging and including multiple ways of knowing.

*The Role of the Educator in Engaging Multiple Ways of Knowing*

The role of the educator in engaging these multiple forms of knowing is an implicit or explicit part of these discussions. These authors discuss or imply that as educators, it is important to first ask questions of ourselves on how we come to know and learn in order to find greater meaning in our practice (Dirkx, 2001; English, 2001). Some questions might include: Do I leave time and room for learners to reflect? Do I integrate poetry, art, music, symbols in my teaching? Reflecting inwardly, do I as an educator spend time finding meaning and exploring my own spirituality? English (2001) contends that when we ask questions such as these, “we are forced to deal with the motivations of our work” (p. 3). Before we begin teaching other patients or students, we need to discover our own attitudes about alternative ways of knowing. Consciously or unconsciously, we choose either to teach isolation and restriction of affect, or we can encourage the use of creative processes (Stewart & Charon, 2002). We can then begin to engage the body, the arts and the imagination into greater meaning making processes for our students.

From a constructive postmodern perspective, making *meaning* is different than finding *truth*. Creating meaning for ourselves cannot be found in a formula or recipe.

The quest involves multiple ways of knowledge that engage all of the functions we have available for knowing, including the cognitive, affective, somatic, imaginal, and spiritual dimensions. Taylor (as cited in Merriam & Caffarella, 1999) has sought to bring a consideration of emotion into learning by offering “a physiological exploration of the interdependence of emotion and reason” (p. 335). As referenced in Merriam & Caffarella (1999), other educators have suggested the importance of learning through emotion and intuition (Brookfield), soul learning, revealed in layers of meaning (Dirkx), levels of consciousness (Boucouvalas), imaging in autobiographical learning, the physical body (Chapman & Schlattner), and the subconscious (Scott). This meaning-making process could relate to a disorienting dilemma (Mezirow, 1991), unfreezing event (Lewin, 1951), and/or a concrete event (Kolb, as cited in Merriam & Caffarella, 1999) that changes the way we view an experience.

These discussions have implications for patient education for those with diabetes. Paying attention to the spirit-body-mind is important in diabetes care. Both novices and experts in diabetes care tend to see what is not “first visible to the eye, but what they expect to see according to the textbook example” (Bleakley, Farrow & Gould, 2003, p. 302). In engaging the imagination, physicians can use an imaginative way of knowing to create a greater depth of perceptual capability in seeing beyond what the patient is telling them, or beyond the medical diagnosis. Patients will begin to ask other questions about how to make sense of their disease (Milstrey-Wells, 2000). In diabetes, patients sometimes become “depressed, fatalistic or confused when they do not have outcomes consistent with their efforts, and these orientations may interfere with decision-making or motivation for renewing their efforts to control glucose levels” (Lutfey, 2005, p. 432).

Encouraging multiple ways of knowing does not wipe out scientific, empirical methods of inquiry. It is vitally important to be educated on how to use the insulin pump, count carbohydrates and react to emergency situations. But, inviting multi-dimensional ways of learning about the world into the realm of diabetes and patient care will complement the current process “with a much wider range of human experiencing and ‘knowledge’ production” (Beare & Slaughter, as cited in Phillips, 2002, p. 155). To understand how we can begin to bring meaningful experiences to patients through the use of alternative ways of expression, we must turn to the arts therapy and education literature.

### *The Healing and Arts Therapy Perspectives*

The healing and arts therapy literature also discusses ways of knowing related to healing and creative or artistic expression. This is an important contribution to educational practices because, for the most part, the discourse in adult education has neglected the research and experience about multiple ways of knowing from art therapy (Yorks & Kasl, 2006). Some of the reasons noted for the lack of research were that educators expressed concern about keeping education and therapy distinct from each other, or that educators did not know how to bring affective dimensions into their classroom, even when they recognized the significance. Several studies document the affective dimension as an important part of learning (Egan, 1985; Loughlin, 1993; Ruddick, 1996; Yorks & Kasl, 2002). From these studies, one can summarize that emotion is a part of the learning experience and, in fact, can facilitate greater meaning making in patient and adult education settings.

This review presents the capacities for emotional and physical healing found in the creative arts, and also specific examples of how artistic knowing can be used in

patient education and action research. As educators, we need to move from the declarative pronouncement of “knowing that” to the creative ways of “knowing how” (Cunliffe, 2005). From a constructive postmodern view, “knowing how” does not mean that there is only one, absolute, right path, but multiples ways of knowing and of finding meaning. As we begin to research and become more competent in the use of creative and artistic ways of knowing, we can begin to create the psychological environment for whole person learning. An environment conducive to learning is especially important in patient education where many are dealing with the anxiety of having diabetes and are searching for healing and meaning through chronic illness.

This section describes how artistic and creative expression can be used in healing processes in general and, specifically, in practice. The literature was gathered primarily from the Web of Science database, including the Science Citation Index, the Social Sciences Index and the Arts and Humanities Index. A secondary resource was ScienceDirect, focusing on the Arts and Humanities. In reviewing the literature, it was difficult to separate the modes of artistic expression into categories, because round things do not have straight lines. The cyclical process of self-exploration often involves several ways of knowing (i.e. imaginal and somatic) simultaneously, and the process is open and inductive (Malchiodi, 2005). Creative expression and the healing, “transformational process is not linear. It affects your whole being instantaneously” (Montello, 2002, p. 171). From a holistic perspective, the review describes ways in which the arts and creative therapies can bring healing and meaning.



*Artistic Expression as a Way of Knowing*

Art therapy contends that the expression of creativity can lead to changes in the psyche. One definition of arts therapy was the “use of visual images and art-making for self expression, insight and healing” (Bien, 2005, p. 284). Through the healing arts, Schroder (2005) said that people can “find meaning in making art with intention” (p. 9). Jung, the forerunner of art therapy, viewed art-making as a means of “expressing the sacred and mysterious” and used art in his own self analysis as well as encouraging patients to “express themselves by means of brush, pencil or pen” (Jung, as cited in Eisdell, 2005, p. 3). Although Jung did not live in a postmodern era, as a constructivist, he asserted the multiplicity of Selves, and allowed for “selving,” or finding self in somatic, affective, and intellective ways of expression (Hollis, 2001, p. 31). To a large degree, Jung said, we have become alienated from our selves as spirit and live with “symbol-lessness” (Mazis, 2002, p. 147). In connecting with ourselves through images and symbolic representations in the arts therapies, we may find a new creative source and develop new connections for understanding and knowing our selves (Payne, 1996). These connections allow us to know and come to understanding in alternative ways.

Casey (1993), a philosopher who is influenced by post-Jungian work, spoke of how we can communicate soul-to-soul with each other, in a similar way that the earth communicates its soul through wounds and scars, such as those left by strip-mining. Casey argues such ‘messages’ allow us to know the world, or at least parts of it ‘at a glance.’ No deep pondering or reflecting needed. At times, the earth communicates directly to us, soul to soul. (personal communication, John Dirx, February 2, 2006)

In this kind of soul-to-soul connection, we feel things, first of all, not through words, but through the body (Casey, as cited in Mazis, 2002). We feel “*with and around, under and above, before and behind* our lived bodies” (p. 245). These types of experiences cannot be known or understood through only rational means.

One pathway to soul-to-soul knowing is through artistic and creative expression, as described in the arts therapy literature. Three intersecting themes emerged from the literature, and included: (a) artistic and creative therapies can bring healing; (b) literal words alone can be restrictive and limiting when communicating soul and emotions; and (c) image and symbol assist in the meaning-making and healing process through imaginative and creative expression.

#### *Healing in Artistic and Creative Therapies*

Before there were counselors and therapists, there were creative activities to express the unspeakable, to “soothe the self,” to heal, and to connect with others who could understand and share the symbolic meaning of imagery (Anderson & Gold, 1998, p. 16). The visual arts are healing in giving outward shape and form to what can otherwise be disquietingly shapeless and formless in our inner psyche or spirit (Sayers, 2004). Creativity lies in images being constantly formed and projected into symbolic meaning, where the “inner creative force serves as a backdrop for healing” (Spring, as cited in Bien, 2005, p. 284). After one patient with Hodgkin’s started to paint his feelings of having the disease, he found that “painting became the most important thing” (Rockwood Lane, 2005, p. 288). When he began painting images of water, he realized the water represented his fear of drowning. The act of painting became his transition that developed into a healing experience as he moved past the curtain of ordinary

consciousness to deep spiritual place in himself. Painting allowed him to use his creative life force to find meaning and healing, and he said, “I am so thankful for art in healing in my life” (p. 288).

Creative expression is not limited to art or painting; in fact, the ways of expression are as infinite as the imagination. Any means of expression that is created “through our time together can be a beautiful record of healing” (Schroder, 2005, p. 78). Schroder used varied art forms with her patients, including silk painting; quiltmaking as storytelling using a mix of patterns, textures and colors; poems expressing sadness; altar or memory space as a result of loss; shadowboxes; pastels; shapes torn and shredded from newspaper; imagery sketching from dreams; and full body tracing to indicate where emotional and/or physical pain is held and to bring healing. One woman worked with clay sculpture which allowed her to make a transition from her diagnosis of cancer to “an abundant and creative life” (Morris, Banting, & Gilbert, 2003, p. 1). More examples of art and ways of bringing these kinds of creative expressions into practice are described in a later section of the review.

#### *Limitations and Constrictions of Literal Words*

A theme that was carried through the art therapy literature is that literal words alone are not adequate enough to describe emotional and spiritual experiences (Horowitz, 2002; Malchiodi, 2005; Rockwood Lane, 2005; Schut, Keuser, Bout, & Stroebe, 1996). Literal words such as, “I have diabetes,” do not describe the emotional experience of living with a chronic illness, but the use of images, metaphors and the symbolic interpretation of them can begin to create an understanding. One patient said, “You have to cope hour-by-hour with fluctuating insulin and blood sugar levels and with insulin

reactions that can hit you like a freight train” (Martz, 2003). The image of a freight train is a way to use expressive words in communicating the symbolic, overwhelming emotions of the experience.

Artistic and creative expression can be powerful in helping people verbalize their feelings and communicate beyond the words to “give voice to parts of life that people may have been encouraged not to talk too much about” (Schroder, 2005, p. 58). This may be especially true when patients are experiencing grief over the loss of loved ones or loss of self, such as in disease or trauma. After participation in creative sessions, it became easier for patients to talk about their feelings in a therapeutic group (Schut, Keuser, Bout, & Stroebe, 1996). Likewise, it is easier for therapists to gain a greater knowledge of their clients through their artwork and use of metaphor, than through verbal interaction alone (Greece, 2003).

Where literal words may fail, expressive words can heal. Several authors (Abell, 1998; Carroll, 2005; Collins, Furman, & Langer, 2006; Jeffs & Pepper, 2005) described using poetry to help people find their voice and gain access to the wisdom they already have but cannot experience because they cannot find the words in ordinary language. Carroll (2005) said that

Our voices are saturated with who we are, embodied in the rhythms, tonal variations, associations, images and other somato-sensory metaphors in addition to the content meaning of the words. Our voices are embodiments of ourselves, whether written or spoken. It is in times of extremity that we long to find words or hear another human voice letting us know we are not alone. (p. 164)

Poetic expression is one example of using language in a metaphorical and affective way to express what is difficult to say through literal words alone. Poetic expression uses “sensual images to disrupt customary language use” to explore the feelings, the fantasies, the imagination, that we all share to some degree as earth bodies (Mazis, 2002, p. 158). Poetry allows us to slow down and feel these sensations, and to point to the many lines of meaning that are present in ambiguous lines of poetic expression. Poetry means more than the actual words, but “to catch the meaning, one must listen with the inward ear” (Selincourt, as cited in Hunter, 2002). Poetry can be used in nursing and patient education to help create meaning, as poetic expression is not just writing about what one knows from an experience, but also discovering what one does not know about the experience (Hunter, 2002; Tooth, 2005).

One study (Tinnin, 1990) described a model that explains the fundamental brain processes that make “accurate communication of emotion in words impossible” (p. 9). In short, when a person tries to communicate an emotion in literal words alone, the conscious mind begins censoring the feelings in reducing them to words. Censoring distorts the message, and the person cannot “retrieve emotional memories that were not verbally coded when they were originally stored” (p. 13). The art captures the fleeting emotional message and we can communicate non-verbally to others on a soul-to-soul level. “Think of the strangeness or the miracle of two strangers sitting down for about an hour, making some art and somehow connecting through the image and stories that come with the images” (Schroder, 2005, p. 19). The beauty of artistic expression is the ability to express emotions through images and symbols to create a space for discovery and healing.

### *Image and Symbol in Creative Expression*

Through creative expression, people use the right hemisphere of the brain which makes use of symbol and image to process material (Abraham, 2005). One therapist (Hobson, as cited in Eisdell, 2005) used a “game” of images to engage in right-brain activity. The game was an interactive play where the patient draws a line and then the therapist goes on with the picture to see what meaning emerges. It is an invitation to express the unconscious through images and the imagination.

Image and imagination have the same key Latin root, *imagi-*, which can be translated to mean a mental picture of something not actually present (Merriam-Webster, 2006). Imagination encompasses the inner world of ideas, concepts, images and meanings (Clark, 1997; Dirkx, 2001; Phillips, 2002). Our imaginative thoughts enable us to project ourselves into another situation and to see or think about the world from another perspective (Currie & Ravenscroft, 2002), which opens opportunities for healing.

Carlson (2004) interviewed a patient and psychotherapist, Ernest Rossi, who used his imagination to heal from a stroke. Rossi’s research interest was studying the ways that consciousness can modify the structure and functioning of the brain and body. He said that although behavioral genetics is valid and useful in understanding the molecular-genetic basis of human problems, it does not value the effect that “human consciousness, creativity, and yes, even spiritual experiences” can have “in raising our state of psychobiological arousal to turn on gene expression, synaptogenesis, and neurogenesis in building a better brain for optimizing the expansion of human possibilities” (p. 307). In other words, imaginative and enriching life experiences that evoke psychobiological responses with positive fascination, such as during creative moments of art, music, dance,

drama, humor, hypnosis, meditation, spirituality, can evoke “cascades of gene expression to optimize neurogenesis, brain growth, and healing” (p. 309).

### *The Healing Arts in Practice*

To express the creative dimensions of our selves, learners can use the expressive arts as knowing in many ways, including (a) engaging in guided imagery and meditation; (b) using phototherapy as expression; (c) moving the body as in dramatherapy; (d) using sand trays or molding in dirt or clay; (e) drawing or painting images; and (f) writing or drawing life experiences in journals or portfolios. This list is not intended to represent *all* types of creative expression available in healing work. Each person has a story of his or her own, and each patient has a preferred mode of expression (Caldwell, 2005), whether that be through the written expressions of poetry, art, and painting, or the somatic expressions of drama and meditation. Some of the ways in which these areas of expression can be used in practice are highlighted below.

Creative artists and healers, Azara and Green (1995), sought to understand that place in us that is “both beautiful and brutal – that place we consistently have to live with – two parts of the many parts of ourselves. I believe we have to make some kind of peace with this tension in order to live our lives, to follow our vision” (p. 36). Azara and Green founded a feminist art school, where women spoke about their experiences surrounding a topic. Women drew in a book as other women were speaking, so that by the end of the evening they had a visual diary of the conversation. They also used guided meditation to find their inner language and described these forms in drawing, painting and sculpting. By using their own creative language and imagination, different images emerged for each woman. They described one exercise vividly:

I would begin by asking you to close your eyes for a moment, listen to the cadence of your own heart, the sound of yourself. Imagine yourself in a circle of trusted women beneath a thatched canopy of trees. Follow your breath as it traces your blood's path throughout your body. Slowly, release your body's aches with each breath and imagine my voice speaking gently in the soothing, promising rhythm of a storyteller ... you can share this journey and interpret the journey for yourself, for your own wisdom. You can paint, draw and build it. (p. 41)

The guided meditation is a way to flower the imagination and then express it creatively through art. In this way, image and symbol are connected. Stralen (as cited in Yorks & Kasl, 2005) used guided imagery to create a peaceful refuge at the beginning of each learning encounter. This became part of a ritual of coming together to create a space for learning and reflection.

In a quantitative trial of mindfulness art therapy for women with cancer (Monti, Peterson, Shakin-Kunkel, Hauck, Pequignot, Rhodes & Brainard, 2005), the women who engaged in art-making demonstrated statistically significant decreases in symptoms of physical and emotional distress during treatment. The art-making included making complete pictures of themselves, engaging in gentle yoga, walking meditation practice, and introducing self-care through guided imagery. The sense of relaxation and symptom reduction found in creative expression opened pathways for emotional healing.

Phototherapy, or the use of photos and pictures to describe feelings, is another form of artistic expression that can lead to healing (Anderson & Gold, 1998; Horowitz, 2002; Schechtman & Tsegahun, 2004). In the context of arts therapy, phototherapy is defined as an interactive system of counseling techniques that uses patient interaction



with “ordinary, simple photographs, such as their own personal snapshots and family albums as well as photos taken by others” (Schechtman & Tsegahun, 2004, p. 367). Not to be confused with the medical definition of phototherapy, which uses bright lights to reduce seasonal affective disorder or other light-dependent therapies for medical conditions (Delano-Wood & Abeles, 2004), the therapeutic purpose is to access feelings or memories that cannot be fully reached through words alone.

We cannot section off ourselves from our body and lose that source of knowledge in artistic and expressive therapy (Springgay, 2005). Learning through our body’s responses, feelings and actions is an alternative way in which we can learn more about our world. “But the body can be more powerfully understood as a seat of subjectivity, where the ‘self’ is held to be an integrated being and the body as a lived structure and locus of experience” (Morris & Beckett, 2004, p. 126).

People can use somatic learning techniques to find greater meaning in their practice. When they experience somatic or emotional discomfort in their bodies, they may participate in recreational activities or in self-care activities such as taking a bath (Beaudoin, 1999). Beaudoin also suggested somatic learning elements that were most helpful to individuals, which involved doing some movement, being attentive to what is happening and then coming back to body sensations. In doing bodywork, it is important to “let themselves to along with what was happening or what they were feeling” and to develop a “quality of presence” (p. 78).

A British therapist and anthropologist (Payne, 1996) used the body in dramatherapy as an avenue for healing. A key concept in dramatherapy is reflexivity and the transformation of meaning as a healing process. Payne described the concept of

reflexivity as one in which participants can stand back from the action of drama so that they can reflect on their own and others' understandings. Through this creative retrospection, meaning may be given to the events and parts of experience, both living through and thinking back, on the images created during the performance.

A way of using tactile therapies in the healing process is the use of sand trays (Armatruda & Simpson, 1997; Bien, 2005; Boik & Goodwin, 2005). In sand therapy, an image is shaped in the sand physically, so that internal thoughts can find bodily form. This type of experience can be viewed as a form of conscious realization of unconscious contents (Kalff, 1990). The primary reason to use sand tray therapy is to assist patients who need a nonverbal method of expressing their emotions or finding their voice (Malchiodi, 2005). The tactile experience of running fingers through the sand is therapeutic in and of itself, where the "sensory experience with the sand causes a loosening of the tongue" (Malchiodi, p. 172). As a variant, patients could use dirt or clay to mold their feelings in the non-verbal material. In any case, the therapist does not provide a reductive interpretation, but rather allows the patient to find his or her own meaning from the work (Kalff).

As the tray provides a place for emotional expression, the canvas also is an open forum for the expression of image and symbol. Many therapists (Estep, 1995; Kellman, 2004; Stockrocki, Andrews, & Saemundsdottir, 2004, for example) used paintings or drawing in patient therapy settings. The therapist can present an idea or focus to the participants, provide an appropriate warm-up and then remove herself from the process. As in sand tray therapy, the role of the facilitator, as in educational or creative activities,

is to be minimally directive with choices emanating from the participant rather than imposed by the therapist (Abraham, 2005).

Although we have discussed the limitations of words, writing expressively can be a healing experience. Writing has been used as a therapeutic means by several authors (Graham-Pole, 2000; Malchiodi, 2005; Pennebaker, 1997; Smyth, Stone, Hurewitz & Kaeli, 1999). A primary difference between writing literally and writing expressively is the use of imagery. In one example, Dirkx (2001) works with images in the process of meaning-making, where learners are encouraged to write non-stop for ten minutes. As the learners reflect on the emotions or images, they can write whatever they associate with the image while staying focused. Dirkx said that naming and recognizing the images that come to mind during the learning experience encourages learners to be in conscious relationship with these images, which expands the learning experience.

One author, Pennebaker (2004, 1997, 1989) works with writing therapy in the experiences of chronic illness. Pennebaker is the leading researcher on the power of creating writing and journaling for healing purposes (Graham-Pole, 2000). He said that although the expressive writing paradigm has generally produced positive results, no single theory or theoretical perspective adequately explains how or why (Pennebaker, 2004). This may be attributed to the fact that “expressive writing occurs on multiple levels – cognitive, emotional, social and biological -- making a single explanatory theory unlikely” (p. 138). However, there is little doubt that writing has positive consequences, and self-report studies suggest that writing about upsetting experiences produces long-term improvements in mood and health (Pennebaker, 1997).

In one exercise, Pennebaker (1997) had students write about their deepest thoughts and feeling about an important emotional issue. He encouraged students to just write, with the only rule being that “once you begin writing, continue to do so until your [15 to 30 minute] time is up” (p. 162). Dozens of replications of these types of students have demonstrated that emotional writing can influence frequency of physician visits, immune function, stress hormones, blood pressure, and many social, academic, and cognitive variables. These effects “hold up across cultures, ages, and diverse samples” (Pennebaker & Graybeal, 2001; Smyth, as cited in Campbell & Pennebaker, 2003).

### *Discussion*

Much of the art therapy literature described creative expression as a path for personal healing, and used a combination of Western (European and American) and Eastern (Chinese, Indian, Japanese) techniques in treatment. In fact, many of the authors present, write, or provide therapy in the United States, Canada, Asia and Europe (Malchiodi, 2005; Moon, 2004; Payne, 1996; Schroder, 2005). This presents a lack of representation in other forms of art, specifically from the rich heritage of the African culture.

Each culture tends to define its own appropriate outlets and methods for creative expression and healing (Ludwig, 1992). In sub-Saharan cultures, health is understood as a balance between the physical and the social worlds, a balance that required “adherence to social mores, respect for the natural and supernatural worlds, and continuity with idealised ancestors” (Reif, 1999, p. 934). The objects of creative expression were not regarded as works of art in the Western sense, but as a means for artists to communicate with the supernatural world in pursuit of health.

At the same time, many of the expressions of African culture also worked with image, symbol, metaphor and the imagination in healing work. In Zulu beadworking, for example, the color combinations and designs symbolize age, social status and region of origin (Boram-Hays, 2000). African masks, wood carvings, ceramics and metalworks are some examples of artwork, which are not featured in the arts therapy articles (Bacquart, 2002; Herreman, 2003; Willett, 2002). On a broader level, the literature found in the art therapy articles reviewed did not describe African art. Art is a universal language, through which hope, creativity and healing are communicated (McCabe, 2002), and all forms of art and creative expression are encouraged.

Another theme for discussion is that most of the psychological and art therapy articles come from a humanist philosophic perspective. Payne (1996) addressed this directly by saying “the humanistic tradition insists that human existence includes unique characteristics such as self-reflection, purposefulness, language and culture” (p. ix). Humanists believe that people can control their own destiny, that people want to become better or strive for a better world, and that their behaviors are a consequence of their choices (Merriam & Caffarella, 1999). There is little emphasis placed on recognition of differences in learners (Tisdell & Taylor, 2000). Although there is a humanist trend in diabetes care to become more collaborative by involving patients and families in the educational process, the doctor still controls the process (Blaylock, 2000). Constructive postmodernists value the differences in each person, there is no “one” way to healing, and the learner is at the center of the process.

Literature related to creative and artistic expression and diabetes was minimal. One book (Kerr & Kerr, 2004) had a promising title that introduced creative ways of

living with heart disease and diabetes. However, after reading through “The Nine Stages of Change” (p. 52) and the four steps to stress management, the remainder of the book (from pages 75 to 480) was filled with recipes. This is hardly creative. In another potential book (Graham-Pole, 2000), the author discussed artistic expression, but from a simplistic, somewhat comedic point of view. Readers are encouraged to “prescribe for yourself (with a little guidance from me) the self-healing medicine of picture-making and poem-making, of dance and song and ‘acting the fool’” (p. xviii). He calls many of the artistic expressions “silly-seeming” (p. 131). In one exercise called “Playing Doctor and Patient,” the “doctor” takes a medical history by asking the “patient” a relevant question that starts with the letter “A,” and the patient must respond with a sentence beginning in “B” (p. 134). These kinds of activities are silly, indeed.

Instead of focusing on silly approach, the integrative and meaningful expression in this dissertation opens the whole body – the identities of self, the body, mind, spirit and the soul – to recovery. Creative expression can work with the imagination to create healing and meaning. McNiff (as cited in Malchiodi, 2005) said that the arts provide soul medicine, and he proposes that we “conceptualize art therapy as a therapy of the imagination. By allowing ourselves to become engaged in the image, we can express our inner and emotional thoughts.

By conducting this research, I have been engaged in an act of creation, bringing my soul to the arts and the participants to make meaning of this research question that is important to me and the greater society. Payne (1996) said that the creative process requires that we “find a place in which internal and external reality can interact to form new gestalts” (p. 130). As researchers, we are inspired by our work and our work

inspires us, an interaction between subject and object. We are creating. Picasso said, “Je ne cherche pas, je trouve” (Picasso, as cited in Payne, 1996, p. 131). Translated, this means, “I do not seek, I find.” Those of us with diabetes hope to find greater meaning, healing and wholeness through the creative arts and expression of our selves.

In medical settings, the stories and creative expressions that we share bring healing. Rather than viewing ourselves as humans who are flawed and need to be fixed by a physician, it is more useful to “include respect for the senses, mystery and possibility in the healing plan ... Opening up the range of possibilities to receive nurturance, hope and care allows a greater chance for the client to heal. They shatter the cognitive reality that keeps the client trapped in a powerless and diseased role, replacing it with a larger reality” (p. 247). Different from talking about the weather or superficial niceties, expressing emotional issues and painful experiences exposes us to an opportunity for greater wholeness (Charon & Spiegel, 2002).

A holistic perspective does not contradict the medical view in bringing emotional, somatic, artistic and spiritual dimensions to learning. Rather, it complements the biomedical view by focusing on not only the sickness and the symptoms themselves, but the whole of the person (Furnham & Forey, 1994). When learners are invited to work with creative and artistic processes that affect more than their identity with illness, they are often made aware of their unconscious feelings. With increased awareness, learners are more able to “create congruence between their affective states and their conceptual sense making” (Yorks & Kasl, 2006, p. 53).

### Summary and Conclusion

Because this study was grounded in constructive postmodernism, informed by feminist poststructuralism, it brings with it the possibility of deconstructing the rational way that diabetes is communicated to patients, and begins to reconstruct and combine the affective with the rational way of understanding diabetes. This review defined meaning making and multiple ways of knowing, as well as explained how creative expression might be used in the healing arts to engage those ways of knowing.

In summary, the literature revealed that the traditional views of diabetes care come from a humanist-behavioral perspective, and the rational approach is not adequate in understanding the experience of diabetes. By engaging multiple ways of knowing, such as those in the adult education and arts/healing literature from a constructive postmodern perspective, the patients can explore creative ways they make meaning of their diabetes and practitioners can understand the way people know and learn to improve patient care.



## CHAPTER 3

### METHODOLOGY

The biomedical perspective may provide the skeleton of information needed to manage the disease, but it is the flesh, the organs, and the embodiment of the spirit that leads to a more holistic, and possibly more meaningful, view of chronic illness. At this point in time, diabetes cannot be cured. It cannot be “fixed.” Living with diabetes is a process of transitions, a fluctuation of moments between being ill and feeling well. It is greater than calculating carbohydrates and units or boluses of insulin. Understanding the experience of living with diabetes requires an alternative view to the medical perspective.

The purpose of this research was to explore the ways in which adults find meaning in their diabetes and to use creative expression as an expression of that meaning. Cognitive knowledge is one way to treat diabetes, but looking at the disease from only a rational perspective has limitations in understanding the experience of living with the disease. The guiding research questions which formed the basis of this study were: “How do adults make meaning of their Type 1 diabetes?” and “What are the ways in which adults with diabetes could engage in creative expression to find greater meaning and wellness?” This qualitative action research study was a response to the lack of attention to the creative dimensions of knowing and to the lack of literature about meaning-making and chronic illnesses such as diabetes.

#### Qualitative Research Paradigm and Rationale

The qualitative research paradigm, specifically a narrative approach to interviewing and action research, was chosen for this study because it focused on how

individuals experience and interact with their social world, and it adds depth and insight to the process of meaning making (Merriam, 2002). For example, suppose we had collected a group of field observations of several classes in the adult education doctoral program, had interviewed a number of students about what makes a “good” professor, and had spoken to some who left the program. How would we make sense of all this data? If reduced to statistics and numbers, the findings would lose some of their *meaning*. Qualitative research provides the means to organize and interpret the information, without losing the richness and individuality of the responses.

Patton (2002) said that “qualitative data can put *flesh* on the *bones* of quantitative results, bringing the results to life” (italics added, p. 193). One way to add flesh to the bones is to include multiple realities and perspectives in diabetes research, breathing life into diabetes care from the voices of those who have diabetes. Qualitative research is the paradigm that accomplishes this, as there is room for multiple perspectives, illuminated by the views of participants (Merriam, 2002). The qualitative process requires flexible, changing strategies, and the results are specific, not necessarily generalizable, although it is up to the reader to determine whether the results can be applied to a particular population. Instead of being a detached, objective observer who administers instruments, the researcher becomes immersed in the study (McMillan & Schumacher, 2001). Qualitative researchers place a “substantial emphasis on how participants in a study make sense or meaning of a situation” (Creswell & Miller, 1997, p. 37). The credibility of a qualitative study increases when the researcher has prolonged engagement with the subject matter and when the findings are checked with participants and are true to their experiences (Lincoln & Guba, 1985).

Qualitative research focuses on the study of issues in depth and detail, and tends to center on how people make meaning out of their experiences. Three characteristics of qualitative methodology are: (a) a naturalistic approach, or studying real-world situations; (b) an emergent design and flexibility, or pursuing paths of discovery as they arise; and (c) purposeful sampling, where the sampling is aimed at insight about the research question, not necessarily generalizable to a population (Patton, 2002), and participants are chosen according to specific, purposeful criteria. The typical data collection methods in qualitative research (the use of interviews, long-term observations, and the use of documents or artifacts that add meaning to, or are used or created in the research context) focus on how participants make meaning of their lives individually or in social contexts (Denzin & Lincoln, 2000; Marshall & Rossman, 1999). This meaning of the world, or the reality of the participants' lives, is not a fixed, single, or measurable phenomenon as it is in quantitative research (Merriam, 2002).

My dissertation interest was to explore the creative ways in which adults make meaning of diabetes and to use creative expression in the meaning process; therefore, a qualitative design complemented by an action research frame was the specific design of the study .

#### Research Design: Narrative Interviewing and Action Research

There are many different types of qualitative research, including ethnography, phenomenology, case studies, and narrative inquiry to name a few (Patton, 2002). Specifically, two types of qualitative research which informed the design of this study and facilitated the purposes of the research were a narrative approach to interviewing and action research. Although the two methodologies are described separately in the

following paragraphs, they are interconnected. Narrative research in general focuses on an in-depth exploration of people's stories related to the study; in this case, their experience of diabetes. Action research attempts to facilitate an action during a study through one or more cycles of planning acting, observing, and reflecting. Given that I wanted to hear people's stories of their experiences and meaning making processes of diabetes and then, based on their stories, implement interventions that would draw on creative expression, an action research approach drawing on narrative interviewing was the most appropriate approach for the study. Each aspect of these components of research will be discussed below. But first, I discuss the participant selection followed by the role that I played in the research process itself.

#### *Participant Selection*

The narratives of ten participants (including myself) are included in the first part of the research, which focused on getting the stories of how participants make meaning of their diabetes and discovering their interests in creative expression for the action research part of the study that facilitated a creative process. (This will be described further below.) Two participants were not able to attend the creative sessions. The remaining eight action research participants were selected from a purposeful sample of those with insulin-dependent diabetes. There are "no rules for sample size in qualitative inquiry" (Patton, 2002, p. 244), but the sample size depends on the context, what will be useful, and what will have credibility. Six to eight participants is a usual number of participants in an action research study to allow for in-depth analysis of individual experiences. The intent of qualitative research is to generate insights about a small sample who meet the criteria set by the researcher rather than to make sweeping, empirical generalizations.

The points below describe the criteria for the participants, with an explanation for the rationale following the paragraph:

- (a) All participants were over age 21 and had insulin-dependent (Type 1) diabetes for ten years or more;
- (b) They were selected from the Penn State Diabetes Center, Hershey Medical Center, Hershey, Pennsylvania;
- (c) Their A1C was greater than 7% and they had difficulty managing their diabetes. (One participant had an A1C of 5.8, but she still had difficulty managing her low blood sugars and wished to be included); and
- (d) They were interested in participating in the study and in exploring creative expression related to diabetes and meaning-making.

All of the participants in this study had insulin-dependent diabetes, which means the pancreas produces no insulin. Insulin-dependent diabetes (Type 1) and non-insulin dependent diabetes (Type 2) are treated in different ways. Although both diseases are caused by an autoimmune dysfunction, Type 1 patients have a greater risk of hypoglycemia and ketoacidosis, both resulting from wide swings in blood glucose levels (Cryer & Childs, 2002). The participants were over the age of 21 and had diabetes for a minimum of ten years, excluding newly diagnosed individuals. Patients who are newly diagnosed are in the beginning stages of understanding life experiences with diabetes and managing insulin injections for blood glucose stability. Those who have had diabetes for ten years or more have had time to learn the medical requirements and have the ability to reflect on what having diabetes means to them.

The participants' A1C was greater than 7% (with the exception of one participant), which is higher than the ideal number in preventing complications. By targeting this group, it was assumed that the participants were struggling with finding meaning through the traditional biomedical approach alone, and some of them were experiencing complications as a result of having diabetes.

Men and women were both recruited for this study, but only women responded. The women are identified in this study by pseudonyms, which they chose for themselves, except for Emily who chose to keep her "real" name. Although it was not a criterion for the study, all of the participants in the study were on insulin pumps. All ethnic and socio-economic groups were recruited, but most women were white (one was bi-racial) and middle-class. The participants were selected from the Penn State Diabetes Center, which has a registry of approximately 8,000 patients with diabetes, and I did not know any of them personally prior to the study. Recruitment pamphlets were handed to patients who had a difficult time managing their diabetes, or who might benefit from participation in the study (see Appendix A). It was clear from the description that the arts and creative expression would be used in the study and that participation was entirely voluntary.

After making initial contact with participants by phone, I verified that they met the criteria for the study and invited them to ask questions about the research. At the end of the conversation, I confirmed their interest and kept a written log of their contact information and dates they would be available to meet. We left the phone conversation with my intent to contact them with a beginning start date, time and location. As I was conducting an action research study which required participants to meet several times, the majority of the research and interviews were conducted at, or in close proximity to, the

Penn State Milton S. Hershey Medical Center. The participants were encouraged to e-mail me or contact me at any time throughout the process. A detailed description of the participants is provided in Chapter Four.

*Researcher Role in Light of Theoretical Framework*

My role as a researcher was to not only record the feelings, experiences and thoughts of the participants, but to actively engage myself in the study as a participant as well. Because of my position as researcher, constructive postmodernist, creative educator and person with diabetes, it would be difficult -- if not impossible -- for me to be a detached observer without offering parts of my own narrative to the process. In light of my philosophical perspective, these identities added to my credibility as a qualitative researcher (Denzin & Lincoln, 1985).

As a philosophical underpinning of constructive postmodernism and feminist poststructuralism, attention to voice is one of the ways my roles of both researcher and participant intersected. In the context of this study, voice is a metaphor for speaking out, and has connections to liberating against silence after being underground, unarticulated, intuited or ignored (Belenky et al., 1986), talking back (hooks, 1989), creating a dialogue (Smith & Colin, 2001), adding a face to a number (Baird, 2001), and disrupting the status quo (Fine; 2005, 1992). Because I am a person with diabetes and met the requirements of the study, it would be desirable to include my voice, along with the voices of the other participants in order for our stories to be heard and recorded.

As a constructive postmodernist, I was also interested in deconstructing the binary category of the researcher and the subjects. In order to deconstruct a meaning or an idea, it is important to understand it as a construction and to “uncover its evolution, unpacking

the interests it serves and marginalizes” (Hemphill, 2001, p. 23). The position of the researcher (me) in this study was work collaboratively with the participants, not to have power over them. Being a researcher is a privileged position, and having the status of researcher should not mean that it is more important or more valuable than that of the participants. Noffke (as cited in McGuire, 2001) said:

Regardless of how we see our positions, we do not ‘give voice’ to those in less powerful positions. Rather, we must see ourselves as part of the process of breaking apart the barriers for speakers and listeners, writers and readers, which are perpetuated through and act to support our privileged positions (p. 62).

One of the ways in which we begin to establish a sense of voice is to listen to the stories and narratives of the women in the studies whose lives have been affected by diabetes.

#### *Narrative Approach to Interviewing*

During the initial interviews (described in Chapter Four), a narrative approach to interviewing was used in the planning stage of the action research design. The main claim for the use of narrative in educational research is that “humans are storytelling organisms who, individually and socially, lead storied lives” (Connelly & Clandinin, 1990, p. 2). Studying narratives allows us to research the ways people experience the world at a particular point and time within a specific context. It has a holistic quality because narrative focuses on human experience, which is multi-dimensional and unique. In narrative research, we are opened to dilemmas, to a range of possible worlds, explanations and the creative imaginations of people. There is no final and conclusive ending to the stories, but a narrative that connects with others (West, 1996).



The primary purpose of narrative research is to create a process in which we are trying to give an account of the multiple levels of experiences. The central task is “evident when it is grasped that people are both living their stories in an ongoing experiential text and telling their stories in words as they reflect upon life and explain themselves to others” (Connelly & Clandinin, 1990, p. 4). We can begin to understand the story by asking these foundational questions of narrative analysis: “1) What does this narrative or story reveal about the person and world from which it came? 2) How can this narrative be interpreted so that it provides an understanding of and illuminates the life and culture that created it?” (Patton, 2002, p. 115).

Much of the literature supported the use of narrative, or telling stories, as a primary way in which adults make meaning of their illness (Angen, 2000; Bailey & Tilley, 2002; Casey & Long, 2002; Wright-St. Clair, 2003). Narrative researchers gather these meanings into a themed collection and pay attention to the structure of those stories and autobiographies. It is the interpretation of the story offered by the participant that is at the heart of narrative analysis (Connelly & Clandinin, 1990; Lieblich, 1998; Patton, 2002). Unlike scientific knowledge, through which a detached and replaceable observer generates or comprehends replicable and generalizable characteristics, narrative knowledge leads to particular understandings about one situation by individual participants (Charon, 2001). Connelly, Clandinin and He (1997) go so far as to claim that there is more of a sense of a person living inside a story than there is of a person living inside of a theory or ideology.

Rita Charon, a general internist and literary scholar, focuses on the outcomes of narrative training in medicine and how narratives function in the construction of

knowledge (Charon & Spiegel, 2006; Charon, 2004a; Charon, 2001). Charon (2004b) said she “came to understand that I had accrued deep knowledge about my patients that remained unavailable” because she had not written down the stories of the patients (p. 404). Sharing what she has learned with her patients is therapeutic, often deepening their mutual commitment and investment. She went on to say, “I feel privileged to have discovered how to fortify my medicine with the narrative gifts of perception, imagination, curiosity, and the indebtedness we listeners accrue toward those we hear.”

Although not using narrative inquiry in the style of Connelly and Clandinin (1990), which would involve the analysis of the unfolding of the stories themselves, I conducted interviews that encouraged narrative responses by asking one initial question: “Tell me about your diabetes,” and a later question, “What do you do outside of your normal work and life responsibilities which you really enjoy?” Although all interviews, lasting approximately two hours, began with the same question regarding the diagnosis of diabetes, the narrative structure of the interviews allowed freedom for the participants to speak about anything from that point forward. As suggested above, as both researcher and participant, I would reframe, ask for clarification, and insert my own experience along the way, but the participant led the direction of the conversation.

### *Action Research*

To begin the process of action research, a narrative approach to interviewing was incorporated into the planning stage of the research design to collect data on the experience of the diagnosis and how participants made meaning of their diabetes. It was also an opportunity to discuss what the action research sessions would involve and get a sense of the interests of the participants. In this study, the action and observing cycles of

the research allowed us to create and explore multiple ways of knowing within a social context.

Action research is often considered a form of qualitative inquiry, although it would be possible to make use of some quantitative methods of data collection in some studies. In general, however, the purpose of action research is to make something happen; in this instance it was not only to listen to the narratives and voices of the participants, but to take action in the facilitation of experiences of using creative expression as a result of the interests and experiences of the participants. Action research is different from a strictly narrative study in that it is meant to improve a social situation; for example, the relationship between patient and doctor in health care or the awareness of diversity in an organization. In other words, I wasn't interested in only hearing patients' stories which were collected through narrative interviewing at the beginning of the study, I also wanted to make something happen — to facilitate further meaning making in creative expression. Action research also involves, and is different from narrative inquiry in these ways:

- a) The researcher serves as a facilitator in the group, and sometimes acts as the catalyst for change between the research findings and those most likely to benefit from the findings.
- b) The results are intended for immediate application and use (Merriam & Simpson, 2000). It focuses on improving practice, looking at the results and making interventions during the research process.

- c) Action research involves problem posing and problem solving in the creation of new stories rather than only listening and recording the content of the stories.

Action research is similar to narrative inquiry in that the design emerges as the study continues, rather than being predetermined. Both are inductive processes, which allow for multiple endings and possible outcomes. In both action research and narrative inquiry, it is important for all participants to have a voice. Voice refers to the meaning that resides in the individual and allows him or her to attempt to communicate meaning to someone else (Connelly & Clandinin, 1990). Voice also is active, implying “the ability to express thoughts and feelings so that they can be heard and understood by others” (Hayes, 2002, p. 80). This action research project opens up a dialogue about diabetes, allowing for a greater sense of understanding.

The origin of action research in education can be traced to Lewin (1951), influenced by Dewey, and his desire to improve social conditions existing in a variety of contexts through action and reflection (Kemmis & McTaggart, 1988). It incorporates systematic procedures that combine analysis, observation and data collection into the process (Kuhne & Quigley, 1997). The process begins with a concept of action and change, and blends together with the purpose of the research and the direction of the group. The cycle involves the core processes of: (a) planning, or deciding how to deal with a problem; (b) acting, by implementing the plan; (c) observing, or paying attention and recording what is happening; and (d) reflecting, by analyzing the outcomes and revising plans for another cycle of acting (Carr & Kemmis, 1986; Kemmis & McTaggart, 1988; Kuhne & Quigley, 1997). Merriam and Simpson (2000) echo this pattern in the

action research cycle, which is one of analyzing, gathering facts, identifying the problem, and taking action on the problem, then repeating this process as new information is presented. In the “phases of action research” section, the cyclical phases of planning, action and observing, and reflecting are described in the context of making meaning of diabetes through multiple ways of learning and knowing.

Habermas (as cited in Quigley, 1997) said there are “three distinct knowledge-constitutive interests at work” (p. 16) in the social construction of knowledge: technical, practical and emancipatory. In technical inquiry, the goal is to understand and generalize; in a practical framework, the objective is to understand or improve relations among individuals and groups; and the emancipatory mission is to understand and redress injustices inherent in groups and structures. Because the purpose of the dissertation study is to create a greater *understanding* of how adults create meaning, the particular type of action research falls primarily within the practical framework. For this study, the immediate purpose is not to create deep change in social situations, but to bring healing to individuals (influenced by social contexts). A secondary purpose is to present this information to the medical field in order to improve the doctor/patient relationships and diabetes treatment. Action research fulfills these purposes by providing the opportunity for groups of people to organize learning from their own experiences, and make the results available to others. Action is embedded in:

unpredictable complex systems which are in a continual process of self-creation and re-creation. In action research, it challenges people to reflect on the place and function of what you do or do not do as part of a dynamic whole. This reflection

can provide more insight into the potentialities and possibilities to act otherwise, and in this way can enhance human emancipation. (Boog, 2003, p. 432)

We need to look at the multiple identities of the person who has diabetes, not just one aspect of his or her life. How does diabetes influence the person's life in other ways? Do they "have" diabetes, or "are" they a reflection of their diabetes? How can one use creative expression to affect the meaning process in other aspects of their identities, not just their disease?

### Data Collection

In this research, data was generated from multiple sources, including the initial narratives, final interviews and the transcriptions, the three group sessions, reflections on those meetings and the creative artwork itself. In addition, I also kept a journal of notes on observations and personal feelings about the process. Each of these will be described below as data collection techniques.

#### *Initial Narratives and Final Interviews*

Most of the literature *about* patient care and education is not *by* patients. The initial narrative interviewing process became a shared experience, an intimate exchange of our stories. Hearing the voices of those affected by chronic illness is important, particularly in light of my philosophical perspective. The feminist poststructural and constructive postmodern perspectives focus on the ways people can reconstruct their identity through the development of their voice and by examining the positionality and power of the teacher and the students (Elias & Merriam, 2005; Merriam & Caffarella, 1999; Tisdell, 2003) or in this case, between the researcher and the participants. The

narratives allowed for each voice to be heard and multiple views to be expressed in order to open our spirit-body-minds to new possibilities and perspectives.

The construction of the narrative leaves room for multiple interpretations of the data, based upon a specific context at a moment in time. The sense of the whole is built from many data sources, one of which is a focus on the significant, concrete events of life that create powerful narratives (Connelly & Clandinin, 1990). In this case, the interviews began with an invitation to “tell me about your diabetes.” The narrative does not depend on a priori knowledge; rather, knowledge is constructed throughout the study. “I noticed too that the stories changed, depending on the audience, the time, and the season; and that sometimes as the telling changed, so did the storyteller” (Chapman, 2004, p. 95).

Narratives are unstable, influenced by what listeners hear, who the teller is, the context of the story, why the story is told, and who else is listening to it (Montello & Charon, 1999). It involves remembering, a process of reconstructing past fragments, and composing the story requires energy, passion, and interest on the part of the listener or researcher. hooks (as cited in West, 1996) said, “Remembering was a part of a cycle of reunion, a joining of fragments, ‘the bits and pieces of my heart’ that the narrative had made whole again” (p. 206).

The first interviews were conducted between June 14 and July 13, 2006 with the final interviews falling between October 17 and November 2 of the same year. The interviews became a way to record the participants’ responses as data (Bochner, as cited in Patton, 2002). With permission from the participants, the interviews were recorded digitally to allow for me to review the tapes and transcribe them after the interviews. In order to not distract participants and the flow of the conversation, I did not take notes as

the participants were speaking, but wrote reflections after each interview to get not only the exact words recorded, but the feel and atmosphere of each interview.

Through the systematic study of the participant's narratives, I learned about their thoughts and feelings of diabetes, the world they live in, and the meaningful stories of their lives (Patton, 2002). Surrounding the identity of having diabetes, we exchanged our stories about our diabetes in the form of narratives and then actively explored creative ways in which people with diabetes can come to make meaning of this chronic illness.

### *Group Sessions and Creative Artwork*

The action research sessions allowed us the opportunity to participate collaboratively in creative expression and exploration of meaning making processes. Like the interviews, the creative artwork and conversations in the sessions were collected as data and compared with the results of the other forms of data collection. The method of data collection to capture aspects of the meaning making process included the use of interviews, observations, and participant documents. Those documents are not limited to words, and may include other creative forms such as syllabi, writings, poetry, or other artistic creations that are generated by the participants (Oliver-Hoyo & Allen, 2006).

Although there were nearly an infinite number of ways we could have explored creativity and meaning making through action research, attending to the body, imagery and photography were the particular media through which our experience was expressed. Like Azara and Green (1995), I sought to understand that place in us that is “both beautiful and brutal – that place we consistently have to live with – two parts of the many parts of ourselves” (p. 36). In light of my philosophical perspective and its focus on multiple ways of knowing, the body and imagery were two creative sources of knowledge



incorporated into the action research design. Although Chapter Five explains the creative process in detail, some highlights of the group sessions are included in this section.

The body is an important source of learning, especially in relationship to diabetes and knowing whether something feels “right.” One participant used her body’s signals as an indicator of when her blood sugar is going low. She often dreams that she is eating, cooking or looking for food, and then wakes up. Another person said that her body alerts her when she “feels weird,” and she is able to get to safety and eat because of the signals from her body. Developing awareness of the body through imagery was one way to access feelings or memories that could not be fully reached through words alone (Delano-Wood & Abeles, 2004).

Guided by a form of focused imagery (such as Stralen, as cited in Yorks & Kasl, 2005), we allowed our bodies to be our guides. Slowing down the mind and focusing deeply within helped us to breathe, relax and trust the creative process. One unique aspect of this study is that I did not ask participants directly, “How do you feel about diabetes?” Instead, I asked, “Diabetes feels like ...” There is a qualitative difference in those two questions. One asks for “feeling” words, and the latter asks for a description, an image, often generated from the body. The data that were collected during these group sessions were initial shapes and metaphors which came from body focusing and imagery, writing about the metaphor, and photographs and descriptions which related to the images.

Although no one in the study had ever thought of their diabetes as a metaphor, they were all able to imagine a shape which came from their body and then relate it to

their experience with diabetes. The option was also available for participants to work individually on alternative forms of expression. Two participants chose to include beading and pottery in addition to the group process, which were incredible additions of data to the multifaceted expressions of diabetes.

In addition to the metaphors and images from the body, another major form of data collection was photographs taken during the group sessions. Phototherapy, or the use of photos and pictures to describe feelings, is another form of artistic expression that can lead to healing (Anderson & Gold, 1998; Horowitz, 2002; Schechtman & Tsegahun, 2004). Images are often stronger than words, and extend beyond written language and cultural barriers. These images were shared and discussed at the group meetings to further construct meaning of the photos. Although written words were used as data, it is interesting that words were not the focus of the group, but the images themselves and feelings in relationship to them. The sessions were recorded and transcribed to reconstruct the atmosphere and interaction of the evening.

Throughout the process, participants were encouraged to record their reflections at the end of each session and to respond to one thing they learned about themselves or their diabetes by participating in the session. It was also a time for participants to plan the next session. These sheets were used in the synthesis of data as an additional source of knowledge about the meaning making and learning process. I also kept a record of my thoughts and reflections after each evening, which was compiled with the other field notes, some of which are included at the end of this dissertation as my own reflections on the process.

## Data Analysis

Action research requires that you “take the time to evaluate what you are doing and create a documented comparison based on the results” (Kuhne & Quigley, 1997, p. 30). With qualitative research, and specifically action research, there is no standard format for reporting, but a diversity of styles which allow for creativity. This does not mean there are not rigorous verification strategies similar to internal validity, reliability and external validity that is used in quantitative research. The initial in-depth interviews, the reflective results about the process of meaning making at the end of each session, the results from the final reflective section, and the creative and symbolic images themselves were analyzed.

During the initial interview, themes were compared across transcripts to establish conceptual categories. As a researcher with a constructive postmodern perspective, I was listening for the ways in which their knowledge about diabetes was formed, how they made meaning of their diabetes through creative expression, and how they resisted systems of power (in this case, the medical system). I coded the qualitative data by using a system of colors to highlight themes and compared the interpretations of the results of the participants, my observations, and the process of the action research, in order to look for consistency in interpretation. When looking for consistency, I counted the number of highlighted colors on each participant’s transcripts to make sure there was a balance between the themes.

The action research process was analyzed using the learning reflection sheets by the participants, the images and the photos. These different qualitative research methods expressed multifaceted ways of knowing and meaningful issues where words and “talk”

failed, and served as a method for data consistency in analysis (Coe & Strachan, 2002). Any alternative form of data collection (such as visual photos) must attend to the appropriate literature, methodology, and theory, but incorporating both the creative artwork with the text of the participants appropriately captured those aspects of the creative responses that were particularly difficult to describe in words (Coe & Strachan, 2002).

Harper (1994) said that the interpretation of artwork is difficult to analyze unless expressed in words because there is a danger that the analysis of the artwork might reflect the researcher's interpretation and biases. To lessen the chance this would happen, I encouraged the participants to put their own words into the interpretation of the photos. There were no clear themes that emerged from the photos themselves because each had a different meaning, so the photos and the participants' descriptions are included with very little comment from me as the researcher. In addition, I evaluated the results of the themes, creative artwork and findings by dialoguing with friends, colleagues, and the participants in the form of member checking (Oliver-Hoyo & Allen, 2006).

As a final analysis, I examined what the data revealed about the research problem, and confirmed that the initial interview addressed the experience and meaning making of diabetes in the participant's own words and that the action research process was designed to incorporate creative expression in diabetes care. In addition, when chapters four, five and six were approved by my dissertation advisor, I sent these chapters to the participants for their comments before distribution to the dissertation committee for purposes of member checking. The analysis of data showed that the interviews, questions, sessions and artwork reflected the purpose of the study.

### Verification Strategies

In this qualitative study, the words of the participants and their descriptions established a sense of trust, as well as the rigor of the researcher to communicate those words and feelings to the reader. In the words of St. Pierre in establishing verification or “validity” (as cited in Merriam, 2002, p. 406), “I will give it my best, since I care immeasurably for the women of this study,” and (in my addition of words) to the research conducted within it. She continues, “As I write and theorize the lives of my participants, I theorize my own.” This has been my experience, as I have spent hours, weeks, and months looking over and analyzing the stories and the artwork of these participants. There are several measures to take in order to produce a trustworthy study, as discussed below.

### *Transferability*

Transferability in qualitative research is similar to external validity in quantitative research, and refers to the likelihood that the findings have meaning in other situations while preserving the uniqueness of the study results in the particular context (Lincoln & Guba, 1985). Although qualitative findings are not meant to be generalizable, the methodology should be able to be replicated in further studies. The findings were specific to the eight participants in the study on a given day and moment in time, but the process could be repeated in another context. In Chapter Five, for example, I provided details of the creative process with the intent that further research in this area would be conducted by other researchers. It is my belief that others will be able to replicate the research process in this study using the detailed description I provide.

### *Confirmability*

Although each researcher brings his or her own perspective to the study, confirmability means that data can be tracked to their sources and confirmed by others (Lincoln & Guba, 1985). There are initial interviews and transcriptions, images, photographs, reflection sheets completed at the end of each meeting, observation notes, a creative vase and bracelet, and my own reflections of the process to map the data. Although the participant's names are confidential and kept separate from the data, the material within this dissertation can be tracked and confirmed.

Rich descriptions also add to the confirmability of the study and corroborate the general findings and lead to the implications (Marshall & Rossman, 1999). Detailed descriptions of each participant's words were used to generate the themes and the findings of the research. The implications of using creative expression and attending to multiple ways of knowing as they relate to this study's purpose are described in the final chapter.

### *Credibility*

Credibility is the degree to which the data described matches the experience of the participants (Lincoln & Guba, 1985). Both qualitative and quantitative researchers take thorough measures to establish a sense of trust and credibility. Quantitative research "must convince the reader that procedures have been followed faithfully because very little concrete description of what anyone does is provided. The qualitative study provides the reader with a depiction in enough detail to show that the author's conclusion 'made sense'" (Firestone, 1987, p. 19). It was important to me as a researcher to include direct quotes from participants to establish credibility, and to provide detailed

descriptions of our narratives and creative processes. This thorough approach to the details has expanded the study to seven chapters, in order to establish credibility and for the reader to be able to follow the steps of the process. The images and words included in this study formed a type of “audit trail” as a method of following along on the journey and created credibility within the study (Lincoln & Guba, 1985).

There are three elements to credibility (Patton 2002), which include: (a) rigorous techniques and methods for gathering quality data that are carefully analyzed, with attention to issues of validity, reliability, and triangulation; (b) the credibility of the researcher, which is influenced by education and training, experiences, position, and presentation of self; and (c) philosophical belief and appreciation of qualitative methods, inductive analysis and holistic thinking. Good research practice obligates the researcher to triangulate the data, to use multiple methods and data sources to enhance the credibility of research findings (Mathison, 1988). Triangulation is not a technical solution for ensuring validity, but it places the responsibility with the researcher for the construction of possible explanations about the research findings. The images, interviews, photos and field notes were used in the triangulation of data. Consulting with experts and colleagues is another method for obtaining investigator triangulation (Lincoln & Guba, 1985). I consulted with my dissertation advisor frequently (approximately once per week) and colleagues who were educated in the use of qualitative methods to establish further credibility.

In addition to triangulation of the data, Merriam and Simpson (2002) add that member checks, peer and colleague assessment of the data the researcher’s statement of assumptions and limitations, and immersion in the research situation improve credibility.

After the initial interviews were conducted and the themes determined, I reviewed the five themes of the initial interview and the participant introductions with the participants themselves for purposes of member checking. The chapters which contained participant quotes were also sent to them for verification.

My personal credibility was enhanced by the support of the Penn State Milton S. Hershey Medical Center from the Institutional Review Board and various colleagues in the Endocrinology Departments, as well as advisor, faculty and peer support from the School of Education and the Office of Research and Graduate Studies at Penn State Harrisburg. Having extensive experience in developing and facilitating professional development programs and focus groups, insulin-dependent diabetes, creative and scholarly writing, and the arts in education helped increase my credibility with the participants. Because I had an impact as a researcher on this process as an interviewer, facilitator, and person with diabetes, I was particularly interested in asking about my effects as an insider on the research process itself and credibility. Although not typically included in Chapter Three, it is important to discuss possible effects the researcher has on the study, as there not any studies in the literature review that directly addressed the researchers' influence on the interviewing process or description of data. The results of the participants' responses are explored below.

#### Effects of Insider Perspective to Research

The participants seemed to establish an open connection with me quite quickly, despite the fact that they knew little about me. Within the first fifteen minutes of the interview, the participants were sharing personal information about their diabetes and other aspects of their lives. To further research this observation during the final



interview, I asked, “You seemed to have shared your story of diabetes with me quite easily. How did the fact that I had diabetes affect (or not affect) our relationship?”

The responses to this question were mixed. Three of the participants said the fact that I had diabetes *did not* influence them, two said that it *did to some extent*, and two said that my having diabetes *did* influence their responses. One woman said that I was in “the background,” and my presence wasn't a consequence to her, whereas another simply responded, “no,” my having diabetes did not influence her and then began talking about how life was better with her being on the pump. Another woman responded that she knew I had diabetes, but:

in retrospect, when I was answering questions or whatever, I didn't think about it.

I wasn't thinking, ‘Oh, she'll understand me because she has diabetes too.’ I guess I really didn't think about that. You know. I don't think that influenced any of my answers.

One woman said that my having diabetes influenced their responses to some extent. She openly tells people about her diabetes, and if I didn't have diabetes and an insulin pump, she probably would have said the same things, but:

The fact that you did, it made me feel better about it. I think, because you can relate to what I'm saying. And when you shake your head, I know you understand it. Where other people say really, yeah, that hurts. It's just a comment, but they don't know what I'm feeling. Not that I wouldn't share, but your reactions were probably a lot more meaningful than just someone else who I would be telling.

Three participants thought that my having diabetes did influence their responses, but for different reasons. From one woman's point of view, my having diabetes helped

her feel less guilty because of “all the wrong things you've done along the way. You know you're talking to more of a nonjudgmental peer.” Another woman said there were certain things that she didn't have to say, because “I assumed you know those things, like how the pump works and that kind of thing.” She also thought that we shared similar experiences, such as people saying to us, “Are you supposed to eat that?” She said I have an “insider view of that” and telling “somebody that’s never experienced diabetes, um, is a whole different thing.” She appreciated not having to explain “every single thought and experience,” because if I didn't have diabetes, there was no way “you could understand, and that would make it more difficult. This was easier for me.” A similar response from another participant was that my having diabetes:

Did help, because you could relate. Then, you could ask a question, and that might prompt another response, so you could relate, because you know how we feel. Your questions were not steering us in any way. It was actually allowing us to expand on what we feel, on what our circumstances were.

She added that my “friendly, caring smile” helped, too. She said, “I think you shared some things, and I shared some things. It was very easy to talk to you.” Another woman said that I could relate to her because I had diabetes. She said:

It feels better to talk to someone without being in a support group, where you have to say certain things. I never went to one, but I can't imagine. I got more out of talking to you two times, then I could have going to a support group for five years.

As both the researcher and insider, I was aware of the dual roles, and made an effort to appear open and nonjudgmental by asking questions that were open ended and non-

leading. It would be impossible to know exactly how my having diabetes affected or did not affect their responses. If I would ask the questions again, the participants would be influenced by previous experience with me. If someone without diabetes would question the participants again, the participants would be influenced by previous responses. In fact, they may respond differently depending on the day, the environment, the context, the time of the interview, and their blood sugar level. From a constructive postmodern perspective, the construction of knowledge is ongoing between the researcher and the participants, which can help inform and improve practice and theory.

#### *Summary*

This methodology of this study was an action research design with narrative approaches to interviewing to complement the purposes and philosophical perspective of the research. This type of qualitative inquiry helps us get the depth needed to present a more holistic way of learning and being by listening to the voices of the eight women in his study and including their creative expression that also communicates the experience of diabetes. This research is significant to not only the greater field of adult education and the addition of multiple ways of knowing in practice, but to the 135 million people who have diabetes (King, Aubert & Herman, 1998). Even if we cannot know a cure, those with diabetes can always look toward healing by exploring new ways of making meaning and finding hope in our relationship with diabetes. Where this chapter provided an overview of the methodology, the next chapter displays the findings of the initial interviews in the planning stage of the action research process.

## CHAPTER 4

### INITIAL INTERVIEW FINDINGS

The purpose of this study was to determine how adults experience and make meaning of their Type 1 diabetes and to engage in creative expression to find greater meaning and wellness through an action research process. In action research, there are four interwoven paths in the methodology: planning, acting, observing and reflecting. The initial interviews were conducted as part of the planning process of the action research design. The planning stage is a process of selecting and identifying the participants, and then collaborating with those participants to determine a flexible plan that will help the participants and researchers reach a response to the research question. The research question addressed during this process was “How do adults make meaning of their insulin-dependent diabetes?” The second purpose to the interviews was to determine what participants enjoyed doing outside of normal work and diabetes responsibilities. The responses to these questions would help shape the plan of the action research design, based upon the interests of the participants. The specifics and results of this process are described below.

After completing the Informed Consent Form (see Appendix B), each interview began with the question, “Tell me about your diagnosis,” and explored feelings toward having diabetes, and ended with the question, “What activities do you enjoy doing outside of your normal responsibilities?” The first and larger part of the interview focused on the meaning making experience of living with diabetes and the feelings associated with having a chronic disease. The intent behind the second part of the

interview was to discover what activities the participants enjoyed. The question was not, “What do you like to do that is creative?” or “Do you do any kind of artwork?” because asking these types of questions may have led participants to believe that they needed to be an artist in order to participate in this study. That is far from the purpose. By listening to patterns in these activities, I incorporated many of these elements into the creative expression group exercise and subsequent stages of the action research process. The unstructured, narrative interviews allowed for flexibility and freedom for the participants to speak freely about their experience of diabetes.

In light of the feminist poststructural and constructive postmodern perspectives, I was aware of my position as a researcher and an educated, white woman with Type 1 diabetes. Feminist poststructuralists explore issues of positionality regarding the way that people are “positioned” relative to the dominant culture, which connects to whose voices are heard and represented in the research. I was able to establish a connection quite quickly with the participants, and I believe that was in part because of my position as a woman, but even more importantly as an “insider” with diabetes who is living the experience. Within the first fifteen minutes of the interview, the participants were sharing personal information about their diabetes and their personal lives. Being an insider was a benefit, not an impediment, to the outcome of this study (as discussed further in Chapter Six). Jennifer said, “No one has ever sit [sic] down and listened to my whole story before. Really. Except for maybe my sister who has lived through most of it with me, but only from out there.” Agnes said that it was nice to know another person who was on the pump, because she didn’t know anyone else. It was wonderful for me to

meet and get to know these women, having the common bond of diabetes. There was instant rapport with these women, each of whom is introduced below.

### Introduction of Participants

In the following paragraphs each participant is introduced, summarizing her diabetes diagnosis, experiences with diabetes, and personal interests (see Table 1 below and Table 2 on page 145). Table 1 provides a summary of each participant's current age, age at diagnosis, number of years with diabetes, number of years on the insulin pump, and current A1C, whereas Table 2 focuses on the creative activities which the participants enjoyed.

**Table 1**

**The Participants' Current Age, Age at Diagnosis, Number of Years with Diabetes and Years on the Insulin Pump, and Current A1C**

	Current Age	Age at Diagnosis	# of Years w/ Diabetes	On the Pump (yrs.)	A1C
Jennifer	60	8	52	11	7.8
Camilla	35	13	22	6	7.2
Sophie	46	8	38	10	5.8*
Agnes	57	15	42	1.5	7.8
Daisey	37	4	33	8	8.6
Coral	37	25	12	10	8.2
Emily	27	6	21	1	7.4
Amber	43	8	35	8	7.1
Roberta	40	9	31	1	7.5
Heather	37	12	25	3	7.9

\*Although one of the desired criterion was that the A1C be greater than seven, this participant said that although her blood sugar was under good long-term control, she still had difficulty managing her low blood sugars and wished to be included. She met all other requirements for the study.

Because I was also an active participant, my introduction is included with the other participants in the study. All of the women were white, except for Roberta who was bi-racial. As the study progressed, Amber and Jennifer were not able to attend the group meetings, and were excluded from the findings in Chapter Five and forward. Their stories are included in Chapter Four because they provided data directly related to how adults with diabetes make meaning. The average age of the participant was 42, with an age at diagnosis between the years of 4 and 25 (average = 10.8). They had Type 1 diabetes from a minimum of 12 years to a maximum of 52 years (average = 31), with 311 cumulative years of experience with diabetes. Although both men and women were recruited for this study, only women responded. Each woman's experience with diabetes and her interest in creative expression are described on the following pages.

#### *Jennifer*

Jennifer has had diabetes the longest (52 years) out of anyone in the group, and is also the oldest (age 60). She is considered disabled and no longer works at her former position in public relations. Jennifer is unmarried with no children, and has one older sister. Jennifer knew she had diabetes when she became ill and went into a coma. One doctor came to the house, and he could not determine what was making Jennifer ill. Her mother called for another doctor, who bent down beside her on the sofa, listened to her breathing, smelled her breath, and immediately diagnosed her with diabetes. She remembers having to practice giving herself shots with an orange until she could do it herself.

Jennifer has quite a few complications as a result of living with diabetes for 52 years, including Charcot in both feet, retinopathy, carpal tunnel, mini-stroke, chronic

renal disease, and gastroparesis, and has also survived a mastectomy as a result of breast cancer. She considers herself lucky to be alive, and is involved in many activities with her church, choir, and diabetes research studies. One of her most difficult struggles was seeing her foot change shape because of the Charcot, and her biggest fear is losing her independence. She would consider herself persistent, upbeat, and creative. She said, “I wouldn’t have gone into public relations if I weren’t creative, but I could not sit down and draw.”

She started stained glass as her way of expressing creativity. She found that all her creativity could go into picking colors, choosing a pattern, arranging the colors, putting it together and seeing it finished. She has her own set of tools and studio at home so she could work on her stained glass art on her time and her limits. Her stained glass work helped her get through her problems with Charcot foot, and she designed several stained glass feet to give to her doctors and health care providers. In addition to stained glass, Jennifer enjoys planning parties and using her creativity to work with the details and special surprises of an event. She also sings solo in her church choir, and enjoys shopping.

### *Camilla*

Camilla is 35 years old and has had diabetes for 22 years. Out of her five siblings, she is the only one with diabetes. Camilla has two children (one passed away at birth), two step-children and a husband. While growing up, she was “dirt poor,” without access to the foods she needed to have a healthy diet. Camilla was diagnosed because she had a sore on her body that would not go away. Unlike the other participants in the study, she did not feel sick upon diagnosis. She began taking better care of herself when



she went on the insulin pump in 2000, but for her it is still a struggle. She was in and out of hospitals over the years, and has had seven laser surgeries for her diabetic retinopathy. In addition to the trauma of losing her son, when Camilla was young, she was abused by neighborhood teenagers. Her most difficult struggle in her life was dealing with the death of her infant son, and fearing going blind because of diabetes. She would describe herself as wild and self-sacrificing for others.

Camilla has a lot of energy, and likes to use that extra energy in taking care of her children and other people. She likes to sing and dance with her children, and hear them laugh while they are playing. They plant flowers in the backyard together. She said, "I don't think about me and my life since everything always revolves around what they [the children] like to do, or what my husband likes to do. She does enjoy sleeping, and reading romantic novels by Nora Roberts. The novels tend to bring out her imagination of what life could be like if a knight in shining armor would come to her rescue and do or say the right thing at the right time. She loves being around people, and getting to know them. Before an injury to her shoulder, she also enjoyed playing tennis.

### *Sophie*

Sophie, age 46, is the second oldest sister out of two brothers and two sisters, and has two children and a husband. She is also at the height of her career in a governmental position. Sophie remembers her diagnosis very clearly. Because Sophie had to go to the bathroom frequently and get water, her teacher thought she had a behavioral problem. She went to the doctor's office and sat alone in the waiting room while her mother heard the news of her potentially devastating diagnosis. Since then, she has worked hard to maintain excellent blood glucose control and has avoided all complications. As far as

Sophie's difficulties, she finds her daughter's neurological impairment to be a challenge, and she does not like to lose control of her mind and body during low blood sugars. She would say she is responsible and independent.

Sophie loved to dance when she was younger, and still enjoys watching her daughter perform with a dance company. She said there were times when she would close her curtains in her apartment in college and just dance. Free-form, expressive dance brings out "what you might not verbalize." It was a way to "bring out what's inside, without having to quantify and define it with words. You're just ... letting it flow away from you." She also enjoys listening to music, although she said she is musically untalented herself. Another activity she enjoys is putting together albums for people, or doing something creative such as inventing new ways to organize or arrange things in rooms.

### *Agnes*

At age 57, Agnes is married, with two grown children, a younger sister and an older brother. She used to work full-time with a local governmental foundation, but is now active with other activities, such as gardening and reading. While studying for midyear sophomore exams in high school, Agnes drank an entire pitcher of lemonade. She knew something was wrong. When she went into the doctor's office with her mother, Agnes saw a pamphlet on diabetes and recognized all the symptoms: increased thirst, frequent urination, fatigue. She went into the hospital for 17 days to be regulated on insulin and shown how to give shots. At that time, Agnes had to use urine strips to test her sugar, since there were no glucometers. She was always the one who gave herself the insulin injections, even though some times it was difficult. Since then, she has

experienced some complications with her heart and has four stents, but she considers herself “lucky.” Agnes is steadfast and positive in her outlook.

Recently, Agnes was accepted into a Master Gardener program to learn more about gardening, plants, and the earth. She particularly enjoys flower gardening, and walking outside. She also belongs to a quilter’s guild and a reading group. Agnes loves to go antiquing, which she says is “another form of shopping,” and collects colorful, Fiesta plates for her daughter, and miniature pigs for herself. Agnes also enjoys reading and photography. She has a wide variety of interests and has been able to do more since she is no longer working.

### *Daisy*

At age four, Daisy developed diabetes at the youngest age of anyone in this study, and a life with diabetes is the only one she has known. Now, at age 37, she is a registered nurse and serves other people with diabetes. Daisy has an older brother. Her father had diabetes, so there was the possibility of her developing it, too. She was getting up in the middle of the night to go to the bathroom frequently and lost a lot of weight. Before she was diagnosed, she had upper respiratory infections and was very ill. After staying in the hospital for about a week, Daisy learned to give shots to both her and her father, which gives another meaning to “shot buddies.” She has proliferative retinopathy and atrophy from insulin injections. Daisy once had glycosuria-induced bulimia, which means she would raise the level of ketones in her body in order to lose weight. Her biggest struggle is with her self-esteem and body-image. She is intelligent, sarcastic, and a lot of fun.

Daisey's main interest is being with nature. She is an "outdoors" person, and likes to go kayaking, snorkeling, and camping. Another interest is photography. She says she tries to always have a camera in her Jeep, because "you never know when you will see that beautiful sunset or rainbow." Sometimes she tries to journal to work through emotions, and write about things that are difficult. For fun, she wrote a few poems while at diabetes camp. Her favorite thing to do was to take a popular song and to substitute diabetes words for it. Within her seriousness, she has a sense of humor that pervades all that she does.

### *Amber*

Amber was in second grade when she was first diagnosed, outside of New York City. Her family was going to Ringling Brother's Barnum and Bailey Circus, and Amber was feeling sick. She was tired, thin, and drinking a lot of punch before her diagnosis of diabetes. Amber was in the hospital for three weeks. When she came home, she started having seizures. Her family couldn't have glasses in the house because, in the morning, she would have a seizure and bite into the glass. Now, at age 43, she has diabetic retinopathy and neuropathy, and she has also lived through sexual abuse and drug use. Life has not been easy for Amber, but she is most grateful for her daughter and her eyesight. She has hope, optimism, and depends upon a Higher Power to get her through the ups and downs of life.

Singing makes Amber happy, because it takes the focus off of herself and onto "the One who is in control of everything." She works out regularly on machines and weights, or exercises by walking her dog. She has always enjoyed roller skating and music, but admits she is not an "artsy-craftsy" person. Neither is she a writer or a reader.

She would rather spend time with her family than behind a book, and enjoys watching her daughter's softball games. She and her husband once worked in a drug and alcohol rehab center, and Amber particularly enjoys working with disadvantaged women.

*Coral*

Coral, now age 37, was diagnosed with diabetes in 1994. She had dropped down to 88 pounds, had an extreme thirst, and was constantly eating. She remembers going to the doctor in the snow on Valentine's Day. Unlike the other participants in the group, Coral didn't go to the hospital, but was sent home with a prescription and an 1,800 calorie meal plan. She wasn't put on insulin injections at first, and didn't really know what diabetes was, or what the next step for her care might be. It was overwhelming. Coral used to work as a tennis professional, but has changed to a more stable career in real estate. She enjoys playing golf and tennis, creating pottery and living life itself. Although she has diabetes, she believes it can be managed, and has a positive outlook on her future. She does not have any complications. Coral could be described as fun-loving and young at heart.

Coral also likes skiing, when she can, and walking outside. Coral works with pottery, and has a wheel in her basement where she spins clay. Some days spinning is calming and soothing but, other days, she says, "you just can't do it right." Coral loves to socialize. She displays her pottery at arts and craft shows, and often runs into people she knows. When she is having a bad day, though, she just wants to take a long drive with her dog. If she feels tired or needs to relax, she'll watch reality shows or cooking shows to take her mind off things.

*Emily*

At age 27, Emily was the youngest participant in the group; she was also one of the youngest to be diagnosed at age six, in first grade. Her symptoms were that she was drinking constantly, going to the bathroom frequently, and had “cotton mouth.” At first the pediatrician did not know what was wrong with her, and she was tested for multiple diseases of the liver before discovering she had diabetes. When she was getting her temperature taken in the doctor’s office, the Mercury thermometer dropped out of her mouth and shattered on the floor. Emily didn’t have shoes on, and the medical staff started yelling because they didn’t want her stepping in the Mercury. She thought they were yelling about her diabetes. Although she doesn’t have long-term complications, she does continue to deal with occasional seizures. Emily is a special education teacher, and has one sister. Emily sings, beads jewelry, and likes to learn history and be with her friends. She is an observer, quiet in groups, and is creative.

Emily likes music, and she is in a band where she sings some of the “new rock” on the radio, but also likes to sing Pat Benatar and some older songs, too. She plays the cello on her own, but not with the band. In addition to singing, Emily makes necklaces and bracelets. She likes to bead, to make things for friends and birthdays, and is always trying to come up with new designs and patterns. She loves going to school, and especially enjoys her art and history classes. Hiking, walking, going to the beach, and being near the water are other activities Emily enjoys. When she can, she likes to be with her friends. Her friends are important to her.

*Roberta*

Roberta, age 40, was diagnosed at age nine. She would faint frequently, and was underweight. The doctors tested her with EKGs, but found nothing, so a friend of the family sent her to the Children's Hospital in Philadelphia where she was diagnosed with diabetes. Roberta practiced giving her own injection with water and an orange. She had no clue what diabetes was, and she didn't remember receiving any formal training. She joked with her mother that she knew what every ceiling in every major department store looked like, because she would pass out and wake up looking at it. Her biological father had Type 2 diabetes later in life, and her biological mother had thyroid problems, so her diabetes may have been linked to their conditions. Her father was half-black and half-white, and her mother was half-black and Hispanic. She was adopted by an African-American family, so she grew up in African-American culture. Roberta has diabetic retinopathy, but it has not severely impacted her vision, and she has had trigger finger surgery related to her diabetes. As a deaf education instructor, this affects her ability to sign. She also plays guitar and percussion, and enjoys eating Japanese, Thai, Vietnamese and Indian food. Roberta is compassionate and spunky.

In high school, Roberta played field hockey and softball. It seems like she was always active, riding bike and playing outside. She still likes to take walks. Roberta likes to go out to eat, particularly to Japanese, Thai, Vietnamese and Indian restaurants. Although she exercises regularly, she really doesn't *like* exercising. The reason she exercises is to see the results. She does like to go to the movies, and to listen to music. She's often been criticized because she doesn't fit the stereotype of someone of her ethnic background. "I could care less about rap or hip-hop," she says. "Give me some Peter,

Paul and Mary, and I'm in heaven." Roberta also likes playing guitar and congos, and has recorded a few CDs. Recently, she went through trigger finger surgery and is unable to play an instrument, so she is using a computer to create a meditation CD using loops.

*Heather*

Now that I am age 37, I can think back to when I was diagnosed at age 12. My mother noticed that I was extremely thirsty while we were watching a gymnastics event, and took me to the doctor. I was in the hospital for a few days, where I learned to give myself my own injections on an orange. Throughout my teenage years, I did not take good care of myself, especially with eating habits, and, as a result, I have diabetic retinopathy, a bit of gastroparesis and nephropathy, as well as Graves disease (thyroid disorder). One could say that sugar was my addiction. I enjoy doing creative things, like writing, painting, and paying attention to nature. People might describe me as reflective and easy-going, but also a risk-taker at times.

Although I would not consider myself an artist, I believe I look at most things from a metaphorical and creative eye. I think, "What could that rock be, if it wouldn't be a rock?" I like to engage the imagination, especially through creative writing, writing from the soul. Being in nature is something I "soak up," whether it be walking or sitting by a lake, and I am happy when I can share that with someone, especially my son. Sometimes I paint when I am in the mood, and I have tried stained glass, sculpting and woodworking, but nothing seems to come as naturally as to write, without conscious thought of what comes next.

The following table (see Table 2) provides a summary of each participant's interests, which were used in the development and planning of the action research.



**Table 2.**  
**Creative Expression and Interests of Participants**

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Jennifer	Stained glass, planning parties and events, church, singing
Camilla	Reading romance novels, being around family, singing and dancing
Sophie	Free-form dancing, making albums, listening to music
Agnes	Gardening, quilting, reading, photography
Daisey	Being with nature, snorkeling, kayaking, photography, writing
Coral	Tennis, golf, skiing, walking, pottery
Emily	Beading, singing, walking, learning history, going to the beach
Amber	Singing, going to church, walking dog, working with women
Roberta	Playing guitar (before surgery), eating out, listening to music
Heather	Creative writing, walking (especially around water), painting

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These interests were used in the planning process to determine possible activities for use with the group creative expression sessions. Not including myself, the more common activities for participants were: singing (4 responses), walking or being in nature (4), dancing (2), listening to music (2), and photography (2). How these forms of creativity were integrated into the first session is described in Chapter Five.

#### Themes of the Narratives

The research question that was explored during the course of these narratives was, “What are the ways in which adults experience and make meaning of their Type 1 diabetes?” My access to the participants as an insider, as well as my own inclusion in the study as a participant, allowed the women in the study to speak freely and openly.

Several themes emerged from these personal, narrative interviews, and the five themes below summarize the majority of the findings. These themes were analyzed from a constructive postmodern view, which deconstructs evidence, such as medical “fact,” to allow room for all ways of knowing, including personal experiences. As participants told their life experiences, the narration of their life was viewed as fluid and ever-changing, a moment of time. The themes which emerged from the data included: (a) Experiencing a range of negative feelings about diabetes; (b) Resisting against diabetes and medical approach; (c) Taking a positive spin on the negative as a way to cope; (d) Constantly shifting awareness of diabetes; and (e) Living for others.

Each of these themes will be explained in depth throughout the remainder of this chapter. Many of the participants’ direct quotes are used, because they reflect the experience and *meaning* of diabetes. The meaning making process itself is socially constructed, as I was included as a participant in the study, and the process allowed me to reflect upon my own feelings, thoughts, and images of diabetes. The analysis of themes emerged from the data, but my theoretical perspective encourages interpretation and re-interpretation of life experiences and meaning making on multiple levels. In Chapter Seven, my own meaning making process as a participant is included, and ways the participants have influenced the ongoing construction and reconstruction of meaning.

After creating the themes, I envisioned how they could relate back to the metaphor of “Dry Bones” as an alternative way of describing the data. As first introduced in Chapter One, Ezekiel’s vision of the Valley of Dry Bones (Ezekiel 37) is about desperation, and an opportunity for transformation and new hope, which describes

my experience with diabetes. This metaphor is carried throughout each of the five themes.

*Living in the Valley of Dry Bones: Experiencing Negative Feelings about Diabetes*

*The hand of Yahweh was on me; he carried me away by the spirit of Yahweh and set me down in the middle of a Valley full of bones. He made me walk up and down and all around them. There were vast quantities of these bones on the floor of the Valley; and they were completely dry (Ezekiel 37:1-2).*

In the Valley of Bones, death permeates the air. There is a smell of disease, a loss of a child, the remnants of war. Before entering the Valley, life seemed “normal” and routine, perhaps even content. The news of the death of a loved one, or the diagnosis of a terminal or chronic illness quickly, and violently, turns the air stale and rotten, like the smell of bones. Anyone who has experienced the Valley of Bones knows its scent, and something within us is repulsed, alarmed.

The diagnosis of diabetes can feel like being carried to the Valley, an unknown and unwanted destination of suffering. The experience is a haunting walk in dark and frightening land in which there are many new things to learn: monitoring blood sugar, dealing with lows and highs, avoiding blindness and complications, and giving injections. To those of us who have experienced a diagnosis of a life-threatening illness, the Valley can feel desolate, overwhelming, filled with dry bones. Although “Dry Bones” was my metaphor for illustrating my feelings about diabetes, the participants described life experiences that also related to the metaphor.

The participants described diabetes as a life-changing event, and some found it difficult to express their emotions about diabetes. Jennifer said, "I knew from the point of my diagnosis that diabetes was going to change my life. I understood that." Coral assented by saying that diabetes changed everything, and "it changed my whole way of

doing stuff," meaning patterns of eating, insulin routines, and added structure to her life. She went from "total freedom" to a very structured schedule, and it "changed drastically," describing it in this way:

I love to play golf. I love to play tennis, and there were so many things I wanted to do. And I had to schedule these around when I was going to eat next. It was such a strict schedule. That was hard.

After they lived with diabetes over the years and started to understand what diabetes meant to them, the participants began to express a range of emotions that described the experience of diabetes. Many of those emotions were negative, including (a) a fear of death, (b) anger and frustration, (c) feelings of difference, (d) depression and moodiness, (e) guilt, and (f) uncomfortable, physical pain. Although these are feelings which many people may feel from time to time, the context in which they are described relates to the ways in which diabetes changes the experience and meaning making process of life.

### *Fear of Death*

All of the participants experienced fear on some level, the most common being the fear of death. Sophie had never heard of the word, diabetes, until she was diagnosed with it as a young child. Her mother told her that she had diabetes. She thought, "Well, I guess I'm going to die. *Die-a-betes*." Roberta expressed, "I think there's a reason why it's called *DIE*-abetes." She thought it was going to kill her, and she really didn't want to think about that. Upon diagnosis, Emily said, "I thought I was going to die." The fear has not gone away for her, and she still has a "total fear" of death. She said, "I can't even

sit and think about it for a little bit. Because I feel like I can put myself there. It is real for me to die."

When Coral was diagnosed, she was thinking, "I have diabetes. I'm going to die tomorrow. This is the end." She said that it scared her to death, literally. "Diabetes is associated with heart disease," she said,

But you hear 'diabetes,' and unless you have it, or really know someone who has it, you don't know. And you learn about it because you always think that people don't live long with diabetes.

Amber expressed a similar fear, wondering if something was going to happen to her when she got older. She wondered if "it's going to kill me young." Daisy also had the lingering fear of death. When she was younger, she thought that if she had any kind of sugar she was going to die, as though she was going to have an allergic reaction from it. Today, she relates the steps of dealing with a chronic illness like going through the stages of death, where there is denial, anger, depression and an acceptance stage.

This fear of death is understandable, because some of the participants had personal friends who died from diabetes. They recollected memories of a young girl in high school who died from kidney disease, or a friend who died at age 24 because no one was around to help her during a low blood sugar. Many of Jennifer's friends are no longer alive, and she is "just fortunate" to be celebrating her 60th birthday, having 50 years with diabetes. One of her doctors said, "You know, a lot of your contemporaries aren't around," and Jennifer responded, "I know. I've watched a lot of diabetic friends die. And they haven't gotten to be 60." She personally experiences the fear of death

daily when she has hypoglycemic unawareness. Sometimes she doesn't want to think about it. It makes her low blood sugars

Scary, and I know I wonder about the morning that it doesn't wake me up. Last Sunday morning, I had a very bad morning. It happened twice during the night: once my blood sugar was 32, once it was 36. And I thought, you know what, I better be glad it woke me up.

The fear of death was on the minds of all participants at some point or another. Chronic illness makes the awareness of death so much closer. Camilla said:

If I died today, it wouldn't bother me other than the fact that I would want to make sure my kids were taken care of. But I know I'm going... I'm going to a much better place. And there won't be a pump connected to me. I could just sit on those clouds eating a big chocolate cake or banana split, and nothing is going to happen to me.

Some participants also stated their fear of death indirectly, expressing their fear of complications, which may lead to death. Although Sophie has avoided all complications to this point, she is still afraid of the hidden things now, like heart attack and stroke. She said there are certain things that she can monitor and watch, but complications can come like a "thief in the night." When Agnes was 15, she thought that if she got to be age 35, she would be lucky. Her fear of death related to "something going wrong" with her heart, which was "scary." Roberta feared the complications of diabetes, because she didn't know when they were going to cause kidney failure or heart attack, and then it would be over. She said, "You can do this or that to slow [complications] down, or to prevent

certain things from happening sooner, but that means it's still going to happen eventually."

### *Anger and Frustration*

Many participants felt a sense of anger because of their diabetes. When Jennifer was eight and was learning how to monitor and oversee her diabetes with her mother's help, she went through an "angry stage" where she didn't want to take her shots. Today, she is it frustrated because diabetes dictates her lifestyle. She doesn't like to carry a juice box with her wherever she goes, in the event of a low blood sugar. She said

The other day I went out shopping, and I was coming home, and I barely made it to the front door. I mean [my blood sugar] was just going [sound of going down]. It was freefalling and I barely, honestly, made it to the door. Sometimes, I've been in the store at a Wal-Mart or a grocery store. I've been in the juice aisle, and bought a pack of juice boxes, and I get to the cash register, and I said, 'I'm diabetic and I had to one of these' ... that's how they happen.

One participant said that she gets very angry -- outraged -- about her diabetes. She gets tired of low blood sugars, especially when she's going to bed and has to keep eating because her blood sugars will go up; sometimes, she can't eat because they're too high. She also gets angry because she often feels sick, and gets infections more than most people. She has to take off of school or work because she is sick, and it makes her mad because other people can just "get sick." They don't have to take care of their diabetes like she does. She said it is hard to talk to other people about this, because she gets so mad. The irony is that:

I don't have anyone to get mad at. At 2 AM, who am I going to get mad at? You can get mad at yourself, but you still have to take care of yourself. It is a constant reminder. You can't get rid of the anger, because there's nothing to put the anger on. It's part of me, and it's easy to be stubborn and angry and to say, 'I'm not going to take care of it anymore,' but that would be more hurtful than helping.

Amber said she also had a lot of anger inside of her, and she was taking it out on herself by eating a lot, not taking her insulin, and taking illegal drugs. Diabetes is hard for her because she feels so tired, and she doesn't want to be a mother or a wife. She just wants to be left alone because she feels so exhausted. She says, "I feel like a drag-along doll. You know, 'just drag me along and ... I'll do what I need to do.'" It makes her angry, because she would like to produce more, but in a sense, she's not able. In another woman's life, diabetes compromised the birth of her child. When she was in labor with her child, her blood sugar was in the high 200s, and the doctors gave her insulin. She didn't want the insulin, and when the doctors cut the umbilical cord, the insulin went into her baby's body. Her daughter almost died because her blood sugar dropped down to 13. She said, "I was most angry at the disease then."

Roberta gets angry at her diabetes when she's trying to exercise. She finds it frustrating when she can't even walk on the treadmill without having a low blood sugar. She finds it difficult to adjust her insulin, because there are so many variables. Although she's tried to adjust her basal rate to compensate, she finds that each exercise class has a different effect on her blood sugar. Sometimes she gets overwhelmed by all that there is to do. Another woman also is frustrated because she needs to miss work "all the time" to come to the doctor, the phone calls, the blood tests, and "all the things you have to do."



She can't stand when other people tell her to test her blood and they ask, "What's your number?" If she gets angry at her children, they might ask her if she needs to check her blood. She says, "Do you always think that I'm angry or short tempered because I'm having a low blood sugar?" It is frustrating for her to try to control her blood sugars, when day to day she could do the same thing, yet get different results. Sometimes, she will get a low blood sugar where she has a "major sweat out," and it is frustrating when her blood sugar doesn't come back up quickly enough. Coral described a low blood sugar in this way:

Having a low blood sugar is just nasty. That's just the word for it. You have a low sugar, and you're shaking. You're really not in control of your body at that point. You're just not in control. Even the thoughts in your head at that time are crazy. You're in a daze. Then you lay there for 15 minutes or half an hour until it comes up again because you're totally drenched in sweat ... it's not fun. It is absolutely not fun. I hate that.

In addition to feeling frustration at low blood sugars, fatigue, and compromised health, the participants also felt a sense of frustration in the lack of understanding from other people who do not have diabetes. When she is having a low blood sugar and eating something sweet to bring it back up, one woman hates when people ask, "Are you supposed to eat that?" She thinks, "Get out of here, you idiot. You are stupid. You know, I get tired of being the only one who knows anything about diabetes, or feel like I do sometimes." She's even had nurses who have whispered in the background, "I don't trust diabetics," which seems so off-the-wall to her. Maybe they think she is going to eat sugar behind their back. She's not sure, but it is frustrating to not be trusted.

Many of Coral's family members don't understand the disease, either. Even though she tells her sister not to buy sugar, her sister still buys Swedish Fish at the store. Coral says, "I don't think she truly understands what it is all about." Camilla also gets frustrated when people tell her that they know how she feels, when they "have no idea." People are often "blind" to her insulin pump, and they don't understand how it works.

Jennifer feels misunderstood, too, in that people don't understand her complications, like her Charcot foot. She said that it's hard to even tell people about it. "Nobody, even another diabetic, doesn't want to talk about it until it happens to them. I had seen the term [Charcot], I had seen pictures, I had read about it, I had an awareness of it. But until you get it, you have no idea." It's also difficult for her to help other people understand what it is like to get laser surgery for diabetic retinopathy. She says, "They have noooo idea," but she was grateful to be able to talk to me, who could relate to her complications on some level. Jennifer said, "No one has ever sit down and listened to my whole story before. Really."

### *Feelings of Difference*

Having diabetes makes people feel different and alienated, like the "other." In their childhood, participants described feeling like the "other" in relationship to their diabetes, especially when it came to eating, typically a "normal" function of life. Camilla felt different because she hated that her friends could get ice cream from the ice cream truck, but she couldn't. She hated that they could sit around and drink iced tea or soda, and all she could drink was diet, which tasted like "crap" back then. She hated that she had to eat at certain times, and the other children did not need to. When the other

children would get candy stuffed in their stockings at Christmas, Camilla would get a bottle of insulin or apples and oranges. She always felt different.

Most participants described what it felt like at “snack time” in school. When Daisey went to school, the days were regimented. Most kids couldn't take bathroom breaks, nor were there any special snack times. She would get called "teacher's pet" because she was allowed to go to the bathroom and the teacher would point out, "You know, Daisey has a medical condition." Roberta felt different because she needed to eat her snacks, which were always Graham crackers and peanut butter, in front of everyone. She remembered when someone once pointed out, "Why does she get to eat in class, and we don't?" This comment made Roberta wish she could crawl under the table. Emily also felt different when all the kids from first grade came to watch a video about diabetes, in order to understand what was going on with her. Although it helped to explain diabetes and why she was allowed to eat snacks, it still made her feel strange.

Jennifer's story is similar to these, as she was the only child in her elementary school with diabetes. She said she felt different when they had "dental health parties" to celebrate everyone's getting a good dental health report. The teachers brought food, but she always had to have fruit while the other kids were eating cake. When it was someone's birthday, and they were having snacks, she would have carrots. "So," she said, "Of course I felt very different." As Jennifer got older, her boss tried to make her feel as though her diabetes was affecting her ability to do the job, but she had one of the best attendance records in the company, and she felt she was being discriminated against because of her diabetes. She said, "As far as feeling different, I think you could probably summarize it by saying, yes, I felt different all my life." Amber felt different all her life,

too. She continues to have days where she doesn't feel well, and she knows that she's not like everyone else. Most of the people she knows work 40 hours a week, but even with her part-time job, it doesn't seem like enough time to rest for her.

Sophie felt that she got extra attention because of her diabetes, and wondered if her siblings were jealous of her being asked by her parents, "Did you eat enough? Have you done this?" She really didn't want people to recognize her diabetes. "As a teenager," she said:

You want to be different, but God forbid you are different. So it's like we want to stand out, we want to be noticed, but ... I never wanted to be noticed because I had diabetes.

It is especially difficult at events where she feels like she's the only one in the room who has diabetes. Sometimes, when everyone is sitting down at a party, and they're starting to serve, she has to figure out how to reach her insulin pump on her leg. She has to think about these things, and other people don't. Other people don't need to go to so many doctor visits, or pay attention to their blood sugar, or worry about how to give themselves insulin at a party. When Coral is at parties, she sometimes doesn't want people to know she has diabetes because they look at her differently. At her cousin's child's birthday, she had a small, one by one inch, piece of cake, an extra thin Pizza Hut pizza and salad, and everyone looked at her. She could tell they were thinking, "Are you eating that?" Camilla would proudly reply, "Yes, I am. Would you like to eat a piece with me?"

Some participants felt embarrassed because of their difference. In seventh grade, Daisey was teased because she was allergic to the pork and beef insulin, and had

developed bad atrophy and scar tissue. She did not tell many people that she had diabetes, and neither did she need to, because she said, "you can get your shot in privacy," and no one needs to know. Emily would get embarrassed to write down her blood sugar numbers in front of her friends. She said, "You can't eat lunch and say 'excuse me' in front of your friends. It is annoying and it is embarrassing."

Having a low blood sugar can also be embarrassing. One participant was in the middle of the "heat of the moment," and her blood sugar just fell and bottomed out. Fortunately, her partner knew she had diabetes, and she was able to talk to him about it. Coral had a different experience. She didn't want to tell her exercise trainer she had diabetes, and she "crashed" with a low blood sugar. He gave her a sweet drink, and then she told them she had diabetes. He said, "Yeah, I figured that out now." Amber would be embarrassed when she had a seizure due to her low blood sugar. She said, "You don't like to be confused around people. I just wouldn't know what I was doing," and it was embarrassing for her to be out of control. Roberta agreed that it was embarrassing to pass out somewhere because of a bad low blood sugar.

One tactic to avoid feelings of difference and embarrassment was to keep the experience of having diabetes quiet. Sophie described another student in her high school who was diagnosed with diabetes and would say, "I've got to take shots." Sophie would think, "Shut up. Sit down. I've got to take shots, too." On the one hand, it was good for Sophie to know someone who had diabetes, but she didn't really feel like it needed to be discussed. Many participants just didn't tell people that they had diabetes and lived in silence most of their lives. Coral expressed, "You look healthy. I look healthy. So people don't really know you have diabetes." They don't know what people with

diabetes go through on a daily basis. Diabetes is an invisible disease, and unless people speak about it openly, diabetes is often kept silent.

### *Depression and Moodiness*

Even though diabetes is invisible on the outside, it can ravage the inside. Many participants experienced an inward expression of depression, moodiness and sadness, and some continue to live with these feelings. When Daisey was in her sophomore year of college, people told her that she was "moody" and "grumpy." She felt depressed, and she learned about the association with mood swings and out-of-control blood sugars. She thought maybe she needed to "shape up." Coral said when her blood sugar is low, or she is having an up-and-down day, her body just takes a beating. She said, "I get emotional. I used to be very happy-go-lucky, and let's have some fun, but with my sugars up and down, I get kind of cranky." One woman said she is "grouchy," and realizes that depression is quite common in diabetics. She wonders if she would be a depressed person if she didn't have diabetes. Sometimes she will be somewhere and feel like she wants to cry all of a sudden, but doesn't know why. Then just as quickly, the feeling is gone. Emily can relate to this, because she says a high blood sugar in the morning really affects her mood for the whole day. Her sugars are low or high, and she said people don't understand why she's not in a good mood. Other people are saying "Good morning!" to her, and she feels like responding, "Whatever."

Everyone wants to be healthy and live as long as they can without complications, but diabetes can rob people of that hope, bringing a sense of depression and sadness. There's the realization that death is just around the corner, but no one knows when. Although death happens to everyone, diabetes or not, the depression that comes with a

chronic illness creates a loss of hope at times. One woman admitted to trying to kill herself by giving too much insulin because she was depressed. Another participant felt that her life will be shortened because of diabetes, and commented:

You see these people that live to be 75 or whatever with their diabetes, but they didn't start when they were [little]. So I keep doing the math, and I'm like, 'Jesus, I'm only midlife right now.' I guess I kind of have myself self-defeated because I'm not sure I'm even going to make it to Social Security. So I might as well spend my money now, because I'll probably be on dialysis by the time I could use the money.

Some didn't believe that having better blood sugars would actually improve their chances of avoiding complications. One woman said, "it doesn't matter if you take care of yourself for not," so it's hopeless. No matter what she did, the retinopathy was going to happen anyhow, so "What's the point?"

The participants in this study feared that their past mis-management of diabetes, or their mistakes, would continue to dampen their hopes of a positive future. When asked, even those who did not have complications, would reply "not yet," or "I hope not." They regretted that they didn't take better care of themselves when they were younger, and now feared complications, which made them sad. One participant said, "I screwed around in the past, and that's going to come back to haunt me." She is uncertain of what else is going to happen to her with her eyes, feet, kidneys, and circulatory system, but sums it up this way:

Back then, you were told you go blind, but they didn't go into the nitty-gritty about it or they didn't tell you what high sugars could do. If I had known, I might

have paid a little more attention because I would've really known what was going on. I would've learned what I was truly doing to myself.

For Camilla, this sense of hopelessness related to the death of her son. She said

I did everything I was supposed to. They told me that if I listened, I would be OK. And he died anyway. I was bitter. I did everything with diabetes that they wanted me to. For once I listened, and it didn't work out. There are no guarantees.

Other women in the study commented on the sense of loss and sadness around the ability to conceive or carry children. Some struggled, because there are many women who have diabetes and healthy babies, but "you really need to have your sugars in order," Daisey said. One woman was nervous to have children because of her diabetes, before there were glucometers or measures of blood sugars. When she did become pregnant, other people told her, "It's not a good idea." Two women said, "I love being a mom," but both of them got their tubes tied because they "wanted to be around," and didn't want to risk having other children. One of them regretted the decision to have the procedure, because she would have tried to have more children, despite her diabetes.

One of the more depressing thoughts about diabetes is the possibility of going blind. Before going into laser surgery, Camilla spent some time with her children, and she vividly described her feelings as she spent the day with them:

The whole time, it was a dreary day, and I was just taking in everything. What the clouds looked like. They're so gray, in the dark over here, and trying to keep everything pictured in my mind. What the trees looked like. What the Dairy



Queen sign looked like. My husband's profile. I just kept looking at him and the children. I gave the kids a hug, and I tried to remember.

Five out of the nine women in the study had proliferative diabetic retinopathy, and the thought of not being able to see, or going blind, was both frightening and depressing.

### *Guilt*

All their lives, people with diabetes are told that they "should" and "should not" eat. There's a sense of guilt when people compare themselves with other people with diabetes. To avoid feelings of guilt, many women simply avoided checking their blood sugar. One participant said, "If I didn't know what they [blood sugar numbers] were, I didn't have to treat them. I didn't have to feel guilty." Sometimes she felt like a "crap diabetic" because other people were bringing scales to restaurants, weighing their food, and thinking that life was not bad with diabetes. She felt guilty and incompetent.

Many participants referred to "cheating" on their diets. Although they followed their diabetic plan for the first couple of months, they started to break away from the plan. Agnes felt guilty when she put some jelly on her peanut butter, because she really wasn't "supposed to" have the jelly, and she remembers being caught by her father. He said, "Mom! Agnes's eating jelly!" which made Agnes feel like she was cheating. Although she says she was generally "very good" and never ate chocolate when she wasn't "supposed to," she still felt like she was being watched. She started to "slide," and she would "slide a little more." She said, "I could live with that. I didn't die. I didn't pass out. Nothing bad happened. I could eat a little more ... so I would just eat things." For her, eating and trying to keep track of the carbohydrates was definitely the worst part of diabetes.

Roberta placed a large part of the guilt on herself for not having good blood sugars. She says she does one thing and it works, and then she does another thing, and it doesn't work. She said, "It's like, 'OK, what am I doing?' I always think it's me doing something wrong. It's like I should be doing something better. Or different." One woman put fault on herself for having complications, while another says her life, and the life of her family, could have done so much better and easier if she would have learned to accept her diabetes. One participant expressed feelings of guilt when talking to me. She told me that when she gets a low, she eats candy. Then she said, "I'm not going to lie to you. I have one here and there." Her guilt might be a result of her thinking that people are judging her, and what she's eating, because they don't understand diabetes.

For some, this guilt led to a feeling of being responsible. Coral said, "Diabetes really does make you grow up, and it does make you be responsible." Roberta would agree with that, because she often feels like she needs to do the "right" thing. Sometimes she doesn't want to be responsible, but she has to be, even when she doesn't want to. She says, "It's like I'm the child and the parent all-in-one. I have this conversation in my head: 'You have to check your blood sugar; I don't want to; I have to; I want to go to bed; I'm tired; but you have to; I don't want to.'" She feels guilty if she doesn't get up to check her blood sugar. Roberta also said that having diabetes makes her less of a risk taker. She says, "What if," a lot more than she used to. "What if I bungee jump, and my pump falls off. What if I want to go across country, but I only have three months' worth of medication, you know. It makes me less of a risk taker." She would feel guilty if something happened to her.

Emily also feels the responsibility of diabetes. She knew other people who used to go to her with diabetes camp, and "they buried themselves in the ground," because they didn't take care of themselves. She says they made "dumb choices." Other friends of hers forget their insulin. She wonders, "How could you forget your insulin? They don't think it all." When she finds herself making bad choices, she catches herself and tells herself that she shouldn't be doing it. She doesn't want to end up in the hospital, or worse. She said that if she's by herself, she has five alarms set and tell someone to call her in the morning, because "we need to think about it. Extra thinking about it."

#### *Uncomfortable, Physical Pain*

From an outsider's view, it may seem that giving shots, pricking fingers, and giving blood samples would be the worst part of having diabetes. No one complained about getting daily, sometimes four times a day, insulin injections (before they went onto the insulin pump). Giving injections was difficult for some participants at first, but they got used to it quickly. Camilla said, "I hated the word 'shot,'" and Agnes would have trouble giving her own injections on occasion. She would "sit there and sit there and sit there, and I couldn't do it. Sometimes it took 20 minutes." Finally, she would make herself do it. Emily commented on how long the "new" insulin pump needle was, but she didn't complain about the pain.

The most common physical pain mentioned was the pain from complications, particularly neuropathy and retinal laser surgery. Camilla said that having neuropathy in her legs was painful, especially in the early hours of the morning. One remedy which seemed to work was to lie in the bathtub in hot water to soak them. Her mother also helped by rubbing her legs and feet until she didn't feel cramps anymore. When she

received hundreds of beams of laser in her eyes, she told her doctor, "This frickin' hurts," because the eyes are sensitive and "You can feel it burn." Daisey also talked about getting 400 to 800 lasers, but she didn't feel the physical pain in the same way, and didn't take any Novocain to dull it. Both felt that having physical pain was worth the price, when the alternative was to go blind.

Participants commented on the feelings and bodily experience associated with having a low blood sugar. They reported the sensation of starting to sweat, trying to get some juice or something to eat quickly, and sometimes talking themselves through it. Sophie said that lows took her out of her comfort zone, out of the "controlled state" of her body, which was a "real problem." Some just wanted to get through it, and others were petrified that having a low blood sugar would mean a loss of independence.

For Jennifer, this feeling was very real, as she found her diabetes was beginning to dictate her life. She would not "let it [her low blood sugars] control me, and dictate whether I can go to church, or I can go to a meeting." Coral complained that low blood sugars impacted her sleep during the night, when she can't rest because of her low blood sugar. Her blood sugar drops and that's the "worst thing" to wake up in a pool of sweat. If she doesn't change her sheets, she is cold, and she needs to move to another bed. In summary to the theme of expressing negative emotions, all participants experienced negative emotions such as fear, depression, and guilt, but they hid their feelings about diabetes on some level or another. Daisey said, "We think we're not allowed to, or we don't permit ourselves to, but we don't allow ourselves to feel anything about our disease." Sophie often repressed her feelings, and realized during the course of the study that she viewed her diabetes as a weakness. She said, "I couldn't be like, 'Oh why do I

have to have this? This is so awful." Later, she admitted that she should probably react to diabetes more, but, "This is a really nasty disease. We don't go around talking about it." This was the way she made sense of her disease. Jennifer's said she would tell other people about her disease so they could understand what her life is like, but "I don't let anyone know."

*Can These Bones Live?: Resisting Against Diabetes and Medical Approach*

*He said to me, "Can these bones live?" I said, "Only you know, Lord." He said, "Say, Dry Bones, hear the word of Yahweh" (Ezekiel 37:3).*

Even though there is the potential to find a better life, it is a question of believing the bones can live. "Do you want to get better?" is the question the physician asks the patient, which is equivalent to asking "Can these bones live?" Patients have the choice as to whether they choose to be part of their healthcare or to resist the words of the physician. The bones of diabetes do not go away; they are not "cured," but they can *live*.

However, many patients resist the medical profession's assistance. When patients enter the doctor's office, they often report to the physician what he or she wants to hear. The participants misrepresented blood sugars and ignored medical advice about checking blood sugars and following their diet between visits. This theme of inward and outward resistance against diabetes and the medical approach is explored in this section through the following areas. (a) Complexity of diabetes; (b) Insufficient medical approach in diabetes care; (c) Rebellion as reaction to diabetes; and (d) Indifferent attitude toward medical advice and profession.

*Complexity of Diabetes*

Diabetes is a chronic disease which escapes medical reason regarding its cause and its cure. All participants experienced difficulty on a daily basis with balancing blood

sugars, and often glucose levels would be high or low without a reasonable medical explanation. Although the main predictors of blood sugars included carbohydrate intake, exercise levels, and insulin regimen, even these fluctuated from time to time. The situation becomes more complex, because each patient has different histories, motivations, and metabolic patterns regarding diabetes. Some of these complexities are addressed below.

Emily's blood sugars in the morning weren't perfect, and they would not go down. Although she would be 90 (a normal level) going to bed, her blood glucose would be 300 in the morning for no evident reason. It didn't make any sense to her. After being placed on a blood glucose monitor, the physicians discovered that between 5:00 and 7:00 AM, her glucose would peak every morning. The doctors "tried everything" to get her stabilized, but until she went on the pump, her blood sugars could not be regulated.

Roberta expressed a similar concern over unbalanced blood sugars. Even though she was exercising, eating right, taking an injection before every meal, and injecting Lantus (long-acting blood sugar) at night, the regimen still wasn't working. She was referred to the pump clinic to get nutritional information, which is how she started with the pump. At first, she was resistant, because she felt like the pump was controlling her. To make it worse, she got it on October 31, and she said, "It was like, Dr. Frankenstein, you're creating a monster."

Even on the pump, Sophie said that no matter what she did, her blood sugar would not be the same from day to day, and asked rhetorically, "Why is that?" "Obviously," she said, "The doctors don't have an answer either, because there's still a lot of research to be done on a search for a cure for diabetes."

Diabetes is also an emotionally complex disease, and there were times when patients resisted taking care of themselves simply because they felt like they were not being heard. For instance, Camilla said that she doesn't really want to take calcium pills or an aspirin as recommended, because doctors assume that she wants to prolong life. She asked, "Who said I want to be alive when I'm 80? I've seen some 80 year old people and I don't think they want to be alive." After meeting with one medical professional, Daisey said he was "a complete jerk. I went out [of that visit] feeling like I was old, fat, and 'Sorry, we can't help you.'" She felt worse, rather than better, about herself. One woman smoked, and the doctor said, "You might as well build yourself a graveyard plot right here." Insensitive remarks like this make people rebel not only against their physicians, but their own bodies.

One of the more interesting stories was about a woman who used her diabetes as a tool for attention when she was young. Her father and other members of the family had abused her, and she thought it was her fault. She would stop taking her insulin, her sugars would go extremely high, and she would go into diabetic ketoacidosis (DKA), or elevated ketones. She would get "really sick" from this and go into a coma, and her parents would go to the hospital with her. At the hospital, she would be safe from the abuser. She said:

My mother would tell me that I needed to go to the grocery store with him. And I would say, no I don't want to go. She would say that I had to help him get the groceries. Then I was trapped every time. So the hospital was a safe place. That became a real pattern for five years for me.

Her going into DKA on purpose became a pattern, and she was in the hospital 64 times by the time she was 22 years old. She said, “Yes, the nursing staff cares for you. They won’t hurt you. It’s all for your good.” Diabetes and her life circumstance were extremely difficult for her. These kind of emotional, as well as physical, aspects add to the complexities of the disease. Sophie summarized her feelings, and many of the participant’s feelings, like this.

There are a lot of things [about diabetes], and it’s not the orderly progression, like, OK, we feel this way, this way, this way. So if we were to make an abstract drawing kind of thing, in my mind, that’s an adequate way to describe diabetes because it’s not boxed. I can’t say that is exactly how I feel.

It is difficult to express feelings about diabetes in words, and to be able to communicate those feelings about others. Through the use of creative expression and imagery, we began to explore those feelings and make meaning of the experiences of living with diabetes.

#### *Insufficient Medical Approach in Diabetes Care*

Because diabetes is a complex disease which is difficult to manage and balance, participants explained times when the traditional medical approach was insufficient to meet their needs. For Coral, the traditional approach of caring for a patient, treating her disease, and sending her home with pamphlets, was not sufficient for her to take care of her disease. Some participants explained their concern about the initial lack of education and care they received when they were diagnosed, and what could be done to better to improve their care today.



From the beginning, some received an inaccurate diagnosis. Roberta's pediatrician thought there was something wrong with her liver, Jennifer's doctor took four guesses ("all of which were inaccurate," she said) before diagnosing diabetes, and Daisey was tested for cystic fibrosis. On Thanksgiving, Sophie was diagnosed with diabetes, and the nurses brought her pumpkin pie. She told them that she could not have cake or pie, and had an argument with the nurses, "I can't eat that." Then they brought her a cup of ice cream, and she said, "I can't eat this either. What are you thinking?" Her mother actually became a nurse because of the insufficient care her daughter received while in the hospital.

At the time of diagnosis, diabetes education classes were either not available or were not offered to several participants. When Agnes was first diagnosed, she was given a pamphlet and things to read. Looking back, she knew very little about diabetes and didn't know enough to ask. Now, she says, "there's so much more information than what I was given." Coral said she had "no clue" what diabetes really was at first, other than it had something to do with sugar. She was told when she was diagnosed, "Here's your pills, here's your meal plan, come back in a week." Roberta doesn't remember receiving any training, except an explanation of "This is diabetes, and this is what is happening. This is how we 'fix' it." She just didn't have the knowledge to be able to take care of herself properly.

At the other end of the spectrum, Amber went to the Joslin Clinic every year to receive new knowledge, but she still described a lack in the care she received. Her week-long visits to Joslin were "torture," but she went under her parent's and physician's persuasion. While at Clinic, the medical staff would take a group to McDonald's where

patients were taught to count out a certain number of French fries. She would meet with a dietitian, who would "come in with a cup and measure out 10 raisins for you. Give me a break," Amber said, especially if the dietitian was heavy. Amber had a "real issue," with that, because the dietitian was telling her to eat healthy, and the dietitian was not following her own advice. As Kralik et al. (2004) described in Chapter Three, it does not work to have patients as passive subjects, absorbing the information; instead, patients must be engaged in the dynamic and active process of learning and exploring the boundaries of chronic illness. In fact, students of any subject learn best when they are actively involved in the learning process.

Daisey said that she did receive enough information upon diagnosis, and she was introduced to diabetic camps where instructors gave her the basics of what was needed to survive. But as technology changed throughout the years, she feels like she has not been caught up to date. She said, "Nobody brings you into a class and teaches you what you need to know now. You're given the basics, and you're going to go with this the rest of your life. There's no follow-up. There's no, 'Hey, how are you doing with this?' It's just like, drop it and run." Although it could be assumed this is the patient's responsibility, more discussion about the responsibility and "management" of diabetes care continues in Chapter Seven. One thing Daisey wished she would have known, however, were the details about the consequences of not taking care of diabetes. For instance, she would have liked to have learned how the blood vessels are affected by having high blood sugars.

Overall, her diabetes control was out of line, not because she lacked knowledge of basic diabetes care, but for a reason that was not addressed or uncovered: She did not

care about herself. Education and knowledge do not automatically lead to better blood sugars. The traditional medical approach to diabetes does not have a strategy for exposing intentions, feelings, or psychological/spiritual aspects of diabetes care.

### *Rebellion as Reaction to Diabetes*

As a reaction to receiving a diagnosis and living with a chronic disease, patients described times when they “cheated” by going off their diets, or eating something that they felt wasn't good for them. According to Merriam-Webster, “cheating” is defined as an intent to deceive, to mislead, or to violate a certain code of perceived rules.

Resistance and rebellion against diabetes was common among the women in this study.

Agnes said she heard the word "cheating" many times when she was younger. Friends and family would ask, "Are you cheating?" When she was older, even the doctors would say to her husband, "Is she cheating?" Once they put her in the hospital, they saw she wasn't "cheating;" her blood sugars were just all over the place, and there wasn't an explanation. Emily said she "used to sneak candy all the time ... all the time." She got into trouble at school for sneaking candy when the lunch aides would say, "You're not supposed to eat that!" But, she didn't really care. She would eat a big sugar muffin as her lunch. She admitted that she would give herself more insulin just so she could eat more sugar, and wondered if it is her way of rebelling against the fact that she's not “supposed” to have it. Emily said that people laugh, because she gets a piece of cake with the rose and the one with the most icing. People tell her that she shouldn't eat cake, and she ignores them. If she is on vacation with her boyfriend and she knows they're going to eat ice cream later, she will tell him that her blood sugar is 60 and she needs to eat. He says that she does that on purpose, and with a smile, she said, "That's bad."

Camilla said, "If I want a candy bar, I'll eat it. If I want a banana split, I'll eat it." In reply to her doctor's controlling her weight, Amber gained 20 pounds each year, because she would tell herself, "I can so have one "

Some deliberately acted on behaviors that they "knew" weren't good for them. Daisey decided to choose looks over health, regardless of her sugar, because she felt that the insulin was making her fat. When the body produces ketones, there is not enough insulin in the body, and the person loses muscle and weight. She valued good looks versus her health, and that was really hard to overcome. Jennifer said she "didn't count" for a long time, and did her best at estimating. But when she went on the pump, she had to go back to measuring in order to calculate her carbohydrates. Camilla said that she could count on "two fingers" the number of times that she brought in her blood sugars to the doctor's, and she never wrote them down for herself. She didn't do it, because she felt like it didn't matter. She said:

You test my AIC anyway. It's going to tell you. I could write any old number down, and tell you 'Yeah, I'm testing.' Look, it was 87 for breakfast and 102 for lunch, and I dropped to 62 at dinnertime. I was active this afternoon.' I could make up whatever ... Why do you need those numbers?

For Daisey, the pattern was to mark down a "high" here, and a "low" there, just so she could put something down for the record. The doctors couldn't understand the pattern, and she would give the excuse, "I don't know. Maybe I'm brittle." She said "a lot of people" think that monitoring is hard. Amber said simply, "I never did [write down my sugars]." She said she knew that she could print her numbers out on the computer, but she had never used that feature.

Although inconvenience was one reason for not testing blood sugars, it seemed to be more than that. If participants knew that better control of blood sugars resulted in fewer complications, then what was the resistance to knowing what those numbers were? I added this question to the final interviewing process to explore this issue further, and findings of that data can be found in Chapter Six.

#### *Indifferent Attitude toward Medical Advice and Profession*

Fortunately, many of the individuals in the study had positive sentiments about their current diabetes nurse educator or doctor at the Penn State Hershey Medical Center. What Emily liked most is that her doctor lets her decide, to a certain point, what she wants to do, and gives Emily the authority as "doctor" to make medical decisions; they talk about what has been going on with Emily's diabetes. Emily was glad the decision to go on the pump was left up to her. She said, "I think that's good, because I know my body better than anyone else. I think she [the doctor] knows that." Unlike some patients, Emily is "totally honest" with her doctor, and "doesn't lie" about her blood sugars. She did not used to write down the sugars that were high, and she said, "If it was 380, I would skip that one." One participant had been drinking alcohol, and deliberately lied to the nursing staff at the hospital when she was feeling ill. She told the nurses that she had the stomach flu, which was what had raised her blood sugar.

Jennifer said that nurses "can listen better and hear better," and that they take the time to think about the patient's problems. She said, "Doctors are up here [motions above her head] somewhere, and they don't really get down maybe to where the level they need to be at." Jennifer doesn't feel like she needs to be "preached at," because she

has had diabetes for so many years. Although, she knows a lot of people with Type 2 diabetes through her church, and she said,

A lot of them just don't get it. A lot of them go to family physicians who don't have a clue. And, you know they've not been given good advice, and they don't have good habits ... I find that the primary physicians are woefully negligent in getting these people the tools to work with.

Although she wasn't confident in family physicians, she believed the specialists at Hershey have "trained" her well in her diabetes management. She said:

Yet, down here [in Hershey] they don't badger you with it [your diabetes]. It's not like they're hitting you over the head with it. I mean, they talk to you like you have some intelligence, and they give you the tools, so if you don't use them, then it's your own stupidity, really.

Jennifer recalled a time when she was nervous to go to the doctor's office. When she would get her blood sugar tested, she believed it was higher because she had a bit of "white coat stress involved with it," so she wondered what kind of reading they were getting.

Both Agnes and Jennifer hate when they go to the doctor for something totally unrelated to diabetes, and the doctor will say, "Well, you know with your diabetes, you should be careful," or "You know diabetes can cause this." Jennifer said, "If one more doctor says that to me, I am going to smack him." She was referred to a periodontist at the beginning of the year, and the first thing out of his mouth was, "Well, you know diabetics are more prone to this." She's very tired of hearing that.

Often, patients felt belittled or patronized by their physicians, and felt like they really didn't understand the experience of diabetes. When practicing how to take insulin injections on an orange, Camilla was told that it wasn't really a big deal, and "it's the same way it feels when it touches your skin." Her response was, "No, it ain't. I could poke an orange a hundred times, but you put the needle under my skin and it's not going to go. So she [the diabetes educator] took it and jammed it into me." Amber was having seizures, and the doctors put her on phenobarberol to try to stop the seizures. Her doctors told her that she needed to have better control over her blood sugars, but she took herself off of the medicine, and decided she would stop the seizures by "never going low again."

When she was a child, Camilla said her food was always referred to her as "special." She said the medical profession labels it that way. She had to eat certain this or certain that, and it made her feel alienated because she had special food. She felt pressured into drinking diet soda, eating at certain times, and forced eat snacks when she wasn't hungry. She "hated" medical staff, because they told her that her AIC was not where it should be and "you" need to get it lower. "You need to eat better." In the beginning part of her marriage, Camilla didn't have money for good food. Availability of resources is another factor that adds to the complexity of living with diabetes. She told the doctor:

Yeah, well, you walk in my shoes ... live paycheck to paycheck like we do, and not on your doctor's salary, and see what I have to work with. Then tell me that I need to do better. I do the best I can. This is what I have. If you could help me with what I have, then I'll listen to what you have to say. I know my AIC is not where it should be. I don't need you to drill that into me every time I come.

As a result, Camilla would cancel doctor's appointments, and go to the physician only when she needed prescriptions. She would tell the medical staff she would promise to do better, and that she'll "work on it," but she was thinking, "Get me out of this office." She added:

I think that if they [medical staff] didn't pressure people into doing this, this, and this, we would have done so much better. If someone would have told me, 'You can have that can of Coke. Give yourself four units of insulin for it, you'll be fine,' I would have been so much better off. But they told me, 'No, you just can't have it.' You can't do that to people. You can't just shut that out. Then they feel like 'You're taking all my luxuries away' .. If they would have just said, 'Cheat once in awhile, or if you eat this miniature candy bar, just take two units of insulin' ... they could have just explained it better ...Now, I just eat, and it's not as bad. Now I eat basically what I want. It's still a probably out of defiance because I was told so long, 'You can't have that.'

Both Camilla and Daisey were told that they were not a "good candidate" for the pump, because their A1Cs were not where they should have been, and they were not testing their blood sugar regularly. Amber was denied being put on the pump because her blood sugars were too low. Some of her doctors said, "it is not necessary," but Amber told them, "I wanted to be healthy. I wanted to give it my best shot anyway. I wanted to be 60, 65 or 70. And be around. And I wanted better sugars." Before Camilla was able to go on the pump, she said it seemed like she needed to make "500" changes. She transferred doctors, and eventually found one who listened to her. If the physician would've really cared, according to Camilla, he would have said, "This pump would be a



great thing for you. Let's try it." Daisey was advised to go to counseling to make sure she worked through self-esteem issues first before going on the pump.

It was important to both of them that the medical staff treated them as more than their diabetes. Listening was important, and the participants realized it is hard to reach out. But, if physicians would be more accepting, rather than demanding, such as "You've got to check four times a day," and more like, "Just think about what you're doing," then it is easier to listen. Camilla detests medical staff who "be-bop" into their appointments and say, "Hi, how are you? Your sugars are not where they are supposed to be. Let's do this, this, and this." She described the positionality of physicians, where they

get to this status that they have the big money now, and we are peons still. It's like politicians. They are so out there, and we are so below them ... Same way with doctors. I'm not saying they're rich, rich. But they don't hurt for money. I'm sure the first 10 years of their working life is spent paying off loans, and everything else. But they don't suffer. I just think they forget what it's like to live paycheck to paycheck. They just don't care sometimes. In the hustle and bustle of the world, they schedule people every 10 minutes. If you are late for your appointment, heaven forbid. You need to reschedule or wait longer. But you could be stuck out there an hour or an hour-and-a-half, and it doesn't matter.

All of the participants in the study struggled with their "dry bones" at some point another, whether it was with their insulin pump, the adjustment to the daily regimen, or controlling blood sugars. Some even struggled with trying to find ways of meaning and healing, such as writing in journals, but they didn't feel like that helped. Emily said, "It is good to write it down. But it doesn't help that much." Amber said that support groups

didn't help either, because "it was just old people wanting free cookies or something. You've got to be kidding me. What is this?" No one actively participated in a support group, even though they were offered free of charge at the Penn State Hershey Medical Center. Rather than her motivation coming from a support group or a physician, Emily believes her influence comes from an inside desire to be healthy. Although, she said, "A doctor can make a lot of difference."

*Breathing Life into the Bones: Taking a Positive Spin on the Negative as a Way to Cope*

*The Lord says this to the bones: I am now going to make breath enter you, and you will live. I shall make flesh grow on you. I shall cover you with skin and give you breath, and you will live, and you will know I am Yahweh" (Ezekiel 37:5-6).*

Even in the midst of the Valley of Dry Bones, where there is constant blood sugar monitoring and worry about life-limiting complications, there is the hope of transformation and renewal of breath, flesh, skin and life. We can never return to the way things were before entering the Valley, but a new way of life becomes possible. The old bones can be covered with a new skin of hope, and a fresh way of knowing. In this place, many will understand the fragility of life and come face to face with a higher spirit and breath that lives within and through them.

Because the Valley of diabetes does not go away, many of the participants looked for a way to view the positive aspects of their disease. They looked for the "breath" to enter them, and the "flesh" to grow. Although living in the Valley can feel hopeless at times, the participants in the study looked to positive powers within themselves or their God to help them live. They wanted to live in a valley of hope and optimism, rather than stay in a place of hopelessness. They had seen people who were negative and destructive in their care with diabetes, even others who have died, and they remembered those times

of feeling a fear of death, anxiety and depression. At the same time, they didn't want to stay in the Valley of negativity, and looked for positive ways to find meaning in their lives with diabetes. Coral summarized her feelings in this way:

You turn a negative into a positive. I'm overall an optimistic person. I believe that whatever you want to do, you're the one to do it. You see the positive. No one likes a pessimist. You're not getting anywhere, if you're pessimistic and growling about things.

Despite the negative emotions that all participants felt, they had an equally powerful positive response to making meaning of their diabetes. The positive outlook of the participants was observed in the following areas: (a) their own ability to endure; (b) technology as a positive influence; (c) faith in God; and (d) the belief that "it's not that bad" as other diseases or circumstances.

#### *Their Own Ability to Endure*

Many participants felt like they needed to "keep going" and try to "go on" even in the midst of difficulties. They didn't want to get "stuck" in their negative emotions, but rather chose to work through their problems. It seemed to be a philosophy of life in general that was also applicable to dealing with diabetes. Sophie said, "Because we have issues we have to deal with, that's not an excuse for anything. You work through it. You move on." She also said that she works diabetes into the structure of her day, so it becomes routine. Some days she thinks, "Ok. I'll just go with the flow, and it will all work out." Another woman says that she keeps going, and when she runs into trouble, she seems to find "a way around things."

Many of the participants experienced positive reactions, and even a sense of surprise, when they were able to "get through" a party, event, or even an evening of sleep, with a normal blood sugar. These positive interludes gave hope to an otherwise frustrating and unpredictable situation. One woman said that when she gets through a party with a blood sugar of 120, she says, "Wow! Wasn't this a great night!" It is looking toward the positive times where blood sugars are good and participants feel well that makes life living with diabetes better. She said if it all works out well, it is a "major accomplishment ... more than people can understand ... and when it does work, it's very rewarding. Extra rewarding."

Having diabetes and endurance seemed to go hand in hand. One participant referred to having diabetes as a "battle," but that all people with diabetes go through the same difficult times. She gains endurance by thinking she can do what anyone else can do, and believing, "You're not going to stop me, and neither is my disease." She thinks this fortitude is a mindset among the majority of people who have diabetes and says that although there are some diabetics who sit on the side and go, "Woe is me," she personally doesn't know any of those people.

Some hide the fact that they are ill. Jennifer said, "I make an everyday effort to convince those around me that I'm just fine." Even though they admit this is not always a "good" strategy to hide their illness, it gives them a sense of endurance to think they can overcome their difficulties and be well. Making light of low blood sugars, many just "get through" the sweating, the lightheadedness, and the disorientation as though it is routine. When she feels a low blood sugar coming on, Jennifer gets some juice and tells herself that she's had her low, and she's going to be fine. She realizes she is becoming brittle,

and she can't deny it or change it. All she can do is try to "stay ahead of it" on a day to day basis. Jennifer gets used to dealing with diabetes, the way that Amber gets "used to" dealing with the blood she has in both her eyes from retinopathy. She said that the bleeds in her eyes have become a part of her vision, and she tells herself to keep going. "You know," she said, "You've got to deal with what you have."

Living with a chronic illness can be difficult, and there are times when it is tough to remain positive. Diabetes is something which does not go away, it is often difficult to control, and there are times when blood sugars are unstable for no particular reason. During those times, Camilla said she does "the best I can," and it will work out in the end. Coral said that even though diabetes is a chronic illness, it is not necessarily terminal, and it can be managed. At the same time, diabetes requires persistence. She realizes there are certain things she can control, and certain things that she just has to "roll with." When Amber feels sick, she could get stuck in negativity, but she knows that if she goes "down that path," it can be a trap. She asks herself, "Is this a truth or not? I will not feel this way for the rest of my life, and I'll probably feel better tomorrow." She has the endurance to make it through the next day, and she realizes that some days are better than others.

Amber shows resilience through "major things" that happen in life, where "you might fall apart." But she encourages others to take the pieces, and put them back together as best they can. Realizing that there's not much she can do about having diabetes, and there's nothing she can do to make it go away, Roberta says she just takes it in stride. Like Amber, Roberta "bounces back," even when things are difficult. She wonders if she would have as much resilience if she would not have diabetes.

*Technology as a Positive Influence*

Many recognized the positive influence the insulin pump has had on their lives in controlling their diabetes and allowing for more flexibility in scheduling. Since all participants first took shots, they think that the insulin pump is a great technological advancement. Although people do not like wearing it, at the same time, they don't know how they handled diabetes without the pump. Camilla strongly said, "I would probably be gone if I didn't have it."

For the most part, the participants looked at the insulin pump as a positive influence on their lives. Jennifer felt that she is lucky to be alive, because when she was diagnosed, she worked with virtually no information. Today, she now has a blood glucose monitor that she takes everywhere, and has the benefit of an insulin pump. The positive influence technology has had on her life is staggering. It gives her hope for children who are now being diagnosed and will have a better life and a chance of controlling their diabetes, and prolonging or eliminating the possibility of complications. "So much more is known," she says. She is "living for" a continuous blood glucose monitor, which is already being developed. And, she says, "I'm not kidding. That's what I'm living for."

One woman said that the ultra-fine needles that people with diabetes use are "so much better" than what she used as a young woman, needing to boil her syringes. Having the pump has been a benefit over "previous ways of dealing with it. It just works into my routine better than having to pull out a syringe." Emily agrees that her blood sugars are better because of the insulin pump. Although she still has some lows and some highs, she can usually figure out what happened, whereas before there did not seem

to be an explanation. That doesn't mean that having an insulin pump is ideal, but it does make participants lives better and has been a positive influence on blood sugars. Daisey had trouble with the pump at first, but she "hung in there" because she valued her health and quality of life that the pump gave her. Roberta valued the pump because it allowed her to sleep in, and not have to eat. It gave her flexibility.

Even since Coral's diagnosis in 1994, she noticed the progress that has been made since that time. She mentioned the improvements in islet cell transplants, and how that brings a promise for an easier future. She said, "Our treatments are OK," but there is much more on the horizon. The participants in this study seemed to be used to their pumps, as they checked their blood sugars, gave their boluses, and ate snacks almost without thinking about it. Even during the interviews, participants gave boluses and checked blood sugars. Roberta said that the pump wasn't too bad, because "I've gotten to the point where I am used to it." Technology and diabetes are integrated in their daily lives.

### *Faith in God*

Some found hope in their faith in God. Those who mentioned God were referring to the God of Christian faith. They questioned why they had diabetes, but not in a negative way; simply, as a way of making meaning and finding a reason why they had diabetes. One woman said:

I should have been dead 20 times over already. Why have I not? Why have I been spared? Why do I not have kidney disease? Why do I not have retinopathy? And for a long while I've asked myself, God, what is your mission for me? What is it?

She questioned not only why she had diabetes, but who she is as a person, and how having diabetes is a part of that identity.

Camilla said she remained out of the hospital for six years "by the grace of God," and that was a positive feeling for her. When she was sick, she pleaded with God, saying, "Please, God, I'll try to take better care next time." She said that she bartered with God over the years, and that he has given her more than she can pay back. In fact, she is alive because of her faith, and may have given up many years ago if it weren't for her trusting in God. Even if she is not happy about having a chronic disease, she believes there's a reason for it. Another woman believed that God was taking care of her throughout her life, and especially with her diabetes. Many said "thank God" things aren't worse. Whether that be a figure of speech, or a deep devotion to God, it was a recognition that there was a greater power who was watching over them.

Faith is what kept some people together, believing they "just have to have faith" as part of their outlook in life and in dealing with diabetes. One participant referred to her keeping her diabetes in line as part of her "good Catholic guilt," which was her religious orientation. Amber was particularly strong in her faith, and found meaning in her "relationship with the Lord." Because of her faith, she believes that whatever is meant to happen, happens. She said,

If I go blind, I can use this thing. I can show other people that my life doesn't have to stop. I'm a blind diabetic. You've got to turn it around for the good, or it will drive you crazy.



Even when things get difficult and she thinks she can't get through tough times, she knows she can with God's help. The women in this study may not understand why their God chose them to have diabetes, but they had faith that there was a reason.

*The Belief that "It's Not that Bad"*

A recurrent theme is that although having diabetes can be awful, there are other diseases and conditions which are "worse." One said, "I know diabetes is a pain, but thank God we are not in a wheelchair." Many of the participants compared diabetes to other diseases, which are "worse," such as AIDS, MS, cancer, and leukemia. Jennifer has seen people who are crippled, have died of cancer, or who have deformities, and she is thankful that through her life, she was able to lead a relatively normal existence. She is thankful that she was able to work and go to college, and that diabetes has not, for most of her life, gotten in her way. "I'm walking," she said, and if she had to pick a disease, it would be diabetes. She continued, "I'd say yes, God, I'll pick that one. I've led a relatively normal life." It is not the worst thing that could have happened to her. One woman said she wouldn't want to change places with her other siblings who have marriage and family problems, because each person has his or her own set of pains and joys. She said:

I think I've settled and accepted my life. I don't always like it. I could be worse. I'm not in a wheelchair, I'm not blind, I'm not dead. I've got great children. And I'm pretty healthy considering how I tested the waters over the years.

Sophie mentioned that diabetes can be overlooked by people in the community because people with diabetes are a "relatively quiet group." Part of the reason may be that people think there are worse things than having diabetes, and that people with a

chronic illness who have the potential to live for years should not complain about their condition. Jennifer tries to not complain about her diabetes, because she considers herself a positive person. She abhors people who complain about their aches and pains, because she seen a lot of very sick children. She has looked at them and their families, and her heart has broken. When she hears people complain, she wants to take them to the Children's Hospital (at Hershey), and dare them to ever complain again. Having diabetes is not as bad as watching your child go through chemotherapy. Camilla has experienced the loss of the child, and said that having diabetes is simple, compared to that. With diabetes, she said it is like:

Take your medicine, do this, don't do that. And if you eat this, this is what you have to do. It's kind of like a trained thing. I'm trained to take care of this. But you have this death of a child, and no one trains you how to deal with that.

As one woman described her surgery for diabetic retinopathy, she explained how it hurt, but also that she was fortunate to have not gone blind. She understands that the "flipside" of dealing with diabetes is that she could have lost a limb already, or been blind, and she could have had "so much happened to me that hasn't." She could get through the retinal surgery, knowing that she would be able to watch the sunset, or look in her garden, and see her children grow up to graduate or to get married. Knowing that she is able to see, having the retinal surgery was not as bad as the alternative. One woman summarized her gratitude in this way:

When it comes down to it, I count myself truly blessed because I could have had things so much worse. I just learned to deal with what I've been given, and just think it could be worse. Just be grateful that this is all you have to deal with.

Jennifer agrees that things could always be worse. Even when she had Charcot in one foot, she was grateful that it wasn't in both at the same time. Despite her many complications, she considers herself a very, very fortunate person. Other things could be worse, and she is also thankful for her doctors and her medical care. Although she's had some "close calls," she feels very lucky to have "two feet. I know it. I know it. And I'm just fortunate to be celebrating my 60th birthday ... So, I try to be grateful for every day." Emily also mentions being lucky because she has escaped many complications. When she goes to the doctor's office, she hears "My liver is good. My kidneys are good. My eyes are good. My feet are good, so that makes me feel like I can go and do all this stuff." When she takes her insulin to cover for extra carbohydrates, she says it's "not so bad" to give insulin. There are worse things. At age 57, Agnes also feels there are worse things than diabetes. It is a part of her life.

A quadriplegic man, who was also blind, inspired Daisey. She said that different students on campus would help him with his homework and test answers. She sat back, watched him, and thought, "He has something that is 10 times worse than what I have, but he's happy all the time." He had a smile on his face every time she saw him, and was making it through college. He was graduating with a serious disability, and Daisey felt inspired to take care of herself. He was "worse" than she was, and she felt grateful. It was a process, but the key to her diabetes care was seeing that man in a wheelchair making the most of life.

#### *Other Positive Spins*

Although participants were fearful of low blood sugars and wanted to avoid having them, they realized that hypoglycemia is inevitable. One participant described the

"upside to a low," which is being in a different state of mind when the brain is not functioning properly. She described this in a metaphorical way, where:

Serious Black [of Harry Potter] died and there is this veil, and it's on the other side of the veil. I think there are a lot of things in ourselves that are right on the other side of the veil. We live such busy lives, we don't have time to reach for them. Sometimes, when you're low and you're just... all those other things that you're trying to keep together just go by the wayside, and you can reach beyond and, 'Wow!' ... It is really neat when it does happen.

Low blood sugars can free the mind and take the body beyond the world of the rational.

Camilla learned to be more forgiving as a child because of her diabetes. She understood that the other children could have chocolate in their stocking, when she had oranges and apples. She accepted that others could have candy, and she couldn't. She knew to accept and forgive that diabetes could be unfair. This positive outlook helped her at more difficult times in her life.

Two people said that if they did not have diabetes, they would probably not be taking care of themselves. One woman said she would weigh "400 pounds." Another said that diabetes actually made her "grow up," and taught her that there is a reason for everything. She's met a lot of great people with diabetes, and before she had diabetes, she never realized the amount of research that's been done in the medical field. For her, it opened up "a whole new world and other doors. We would not have met if it wouldn't be for diabetes. To a degree, there have been some positive aspects."

Both she and Roberta used humor to make meaning of their diabetes. Roberta said that she jokes with her friend about going blind. "If that ever happens," she says,

"Please do not dress me in polka dotted shirts or striped pants. Please, make sure my hair looks right. I'm so vain. I'm blind ... but I'm vain." One woman summarized her feelings this way:

I don't know why we put such pressure on ourselves to accept [diabetes] and have positive feelings. I think that we're very hard on ourselves.

Coral made meaning of her diabetes by coming to terms, or accepting, that her diabetes would not be under perfect control. She said, "I'm happy with it [her AIC]. I'm not jumping for joy doing cartwheels down the sidewalk, but it is better than nine. It's better than 10 or 12. I think 8.2 is where I am." To keep a balance between the positive and the negative, she did not obsess over a perfect blood sugar, but accepted that is where she needed to be in the moment. It is not perfection that people with diabetes work toward and hope for, but a more healthy and balanced life.

*Hearing "the Noise": Constantly Shifting Awareness of Diabetes*

*There was a noise, a clattering sound; it was the bones coming together. And as I looked, they were covered with flesh, yet there was no breath" (Ezekiel 37:7-8).*

In the background, a noise startles and confuses. It is difficult to ignore, and suddenly the sound is in the foreground. Maybe it is the sound of a child's cry, or the squealing of tires speeding down the street. Maybe it is the blast of a gun, and the family's feet rushing to the window, hoping that death has not found one of their own. The awareness of these sounds shift throughout life, fading from the foreground to the background and back again.

The noise of diabetes is not something that participants focused on all the time, but their awareness shifted between the foreground to the background and back again

during the course of their day. At some times, such as a low blood sugar, diabetes became front and center. It was a noise, a clattering sound, which could not be ignored. Other times, when participants were working, playing, or having fun, diabetes shuffled to the background. The awareness of diabetes was constantly shifting from the foreground to the background and back again.

Participants could not equally focus on their diabetes and other activities of their daily life, and they gave specific examples of this shift. Roberta said that when she was having a "really hard time with my blood sugars and stuff, I think about it [diabetes] a lot. Usually day to day, I don't." Sometimes, she forgets that she is wearing her insulin pump. For example, she might leave the house, drive down the street, and think that she forgot to put on her pump. She'll check, and it will be there.

#### *Diabetes in the Foreground*

Emily said she "can't forget about it [diabetes]" because she needs to think about how many carbs she's eating, and write down her numbers. She described her awareness as "going in waves," where sometimes she doesn't even think about her diabetes, but writing her blood sugars down makes her think about her disease "all the time." Her words were:

It like goes in waves and... certain times, where like I'll have a bad day of sugars, and I can't handle it... I'll break down ... People think that when you go on the pump, you don't have diabetes. But it [the pump] is right here (pointing to her side). If anything, it's more of a reminder that I have it because it is on me all the time. Instead of just taking a shot, in and out, it's just here. And it's more like a reminder.

When Coral is in a restaurant, she will have to stop her meal and think, "OK. I think that's 72 carbs; now how many units is that? My sugar is 120. So I need to do this ..."

Another woman mentioned trying to keep track of the carbs at a restaurant. She becomes more aware of her diabetes when she eats because she thinks, "How am I going to figure it out?"

Diabetes doesn't ever disappear from the background completely. Even when people aren't thinking about it, they know they "can never get away from it. It's always there. No matter what you do." Amber said that some days she feels better than others, but within hours or moments, her blood sugar can go up and down. She wonders if feeling "normal" or "cured" would mean that she wouldn't have to think about diabetes. But, she says she doesn't want to think about feeling sick for too long, because "you can begin to feel sorry for yourself, and you have to be glad for the time you had, when I did feel good."

Many participants warned of the dangers of thinking about diabetes too much (i.e. keeping it in the foreground too often). One woman said, "Diabetes should not control you. It should not consume everything. I spent the first six months [after my diagnosis] with that ... you can't really let it consume you." Another said that there were times when diabetes seemed to rule her life emotionally, and that was not healthy.

Those with diabetes have to deal with their disease every day. Even though they live relatively normal lives, it is with them:

every minute, every hour, and there's not really a lot of time that I don't think about it. You know, when am I going to eat? Every time you take a shower, you

need to take the pump off or, if you have a waterproof pump, you need to figure out where to put it.

One woman stayed up one night, thinking about what she ate during the day. She said, "My mind would race because I ate Hershey kisses. My sugar was okay, but I would sit there and stay awake at night, and think about what I ate all day." People who don't have diabetes may feel guilty because of eating unhealthily, but they don't need to think about how it's going to affect their blood sugar throughout the night. Agnes talked about how she views eating, diabetes, and the consequences of complications by saying:

If they said that by the time you would *finish* that piece of pie, you were going to go blind, maybe you wouldn't eat that piece of pie. But if they said 10 years from now, you *might* be blind, you might eat that piece of pie, and maybe a couple more. I had trouble getting my point across [to my friend], but she kind of said, 'Well, OK.' I don't think she really grasped it, the whole idea of what diabetics go through every day. Every minute of every day. In my opinion, it is a choice all day long. All day long you're going through that in your mind, just going, 'Well, what am I going to eat? Well I shouldn't eat that. Well, but I shouldn't eat that.' Back and forth, and 'What's my blood sugar?'

This is a wonderful example of diabetes coming to the foreground. Later, she mentioned the awareness of diabetes again:

You have to think about it almost all the time. The whole numbers' routine, and what time is it? How many carbs did I eat? What is my blood sugar now?

Before you do anything, like going for a walk, you have to test, to make sure I have my little carb of extras in my pocket ... It's just part of life.



Diabetes can come to the foreground at unexpected times, as I observed during an interview. One participant was talking about her being a responsible parent, and I noticed that her facial expressions changed. I asked if she needed some juice, and she replied that she did need a little. After taking a short break, we continued where we left off with the discussion. This is an example of how living with diabetes can change from the background to the foreground in a matter of moments.

### *Diabetes in the Background*

The irony is that diabetes is often invisible, and it is easy to shift the illness to the background. For the most part, it is not like a paralysis where people need to spend time in a wheelchair, which is visible to the world. With the exception of the insulin pump, there are few, if any, visible signs. Telling people about diabetes, and the timing of knowing when to bring it to the front, was similar to letting out a secret, or "coming out." Coral said, "When you go on a date, do you tell him on the first date? Second date? When do you tell them? When you're on the pump, it's kind of hard to not tell them."

Another woman said her diabetes is invisible because her friends look at her and say, "She's great. Look at her. There's nothing wrong with her," but when she has a low blood sugar, she becomes aware that she is not like her friends. Her reaction to low blood sugars affects her day-to-day life. Diabetes can be unfair, when one of her friends is shopping, for instance, and she needs to think about having to go change her pump or checking her sugar, or having to get a juice box. Where other people can think about traveling alone and without medical supplies, she needs to keep her diabetes in the forefront to keep herself safe. Her sister says to her, "You know why people don't think

you are sick? They think you look so good. They have no idea what's going on inside your body, or what those low blood sugars are doing to you. They have no idea."

Some women kept their diabetes in the background because they didn't want to stay stuck thinking about the negativity of having diabetes. They decided to move forward with their lives, because they didn't see a point in dwelling in thoughts, particularly negative thoughts, about diabetes. Some women focused on others as a way to keep their attention off of diabetes. One participant admitted that she took care of other people as an excuse to not worry about her own health.

Ignoring diabetes was one way to keep it in the background. One woman ignored her disease for a time, and said, "I actually got somewhat adjusted to it [high blood sugar] and I would feel low if I did drop to 200." She would not test her blood sugar. If she didn't know what her number was, she wouldn't have to treat it. In other words, if she pushed it to the background, then she wouldn't have to deal with it in the foreground. She said:

It makes it [diabetes] more real, when it's on paper. You have to do pattern recognition and far more thinking about it then when you're just, 'OK, I'll just test it, and put what I need to in my pump, and go on.'

Because there are few immediate consequences to ignoring symptoms, ignorance is one way participants handled their diabetes. Three participants in the study drank alcohol and one had taken illegal drugs to move diabetes to the background. One woman confessed that when she was high, "I didn't have to think about my diabetes or anything like that." Another said, "You don't have to worry if you're *low* [blood sugar], if you're

*high* [on alcohol].” Although they were aware of the negative affects of alcohol and diabetes, drinking helped them escape the reality of their disease and their life.

One woman "pretended" that she didn't have diabetes when she was younger and wasn't “diabetic according to her.” The only time her illness came to the forefront was when she gave her shots. It was the only part of her diabetes to which she paid attention in order to maintain her semblance of normalcy. Camilla added that she doesn't "think too much [about complications] ... half the time, I don't feel like I have diabetes. I just go and do my everyday thing." But, another participant warned, "You can't put it on the shelf forever."

*Standing as a Great, Immense Army: Living for Others*

*He said to me, “Say to the breath, Come from the four winds, breath; breathe on these dead, so that they come to life.” The breath entered them; they came to life and stood up on their feet, a great, immense army (Ezekiel 37:9-10).*

After receiving life-giving breath and healing, the bones came to life and stood as an immense army. To me, the army represents family and friends, other people who have been in that Valley, too. Together, we can stand in the Valley of difficulty as a great army, warring against death and diabetes. In these participants’ narratives, the role of the family was the most predominant in the “great army.” We are not alone in our fight, because we have breath, and there are others standing with us.

In Jennifer’s experience, it was her family who tried to help her with her diet, fighting right alongside her. Jennifer said, “We all tried to eat a diabetic diet. Diabetes changed the family dynamic. It changed everything.” This was true for Daisey, as well, where the whole family ate sugar-free food and grew up used to having "diet stuff." Before dinner, Camilla’s family created a game with her blood sugars, where the children

would guess her blood sugar number. Camilla would "win." Her family would say, "That's not fair. You know how you feel. You guess first." The family was involved and interested in her diabetes. Overall, the women's families were compassionate and supportive of taking care of the practical side of diabetes (doctor's appointments, low blood sugar reactions, insulin injections).

Only one woman in the study, Sophie, specifically mentioned her family history as having an impact on who she is today, and how she views diabetes. Her family history was the "German milkmaid syndrome," where her father's family was German, and her grandmother came from Germany at age 20. She said:

You could have like one leg cut off, and you kept working. It was just the thing.

You just muddled through. So I'm probably not the most sympathetic person.

Ask my husband when he gets sick. I'm like, move on.

Many participants mentioned having low blood sugars, or seizures, and were afraid of that effect on others. Interestingly, participants did not discuss the effect the low blood sugar had on them personally. Amber had a seizure in front of her family approximately a year ago, and she said, "I felt so bad for *them*." Emily had a seizure, where her roommate found her, and she couldn't get her out of bed. She says, "*She* was really scared," not mentioning her own feelings. At the time of for diagnosis, Coral's father had a massive heart attack, and she was concerned that her family didn't need to have another "terminal illness." When she told her mother about diabetes, her mother was "a little in shock," and her father was "sad," but she did not describe what having diabetes meant to her personally.

Overall, the pattern in this section was that many of the women mentioned that they wanted to be healthy in order to be around for others, particularly for their children. If the participant did not have a child, then her motivation for taking care of diabetes was to stay healthy for her significant other. While they may have wanted to be healthy for their own well-being, the relationship which they held with others, was a stronger motivation. Diabetes affected the lives of the participants most widely in the roles of (a) mother, (b) significant other, and (c) daughter.

### *Mother*

In this study, the identity of mother was a powerful influence on diabetes care. For several women, diabetes took on new meaning when they found out they were pregnant. Specifically, Sophie and Amber found meaning in diabetes by keeping healthy in order to stay alive and well for their daughters. Sophie said, "Please God, keep me healthy so I can make sure ... my younger daughter, is OK. Amber also talked about her daughter's influence on her health:

When I had a child, that changed a lot. I wanted to be there for them. It gave me such stability ... It brought consistency and regularity into my life. Having a baby brought more stability, and even helped me with my diabetes, in a way.

Camilla called her first pregnancy a transformational point in her diabetes care. She hadn't been listening to her doctors, and she remembers their telling her that she would never have children. In her words, they told her, "You'll never have kids if you don't take of yourself right." So, to her, having the gift of knowing what it was like to be pregnant and to care for that child changed her thinking about diabetes. She took care of herself because she knew "there was somebody else depending upon me to be taken care

of." She started to take care of herself and test her blood sugar six to eight times a day to make sure "the little creature was OK."

The women realized that diabetes affected the family, especially their children, because their kids have had to deal with diabetes, too. Sophie said that diabetes is a "far reaching" disease in that respect. She said her children know when she is having a low blood sugar, and they say to her, "Mom, you're acting oddly. You need to test your blood. Test your blood. Test your blood." Amber felt her children bore some of the responsibility of taking care of her diabetes. If she went blind, her daughter said she would take care of her mother and told her, "Don't worry, mom. We'll get you a dog." She didn't want a dog, and she didn't want to be "wandering around," led by her daughter. Her family bought a cell phone for medical safety, in case she or the children needed to make an emergency call.

Other women were influenced by their daughters to go on an insulin pump. One daughter said to Agnes, "Mom, I keep talking to people [in the food industry], and everyone of them told me they loved the pump." Her mother would say, "OK, OK. Maybe someday." This daughter was the one who encouraged her to go on an insulin pump. She had heard of many people who went on a pump, and she wanted her mother to be healthy.

### *Significant Other*

If participants did not have children, then their significant others were the greatest source of inspiration and motivation. Daisey said that she makes meaning of taking care of her diabetes not only for her benefit, but because she wants to be "around" for her significant other, and she wants to be together with him for a long time. He wants to

know a lot about her diabetes and has been supportive. Coral received a lot of support from her boyfriend, too. They had been dating for years, and Coral's diabetes has taken them through many learning experiences. One night, Coral did not eat her snack before going out to dinner. She was at her boyfriend's house, and she told him they needed to go out to eat soon. He replied:

'I'm not hungry.' He knows I have diabetes. And the next thing you know, I've crashed. Well, he's throwing pizzas in the oven to try to get my sugar back up. So the following week, I go over and I said, 'We need to go and get something to eat. I think I'm okay. I'll be OK for a while.' This was just a fluke, but for some reason I got the flu. The next thing you know, God love him, he's making pizzas. He thinks I'm crashing. And that's the last thing I needed to eat.

But he is willing to help her. When she is going low, he realizes she is getting irritable and asks, "Hey, did you test your blood sugar?" Daisey's husband also asks her if she is going low.

Amber believes that having a husband brings her more stability, and getting married to him changed her view of diabetes. She made regular breakfasts and dinners for him, which brought a sense of regularity to her eating habits, and therefore blood sugar. Because of her retinopathy, she also relies on her husband to do most of the driving, especially at night and in the rain. Camilla's husband was supportive of her when she developed retinopathy and had to go to the eye doctor. She called her husband at work because she was seeing something in front of her eye. She explained to him,

'I have this claw-looking thing,' and he's like, 'Can you see it?' And I say, 'Yeah, I can see it,' not thinking of what he's thinking that it's something that's protruding

out of my eye, like a claw. So he rushes over to meet me at the eye doctor, and he says, 'Well, you look OK. I was thinking I was going to see this monster.'

Camilla's husband was also influential in telling her about the benefits of the pump, and asking her to consider it. Although she doesn't talk openly about diabetes to her husband, she knows he cares about her well being. Emily is glad she can open up to her boyfriend, and she relies on him to talk about issues related to diabetes, especially when she is feeling angry or upset. Coral summarizes the general feeling of the group when she said, "Thank God for family and friends who support you, because there are emotional days."

### *Daughter*

When the participants were younger, the greatest influence on their lives was their parents. Upon diagnosis, several of the participants did not express their *own* feelings about diabetes initially, but explained how it made their *parents* feel. One example is Jennifer, who was put in the hospital while on vacation. She said, "It scared my *mother* to death." Agnes remembered her father empathizing, "I wish I were diabetic instead of you." Amber resented having her mother running after her on her bike with sandwiches, saying, "Eat this!" She didn't want to eat it, and she would often say, "You can't catch me. I can run really fast!" to avoid her mother.

Although parents were generally supportive, making breakfast and giving insulin, for example, not one participant said that their parents talked about how it felt to have diabetes or a conversation about what living with diabetes meant. Three daughters relied on the support of their parents initially to give them insulin injections. Emily said, "I didn't want to do it to myself. I'd rather have them -- parents -- do it and not look."



Roberta had an interesting relationship, because both her parents developed Type 2 diabetes, and they gave each of their shots. Daisey and her father also gave each other shots and she said, "We were like buddies." He guided her through some of her childhood with diabetes and now she is able to return the favor by teaching him how to go on the pump. Participants also relied on their parents to get them some orange juice, or other sugar, to bring up their blood sugar. Sophie's mother was the band nurse, marching alongside the band. It was her way of looking out for Sophie, without being in the way. Every once in awhile she would say, "I think you need some juice," but usually she didn't bring attention to Sophie's blood sugar. Agnes remembered an incident her parents and a low blood sugar:

'Mom, I need some orange juice.' Then, 'We don't have any orange juice, honey,' and she didn't realize the situation. 'Mom, I need orange juice.' So, my dad went to the store and brought it back. By the time he brought it back and mixed it up, she said I was going like this (shaking her hands).

For Emily, her family (particularly her mother and grandmother) influenced her since she was a child. They always said that her health was the most important thing, so when she thinks about her diabetes and the choices she is making, she thinks of them. One daughter followed in her mother's footsteps. When growing up, her mother fed the children first, then said her husband, before she ate. "That's what I did. That didn't always work" for her, because she had diabetes, and needed to make her needs a priority. However, she said her mother did a "great job," with her diabetes.

With the participants overall, there didn't seem to be a feeling of over-protectedness from their parents, or their parents' stopping them from doing activities or

achieving what they set out to do. Most parents were compassionate, and tried to help. Coral said that her mother was "really good" when it came to injections. When Coral had to take her morning shot, and couldn't do it, her mother told her to "sit down for awhile, and if you don't do it right now, come back in 20 minutes. You're putting way too much pressure on yourself." Diabetes does create added pressure for children and teenagers with diabetes. Sophie remembers back to her teenage years, when she didn't want added attention from her parents, even though she had "another level of need beyond the 'normal' teenage need." Parents were important influences in shaping their children's identity with diabetes.

### Chapter Summary

In this chapter, the participants were introduced and, after highlighting the theoretical perspective on which this study is based, I discussed the themes of the initial interviews. Five major themes emerged from the narratives of the participants. They included: (a) Experiencing a range of negative feelings about diabetes; (b) Resisting against diabetes and medical approach; (c) Taking a positive spin on the negative as a way to cope; (d) Constantly shifting awareness of diabetes; and (e) Living for others.

When talking about the experience of diabetes, participants expressed a fear of death, anger and frustration, feelings of difference, depression and moodiness, guilt, and uncomfortable, physical pain. To make meaning of negative emotions, all of the participants focused on positive aspects of having diabetes by having endurance, focusing on the improvements in diabetes care through technology, having a strong faith in God, or comparing diabetes to other diseases, so that "it's not that bad."

Although diabetes does not go away completely, the awareness of its effects shifts between the foreground and the background throughout the course of the day. Many participants resisted, or did not follow, the recommendations of their physicians or the medical model of care. Rebellion was one reaction to having diabetes, as well as a resistance to writing down blood sugars. The medical model was insufficient to capture the experience of diabetes, and diabetes needs to be more than “managed.” Physicians and health care providers influenced care, but others had greater, far-reaching influences in the way they viewed diabetes. Being healthy for their children or significant others gave participants a reason and a meaning to take care of their diabetes. *What would diabetes look like if we put flesh and muscle on our dry bones in order to breathe and live?* To begin searching for an answer, we looked to the creative process in Chapter Five.

## CHAPTER 5

### THE CREATIVE PROCESS AND FINDINGS

In action research, the design emerges as the study continues, rather than being predetermined. The research is an inductive process, allowing for multiple endings and possible outcomes, based upon the direction of the participants in the group. The “action” in this research process was to explore the ways in which meanings about diabetes could be expressed through creative avenues. After transcribing and reviewing the first set of interviews, my thoughts began percolating as to *what* and *how* this might come into practice with the participants. I began jotting notes about how we might use creativity in the sessions, but nothing seemed to really “fit.” For two weeks, I stopped thinking about it so intently, and let intuition flow.

The idea of using creative expression through the use of shapes and imagery came to me while on vacation to the Delaware Shore. While watching my son play in the salt water, I felt a full sense of awareness and connectedness to the ocean’s waves and rhythm. In this focused space, my left index finger began drawing circles, lines, and triangles in the sand, as though my body were communicating, “Look to the sand. Here is your answer.” In bypassing the mind and attending to the deep understanding and signs of the body, I was able to discover the possibilities of creative expression. These forms of guidance (which I experienced as spiritual) were embodied in the elements of nature, leading us to create images which included, but were also greater than, rational thought.

The constructive postmodern and feminist poststructural perspectives, from which this research is grounded, allow for multiple interpretations of the images and meanings

created. There is not one, *right*, answer. The process of interruption and interpretation itself is one of deconstructing and reconstructing meanings, not a one-time event which remains static over time. Just as one meaning is discovered, another one is moving onto its path and becoming new. Throughout this process, my role of both facilitator and participant was also in flux, shifting from leader to listener, and back again, as many of us do when interacting with others. Because I wanted to know how the participants made meaning of their images and pictures, largely what is described below are the participants' interpretations of their experiences with diabetes. Mostly, the participants' voices will be heard, explaining what the most powerful images were for them, and how they defined and interpreted the meaning. At times, I offer my own alternative translation of the image, and tell the reader specifically and explicitly when it is my own addition to the participant's text.

The first session related to using images from the body in order to explore the meaning of diabetes. Sessions two and three are combined below, as these sessions were interrelated and connected with using photographic images to communicate the experience of diabetes. The photos are included as figures within the text. The creative *processes*, in combination with the end *products*, are examined together in this chapter of the dissertation.

#### Session One: Visions from the Body

Incorporating various creative forms of knowing, such as art or poetry, into the practice of adult education can enhance the experience of a learning environment. But, developing and facilitating a creative "activity" for the purposes of including an artistic form in a session can become just as rational, redundant and cognitively-driven as writing

a traditional research paper. Often, nothing new is learned. In order to access those parts which live in the body-spirit-mind, the instructor needs to move beyond what is known rationally into the realm of the subconscious through multiple ways of knowing. The knowledge found in the body is one way to access these parts of selves which are hidden, unexamined, or even unknown. By using somatic, or body, knowledge, there is the potential to discover new things about ourselves and our experiences.

### *Setting and Introductions*

This section describes the environment in which the first session took place, as well as the introductions of the individual participants to the group. During the first session, the participants met in a large, comfortable room which could easily accommodate the group. Unlike many of the hospital meeting rooms, this space was furnished with cloth chairs, carpeting, and artistic pictures on the wall. Two tables were set in the center, facing each other with chairs around the tables. As the participants arrived, I greeted them and made small-talk and conversation. As expected during initial introductions and the first stage of group dynamics, they were quiet with one another, but comfortable talking with me. Creating an atmosphere of both energy and comfort, I played upbeat, background music from Cirque du Soleil (*Delirium*, 2005), and supplied light refreshments. We met for approximately one hour and 45 minutes, beginning at 6:00 PM on Thursday, August 24, 2006. All participants attended, with Camilla and Emily arriving shortly after the others.

The first session began with introductions, where each participant wrote down the response to three questions: (a) What is your "code name?" (b) What are two or three things you would like us to know about you? and (c) What is your favorite color and

why? I told the participants that this second question could relate to diabetes, but did not need to. They were invited to tell us some things that they told me during the interview, why they were participating in the study, or anything about them that they would wish to share. Participants (including myself) took approximately ten minutes to complete the sheet. When the participants started to finish, they began talking to each other about where they lived, and how it was difficult to find a parking spot. They discovered that all of them were wearing an insulin pump.

Coral volunteered to begin the introductions, and she asked specifically what I wanted her to say. My reply was, "Anything on your sheet, or anything about yourself." She said she loved playing golf and making pottery, and that her favorite color was coral. Emily replied that she was a teacher and sang in a band, she liked to make beaded things, and she has a Boston terrier. To that, Sophie responded, "Maybe all the talented people can make crafts for people who aren't talented." Daisy introduced herself as someone who loves to sing, especially karaoke, and often appears at a local nightclub. She also loves to wear costumes and dress-up to be someone she's not, even if it is not Halloween. She has to match everything, and she means *everything*. "It's a little bit of OCD," she said. Roberta plays guitar and percussion, likes to sleep late, and told the group she recently lost weight.

One participant said her nickname for the study was Agnes, because that was what her husband called her. She just started the master gardener program, which is part an educational endeavor and part volunteerism related to gardening. She collects quilts and has "been known to teach basic quilting, but I'm not real talented that way," and recently attended her 40th class year reunion. Camilla introduced herself as the "one with

the weirdest name." She loves butterflies, reading, and dancing. Camilla said she was never asked why green was her favorite color before this evening, so she would have to think about it. After explaining that I was also part of the study and would be a full participant in the group, I shared a story about my 10-year old son, and about my experience with skydiving and my interest in creativity. Purple is my favorite color because it can be both deep and rich, and fun, all at the same time. Sophie said she does not make enough time for herself, so she feels as though she is not creative at all. She was a dancer, and took adult ballet last year. She is married and has two children. She said she's very busy, and doesn't have the time to "stress about diabetes."

I pointed out that it was interesting we did not talk about their diabetes, and that was "fine" with me. It was also relatively obvious that we were a group of women, and so I mentioned that the study was not intended to be that way, nor was it intended that everyone be on a pump. I told them that it was really a privilege to read the transcriptions of their personal experiences with diabetes, and it was great that all of them could come together. After collecting the introductory sheets, I said that my hope for participating in this group and this evening would be relaxing and enjoyable for them.



To create an atmosphere of potential connection and trust, I showed a painting of mine, completed when I went on the insulin pump in 2003 (Fig.1). During my first few days on the pump, I had a miserable experience. The 43-inch cord felt long and awkward, and wrapped around my body. It was difficult to get used to the long, intrusive

*Figure 1. Pump.*



needle, and I hated when the site would bleed. At that time, I felt like diabetes was taking control of me, and I did not have anything to say about it. Now, the insulin pump gives me the freedom to eat when it is convenient, and to receive a continued basal of insulin, which has dramatically improved my blood sugars. I have fewer low blood sugars during the night, and more stable sugar readings throughout the day. Participants commented that they found the cord to be problematic at first, as well, and it was difficult to get used to having a “leash” attached. One person said her infusion site wouldn’t stop “oozing,” but now she knows what to do in that situation. After some time, however, the pump has become easier to manage, and has been a benefit for all of the participants in their having more stable blood sugars.

#### *Artistic Process*

It was important for the group to trust the creative process of the evening, and allow me to be their guide, not their “teacher.” Their bodies and their own knowledge of diabetes would show them what they needed to know. Because there was the potential for participants to focus on the end result rather than the process, I did not share the steps or an agenda for the evening, but encouraged them to follow the creative process.

The Cirque du Soleil CD playing in the background was replaced by celtic harpestry music (*Harpestry: A Contemporary Collection*, 1997, Imaginary Road), which was soft and contemplative. I asked the participants to get as comfortable as they possibly could, to relax, and listen to the first song, without my saying a word. The song ended, and went into the next one (*Hornpipe in E Minor*, Maureen Brennan).

#### *Focusing on the Body*

With that, I began the meditation, speaking slowly and calmly, using the following words:

“We have all had diabetes for a very long time. We're going to take a few minutes to just focus on how we feel about diabetes. There may be something within us that we haven't expressed, or we have been embarrassed to express. Maybe we haven't even thought about our feelings. We are going to let our bodies tell us how we feel about diabetes. Trust the process. If you don't get it the first time, that's OK. We can do this as many times as we need. But I would like you to relax (pause). As you relax, focus on the part of your body that feels like it hurts, a physical body part, a part of your soul. (Turned off the music to silence). As you feel that part of your body, focus on it. Listen to that part of your body. Don't think critically about it, just focus on it. Try to silence your mind. Focus on the way it feels. Maybe there will be a certain kind of energy around it. Focus on that part, and the energy around it (pause). Allow the energy to form into a simple shape. As you begin to see it through your body's eyes, note the color. The position. The texture of it. Focus on the shape. Focus on the color. When that shape is in your mind, slowly open your eyes.”

I instructed participants to take any color of paper available and to use the coloring set, one for each person, in front of them to draw the shape. If someone didn't have a shape appear to her, she should let me know, and I would come around to help. All of the participants, including me, drew the shapes in silence. I said, "Don't think about it too hard. Just get it down on paper."

### *Moving from Body to Shapes*

After drawing the shapes, the participants were asked to list “approximately five things you think that shape could be.” Questions to prompt their imagination were: (a) What is that shape?; (b) What is that symbol?; and (c) Have you seen it before? Sophie

asked if it should be an object, and I replied, "A concrete object would be fine, but if it makes sense to be an abstract, then that's OK too. Just write down something that you see." The group was able to do this easily and freely. Daisey said, "Does spelling count?" followed by laughter. I also asked the group to write down the place where they felt the pain in their body. As Camilla was working, there were tears in her eyes.

### *Creating Metaphors from Shapes*

After giving a name to the shape, the group worked in pairs for a few minutes to see if the two collectively could list more names for the shape, thus providing an alternative perspective. Then, each participant was asked to select one or two names to which they felt or could say, "That's what it is" and then number the names, "1, 2, etc." according to the way the images spoke to them, with "1" being the most aligned with their thoughts and feelings about the shape.

The group members were asked to choose another piece of construction paper in any color of their choice. On that new piece of paper, I asked them to write the beginning of the sentence, "Diabetes is like," and then insert the word that most described the image. Holding up my image of a pink-purple wave, I gave the example of, "Diabetes is like a snake." One person asked if they needed to make a connection to diabetes first, before writing down the word, and I responded, "No, we will make that connection in a moment. Let's write the word first." Sophie wrote, "wedge," but said that it did not describe how she felt about diabetes. Instead, she said diabetes felt like a tornado. Although she could change her shape, I really wanted her to go with her instinct that diabetes was like a wedge, and to trust her body, even if it didn't make sense in her head

at that moment. One woman said that Sophie's image was really a "wedgie," because diabetes can be a pain in the rear end, which brought more laughter from the group.

After cautioning them to not analyze this part of the process too much and to go with what they were feeling, they wrote "because ... " and completed the sentence, "Diabetes is like a/an (image) because (fill in the blank)." In other words, "What is the relationship between diabetes and your image?" Roberta asked if she could change her image to a box, and I encouraged her to go with her instinct, or write about both.

Participants wrote in silence, as they reflected on the meanings of their image. I noticed that one person crumpled her first piece of paper, and began again. As the participants finished, they began talking to each other about people they knew at the diabetes clinic, and subjects unrelated to diabetes such as college, work, and family. To this point, we had accessed parts of knowing about diabetes from the body, gave that knowing a shape and a name, and then connected the shape back to diabetes. Now the participants were giving meaning to the shape and image in relationship to their feelings about the disease. This would be the last step to the process of the evening.

### *Shapes and Metaphors*

Opening up room for discussion, I asked if anyone would be willing to share their images and what they wrote. Camilla went first, followed in a circular order by everyone in the room. The shapes, and the meaning of the shapes, are described below, and are included in Appendices D through K for visual reference.

#### *Broken Heart*

Camilla said her rainbow-colored image could be a human heart, a broken heart, a raindrop, a tulip, a teardrop, or parachute. Her sentence was, "Diabetes is like a broken

heart," because that was what it looked like to her most, and it was missing the other half of the heart. Her image was her own heart, but she also felt it in her head. For her, it was two images in one. She wrote that diabetes was like a broken heart, because

It's broken me, and it seems like it is a slow healing process. There is pain, misunderstanding, and confusion. It seems like there's always a temporary fix to adjust and keep going, yet it's never going to be completely healed or mended. Whether you do what you feel is right, or listen to advice from others, I always seem to feel alone and broken. It suffocates me to where I feel I can't breathe, while at other times it beats so fast. But, mostly it feels like I don't have control over it.

She feels like the blood that flows to her heart is constantly poisonous, and diabetes is just waiting to kill her. This reflects the theme in Chapter Four of a strong fear of death, but it may also have been influenced by my image that evening of diabetes being like a snake.

### *Eye*

Agnes said her diabetes was like an eyeball, because she had dry eye in her right eye, and her eyelids felt like sandpaper. When she was asked to focus on the pain, she felt the pain in her eye. Other participants interpreted her round image as being "eyes watching you," because so many others are watching what she eats and giving her medical care. She wrote that diabetes was like an eyeball, in that

You must keep an eye on the clock, an eye on your glucometer, an eye on your pump, and, heaven knows, an eye on your eyes. The circle that represents the eye is something like a full day in the life of a diabetic, and you start at the same point

every day and continue for 24 hours until you're back at the same point again only to start over again day after day, week after week, and year after year ... if you are "lucky."

Agnes felt that a lot depended on that "luck" because there is only so much she can do to control and manage her diabetes.

### *Ticket*

Roberta's rectangular image was felt in her shoulders. The first thing that came to mind was that of a ticket, although she was not sure at the time how that related to diabetes specifically. She said that she carries a lot of stress on her shoulders, and "that may be related." The image also represented a box to her. Camilla commented that if diabetes were a ticket, she would have given it away. Roberta said diabetes was like a ticket, because:

It 'got me into' the person that I am today ... regulated, controlled, limited, confined, self-absorbed (not in a bad way) and very hard on myself. Yet optimistic, positive, steadfast, ongoing, and persistent.

She added that she wasn't sure if it was diabetes that made her persistent, but maybe she would have been a "fat, lazy slob" if she didn't have it. Roberta's comment is an example of taking a positive spin on diabetes.

### *Mr. (or Ms.) Potato Head*

Daisey felt a "soul" pain in her stomach. Although she has a lot of physical pain, she said those are "easy" compared to emotional aspects of diabetes. For her, diabetes was like Mr. Potato Head because he can change his smile, his face, and his expression. When Daisey talks about her diabetes, she sometimes feel like she has a smile pasted on,

saying, "It doesn't bother me," when it really does. She wrote that diabetes was like being Ms. Potato Head, because

You have to wear different expressions, and your body parts change, and you have no say in it. People just see you and think you're fine. Ms. Potato Head never cries or wears a frown; she hides behind her smile.

Both Coral and Sophie commented that was "True, very true." I made the mental note that Daisey changed the gender of the surname from "Mr." to "Ms." My interpretation is that "Mr." kept the image at a distance, outside of herself, where "Ms." began bringing the image closer, to a personal level.

*An X*

Emily felt a physical pain at her infusion site, so she wrote that diabetes was like an "X," or a crossroads. Since her shape was red, other people interpreted her image as being a "keep out" or "danger" sign, but Emily said she took a more positive spin on the image by thinking of it as a crossing of paths. She wrote that diabetes was like a crossroads, because "there are too many roads and paths it can go." After reading her description, she said she feels like there's always something different (like her insulin pump), or something that she has to do next, or something she finds out (like hormones from the insulin can cause mood swings). Sophie thought it was interesting that Emily chose a crossroads, because it reminded Sophie of an "X" as in one who is marked to be shot. Emily explained that she had listed "X Marks the Spot," as a possible metaphor, but she didn't want to use it and wasn't sure why. Camilla added that it was the site spot where she had to inject the needle. Emily thought that made sense, because her site was

hurting her in a particular spot. The participants were connecting and co-creating knowledge of the images, and developing further meaning through discussion.

Sophie said that Emily was “taking a positive spin on diabetes,” because the image could also mean an “X” who is marked to have diabetes. She thought “X” had more of a bad connotation, like an “X” on a paper that a student gets from her teacher. Emily said that she didn't mean it in a positive way, but that she meant it was annoying that she had to get used to the pump. She was used to giving herself six injections a day for 20 years, and didn't know what to expect when she went on the pump. Camilla said she is always afraid to try new things, because it “messes” with her, and seems to set her back five steps. Then she has to climb back up those stairs to get herself back to where she needs to be. But, she said that she has been out of the hospital for six years because of the pump, and it has been positive for her. She said she tries to push her feelings in the back, to those untouched feelings that “you're not allowed to go to.” I responded that one of the purposes of the study is to examine those feelings, where they don't need to be pushed to the back, but brought forward so healing can begin to take place.

### *Steps*

Although Coral felt that her blue-green triangular image could represent a dagger that she felt in her neck, as she looked at its jagged edges, her image reminded her more of steps. She said, “Diabetes is like one step at a time.” After looking further at the image, she also thought it could be an arrow head. The group joked that it might even look like pizza because “we always seem to have food on our minds.” Coral said, “Diabetes is like one step at a time, because I need to be patient with myself and with others.” She thought that people don't understand diabetes, especially the fact that she



has to eat and do many things to take care of herself. She tries not to impose herself, or what she is going through, upon others, and chooses to keep her feelings to herself. I took note that Camilla had just mentioned stepping back “five steps” and needing to climb up again. In my opinion, the most interesting aspect of Coral’s writing is that she drew a deep red, brick wall after the words, “Diabetes is like,” as though she did not want to continue or go further in her writing. This was examined with her in the final interview, and will be discussed in the next chapter.

### *Wedge*

Sophie felt her pain in her shoulder, and she was reluctant to call it a wedge, because she wanted to make it into a multifaceted rock or diamond. She never thought about feelings of diabetes before, except in other people, but she thought it felt like a pain that “you carry on the shoulders, having to be so many things to many people,” and it was difficult to balance all the weight of diabetes and expectations of others. It may also be a wedge between “yourself” and other people. Daisey added that it could also be a wedge between “yourself” and “your” feelings. Sophie replied that “you” don’t have time to think about how diabetes makes “you” feel. Although both Daisey and Sophie were speaking in second person, I suspected they believed these things about themselves in the first person. Before beginning her explanation, Sophie said she felt like “Heather was pushing me.” I did not make any verbal comment at that time, but she seemed to be frustrated by her negative feelings of diabetes. Sophie had written that diabetes was like a wedge, because

It creates problems between herself and other people [which, she said, she wasn’t sure she was willing to explore in this group], creates burdens between herself and

perfection, and it places a distance between allowing her to connect with what she really feels about ‘stuff,’ meaning having to be positive a lot.

She says she was on the pump because of her hypoglycemic awareness. Her husband would notice when she was going low and tell her, "Do you know what you look like?" She would say that she is not purposely trying to have a low blood sugar, but that kind of interaction created a wedge of “major frustration.” Even though she is a professional working adult, she also felt the burden for her parents, who continue to watch over her if she is late, and worry about her. It creates a wedge of worry for Sophie. Diabetes is also a wedge between perfection. She wants to be “perfect,” and diabetes does not allow her to be perfect. Daisey said that perfectionism is a “strong thread that runs through people who have diabetes, especially those who were diagnosed young,” because there was no room for flexibility. She said, “Either you be a good, little patient, or you are going to die.”

Before sharing my image, I commented that it was really important for Sophie to not change her image of what she thought it was initially, and to stay with the moment and her instinct. I asked if anyone felt like diabetes was a wedge, and Camilla said, "Diabetes is like everything that everyone has said. Honest to God. I was raised to believe that I should just get over it [diabetes], because I'm not in a wheelchair." Daisey agreed that people thought there was nothing wrong with her, because diabetes did not show physically. Camilla responded that she was always told that things could be so much worse, but she could not bring herself to say:

Thanks for giving me diabetes. Out of six kids in my family, I got it ... and you're not allowed to express your feelings. No one truly, honestly, understands how you feel, unless they go through it.

She said she could relate to the image of the eye, because she was afraid of losing her eyesight, and she could relate to the rectangle, because she carries all of her stress on her shoulders.

### *Snake*

This was my image. Diabetes reminded me of a snake, and closely related to that, a pump cord. It was between one and the other. The snake, being a pink/purple color, looked like it hurt. Maybe it was bruised or suffocating. I wrote that diabetes was like a snake, because:

It hurts to think about an insulin pump being tied to me all the time. It is slithering, always there. It sheds its skin and comes back a new snake. It is unrelenting, ready to attack. Diabetes is not easy. I cannot fly away. It is not a bird, but a snake. I hate the snake. Don't make me go near the snake. The insulin pump suffocates me. It grabs me by the neck and chokes me. It is poisonous.

Although the snake could be perceived as a negative or a *dark* image, I believe that by exposing these images and deep feelings to the *light*, there is the opportunity for healing. Camilla commented how similar our descriptions were, with diabetes being suffocating and poisonous.

In the beginning of the sharing of images, few people commented on each other's explanations. Camilla was the one to express her feelings freely, saying that diabetes is hard, and she doesn't appreciate physicians saying that she needs to get better numbers.

Coral replied that all we can do is try our best, and not get stressed about it.

Conversations began to pick up after Emily started to talk about her image of the crossroads.

From there, the group talked about their insulin pumps. Daisey discussed that she likes to kayak and snorkel, and has a waterproof and salt-proof pump, called a Deltec-Cosmos. All participants were interested in hearing more about the features of that pump because the remainder of them had Mini-Med pumps, which were not waterproof. We also discussed the pros and cons of "skins," or covers, to decorate the pump, and experiences that people had while at the beach with a pump. Everyone began talking at once, and the group became very animated.

As the participants were speaking, I jotted a phrase or two from each person's description of diabetes, and compiled it into a "group mosaic poem," which communally expressed our feelings about diabetes. I had not planned on creating a poem, but took the opportunity of the moment to bring the individual images and words into a collective.

The poem read:

Avoidance.  
 Don't make me go near.  
 Diabetes has broken me.  
 Limiting and confining,  
 It is not going to be healed. It suffocates.

Wear different expressions,  
 Never cry. Hide behind smiles.

Keep an eye on everything, day after day.  
 There are too many paths,  
 Something different, never knowing.  
 Not allowing me to connect.  
 Patience.

Sophie's immediate response was, "We're just all too damned depressed," followed by laughter from the group. We took a five-minute break. During that time, the recorder was left running. Camilla, Agnes and Sophie stayed in the room to talk, mostly about raising teenagers. Sophie asked Agnes how long she had diabetes, to which she replied, "42 years." They began talking about the fact that there were no glucometers at that time, and that it was the "dark age" of diabetes. In turn, Agnes asked Camilla and Sophie how long they had diabetes. Camilla talked about growing up with diabetes, and what it was like to be pregnant with diabetes. They did not discuss what living with diabetes was like in the present.

After Emily and Roberta entered the room, they began talking about universities, and the quality of education. Camilla asked Coral and Daisey if they had children, to which they replied, "no." Daisey said it would be risky for her, and Coral said it was difficult enough organizing herself, much less a family. When everyone entered the room, they all began having side conversations about their interests, whether that related to education, career or family. Their conversations were consistent to what they said in their initial interviews.

After a few minutes, I collected the images and written pages, and explained the next phase of the process (described in a later section of this chapter). Because this is an action research process, the schedule and plan are not predicted in advance. It is an evolving process, with decisions made collaboratively between group members. The ideas for the next phase evolved from their initial interviews, in which there was clearly a theme of wanting to be outside in nature. Some of them also enjoyed photography and singing. Sophie said, "Don't make us sing," and Daisey joked, "We could make a song

about diabetes." The direction to proceed needed to be made that evening, as it would determine how and where we were meeting next. All of the group members had access to a digital camera and were comfortable with taking pictures, so we made a collaborative decision to move forward with photography. Coral said she had an extra camera, if someone needed to use it, which was a good alternative.

Since participants enjoyed being outside and were physically able to walk, I suggested that we meet along the Susquehanna River in Harrisburg to take photos of images that reminded them of their diabetes. Harrisburg was a central location and a practical place for taking a variety of pictures, because there was ready access to city sidewalks and action, as well as nature, gardens, and the river. If it rained, we could go inside to the nearest mall/plaza area.

Keeping the images and colors created during this session in mind, they would be asked to take photographs of anything related to the image, or actually anything at all that seemed to strike them as interesting. I again reminded them that it would be a free flowing process of taking photos, and they should not think about it too logically or from an aesthetic point of view. We would meet at the Harrisburg Hilton, rain or shine. I also suggested that we could go out to eat either before or afterwards. Because she was concerned about driving at night and because we needed the most sunlight, Agnes suggested that we try to take pictures earlier in the evening, and then go out to eat. I said that if all participants were not able to join us for dinner, that would be fine. They should come anyway, just to take photos with us.

After deciding on September 7 from 4:30 to 5:30, followed by dinner, we figured out the logistics of directions, car pooling and transportation to Harrisburg. Camilla

would not be able to make it, but she said she would take pictures on her own and e-mail them to me. The last agenda item for the evening was the completion of a "Reflections on Learning" page (see Appendix C), which assessed their learning and experience of the evening. Results of the reflections follow:

*Reflections/Learning of the First Creative Session*

I thanked everyone for their participation, and told them it was great to have them all together in one location. From the seven reflection sheets I received anonymously from participants, everyone enjoyed talking with the other participants, especially about their feelings regarding diabetes. Overall, it was a positive experience, but one which was not necessarily familiar, because expressing emotions about diabetes was new for all of them. One woman said:

I liked knowing, for once in my life it seems, that I am not alone. I liked hearing and seeing everyone else's views and perspectives on diabetes and how it takes a toll on their life.

Another expressed that she liked talking to others, and "hearing how I feel through their words." One said that it helped her realize feelings she didn't recognize, or denied recognizing, in herself. For others, it was a sense of being understood by other people who had diabetes, and sharing those experiences. One woman appreciated the laughter and openness of the group. Only one person mentioned the actual creative process, writing that she enjoyed imaging and comparing those images with others.

Explaining how they felt about diabetes was difficult for all participants. It challenged them to think about how diabetes made them feel, after years of not being "allowed" to feel or think about diabetes. It was hard for one woman to verbalize her

feelings about her image, and the way that diabetes creates problems in her life. Facing issues around diabetes was also hard for one participant, who made herself “not cry” during the session. Another woman commented that it was challenging to put diabetes in words, and one woman felt “less creative” than others in the group, whom she perceived to be able to express themselves in words better than she.

By participating in the session, each member of the group learned something different about themselves and their diabetes. Some of the comments related to a feeling of community, describing the commonalities of others with diabetes. This was described through comments such as, “I am not alone,” and, “We all have just about the same feelings.” One participant said:

It is wonderful to share feelings about diabetes in this forum. I don't think I've ever done this. It was fun to laugh about similar feelings we all had, too!

Writing about her great support system with her families and friends, one participant mentioned that she was very positive about her diabetes (or tried to be) more so than the other women in the group. Two women mentioned that they learned more about their negative feelings of diabetes, with one realizing, “I still have body image issues,” and another saying, “I still hate it after all these years.” It was difficult for one woman to share her feelings about diabetes, because she viewed crying or showing emotions as a sign of weakness.

As an observer of the group, I was pleased that each group member was able to easily identify a shape, color, and image by focusing on body knowledge. Although there was room for conversations and diversions, we kept this session focused on diabetes, and the shapes and feelings surrounding our chronic illness. During this session, I felt



extremely relaxed and comfortable, even though it was a relatively new experience for me. I just trusted the process.

The group believed that they had similar feelings about diabetes, and I would agree that there are some commonalities, but each person experienced the meaning of diabetes differently. In metaphorical terms, they may have similar root feelings (fears, feelings of difference, anger, frustration, for example), but the leaves of the trees are different in how they look and interact within the world. If the experience would be exactly the same for each participant, then they may have come up with similar shapes. Instead, each shape was uniquely different. The meaning given to each shape, whether a wedge, an eye, or an “X,” was deeply personal. The similarities are in the struggles, and the search for meaning in a chronic illness.

#### Sessions Two and Three: Images in Photography

Photography is a dynamic representational system that uses signs, symbols and images to construct and communicate meaning (Moran & Tagano, 2005). According to Saussure, a *sign* has two elements, that of *signifier* and *the signified*, with signifier representing the form (in our case photographs) and the signified representing the associated conceptual understanding provoked by viewing a photo, or its meaning (Berger, 2004). For meaning to be constructed, these two elements must exist *in relation*, and they are interpreted by the viewer of the image. Although the images (signifier) remain relatively stable, the interpretations and meanings of those images (signified) shift over time. This section describes the process of taking photographs during session two, a brief discussion of my observations and conversation at an informal dinner, and a detailed explanation of the interpretations and meanings of the photographs discussed during session three.

*Session Two: The Photographic Process*

For our second session, the participants met at the Hilton Harrisburg lobby. Emily and Camilla were not able to join the group, but took photos on their own. It was a pleasant, sunny and temperate evening, so we were able to travel outdoors to take photos of our experience with diabetes. Although at times we separated into smaller groups of two or three, we remained relatively close together. Participants did not form static groups, but interacted within and among groups. Because of the traffic noise and our constant movement, I was unable to record the session. Neither did we complete a *Reflections/Learning* sheet for this evening, but I took field notes and observations, which are woven throughout the text.

*Guidelines for the Creative Process*

The group was given a sheet with questions and guidelines: (a) Where do we want to eat for dinner?; (b) What do we do?; (c) How many pictures?; (d) What do we do with the pictures?; and (e) What do we do next? After deciding on a dinner location, I reviewed some of the guidelines as summarized below:

Just take pictures of anything – they may relate to what you did last time with your image, or it may just be something that strikes you that reminds you of your diabetes, or how you feel about your diabetes. Take as many pictures as you want.

With these guidelines, the group took pictures, which reminded them of their image specifically, or of diabetes in general. Agnes said, “This is fun. I’ve never done anything like this before.” At the time of our photo session, Harrisburg was having a Kite Fest, with temporary cloth and metal kites exhibited in the center of the city. Many

of the participants talked about the kites as we walked, and incorporated the kites into their images of diabetes.

### *Observations of the Session*

Sophie said, “These flowers look dried and dead. I’ll take a picture. That feels like diabetes.” Roberta seemed interested in the textures of the sidewalk, and the stone of the buildings. Agnes took a picture of a home security camera lens, which also looked like her circular “eye,” while I took a photo of the dried, crackling paint next to the doorbell. The owner of the home came to the steps as we were taking photos on his landing, so I briefly explained to him the purpose behind the research and apologized for any inconvenience.

Roberta asked, “Where’s Daisey? She was right behind us,” and went back to look for her. Daisey was quiet during the evening and often walked by herself. We kept “losing” her. One participant asked whether anyone else was on medication for depression, because they heard that depression was common in people who had diabetes. Three other participants that evening said they had either taken medication for depression, or were currently on medication. Coral kept the group lively with her laughter and talked about her pottery to be displayed at the upcoming Hummelstown (local) craft show. When it felt like people were slowing down and taking less pictures, Agnes said, “Should we go have dinner?” The group said, “Yes.” Daisey had another commitment, so she was not able to stay for dinner. Before she left, I reviewed two areas for consideration.

First, because this was an action research process, I checked with the participants to see whether they felt we needed more sessions to create other images and ways of

expression. The participants responded that they felt the creative process was “finished” for now, but that they wanted to continue to get together from time to time for dinner. Friendships were beginning to form around the common experience of insulin-dependent diabetes.

Second, the work we had done to date focused on group work, and I offered an option for individual expression of creativity. Each participant could choose to work individually on a creative project that reflected the experience of diabetes and personal interests, such as beading, pottery, writing, or gardening. Each could share the expression of creativity with the group at the final meeting, or share it with me during the final interview. Although it was not mandatory for them to build upon what we had done in the group, I encouraged their participation in making meaning through individual, creative forms.

### *Dinner Conversation*

As the pictures were not available for viewing that evening, the participants e-mailed them to me over the next few weeks. These photos are described and analyzed in a later section of this chapter. After discussing our meeting time and place for the final group session, Roberta, Agnes, Coral, Sophie and I met for dinner. We chose a metropolitan, contemporary restaurant in the center of downtown Harrisburg. The dinner itself allowed some unstructured time for participants to become better acquainted and to allow their “relaxed” identities to emerge outside of a classroom environment. Most of us ordered diet coke or diet iced tea, with one participant ordering a glass of wine. Although we could take extra units of insulin to balance the sugar in a regular soda, I observed that none of us chose to do that. Roberta said, “Why drink your carbs when you

can eat them?” At the end of our meal, none of us ordered a dessert, although, again, we could have taken a bolus of insulin to cover the extra carbohydrates. Perhaps we didn’t order dessert because it was getting late, or because we didn’t want to look “bad” in front of other people with diabetes.

The dinner conversation centered on our insulin pumps, which models and features we had, and the difficulties with infusion sets. Roberta said her pump became clogged when she tried to use one particular style, and I commented that I had the same problem. Agnes shared what life with diabetes was like before glucometers and disposable syringes. Sophie also talked about her experience with diabetes over the past 40 years. Agnes, Sophie and I reminisced about using urine tests to check blood sugar levels, and we laughed about how difficult it was to tell the various shades of tan. Sophie said, “Was it orange, or was it tan? Who could tell?” The conversation moved into discussions of friends and family, such as how many children we had, what they were like, and what difficulties we faced during different stages of our children’s development.

Overall, the conversation in the group replicated the content of the individual initial interviews. The group shared “safe” topics, getting to know each other, and finding commonalities within life experiences. Interestingly, we did not discuss the progress of the research or the photographs we had just taken. The dinner was a chance for participants in the group to get together and share about their diabetes and their lives.

### *Session Three: Sharing of Photographs*

Creating images is one way to expand our understanding and make meaning of many life challenges, including chronic illness. Through the use of photography, we were able to capture the meaning of diabetes at a particular moment in time. Each

participant sent her photograph(s) to me, noting which photo reminded her of diabetes the most. Although the participants had taken a total of 47 photos, I had the eight “favorite” photos processed and mounted onto white paper. The photos would be the focus of discussion for this third and final meeting with the participants as a group.

Roberta was not able to make it to the meeting, but gave her permission for me to share her photos and her comments about others’ photos with the group. We began the session with my thanking all the participants for being prompt in sending their photos, and distributing duplicates of the photos which the participants had taken. Agnes commented that she had difficulty sending me this picture, and that her selected image seemed to have cropped the satellite dish off the top. This will come into play later, as it was important to her explanation of the relationship between the photo and her diabetes. All of the participants began talking about their pictures in side conversations, and then took turns discussing the different noises their insulin pumps made. Daisey joked that hers sounded like, “Mary Had a Little Lamb.”

When the conversation quieted, I explained that eight pictures were displayed on separate tables around the room. The following table (Table 3) below provides a summary of the eight selected images. Paper, pens, and crayons were available at each photo station. The participants were asked to write a phrase about the meaning of the picture. In other words, “What did the image mean to them?” Participants moved around the room from photo to photo in any random order, and sat down in their seats when they were finished. When all were seated, I asked how they would like to proceed with the sharing of their photos.

**Table 3.****Summary of Selected Images and Photographs**

Participant	Initial Image	Figure #	Title of Photograph
Agnes	Eye	2	Watching Eyes
Coral	Steps	3	Friends
Daisey	Potato Head	4	The Spot
Heather	Snake	5	Dry
Emily	Red "X"	6	Danger Flower
Roberta	Ticket	7	The Key
Camilla	Broken Heart	8	Underwater
Sophie	Wedge	9	Metal Kite

Daisey suggested that we should start by hearing what everyone had to say about one photo, and then having the owner of the photo talk about its meaning. We agreed, and began with Agnes's photo (Fig. 2). Emily needed to leave shortly after we began this part of the session, but she left her comments with me to read.

*Watching Eyes*

When she initially wrote about her image (p. 10), Agnes said "You must keep an eye on the clock," so Agnes took a picture of a clock and a satellite dish, which represented her eye shape and "watching" over her diabetes. She said that she had the image of a circle in her mind. The circle represented the clock, but when she looked at the picture again, she saw the satellite dish at the top of the building. After reflecting on the meaning of the photo, she noticed that the clock was old, 19th century design, and the



*Figure 2. Watching eyes (Agnes).*

satellite was new, 21st century. In the 19th century, she would have died at age 16, but in the 21st century, “she stands a much better chance of wellness and, perhaps, cure.” She had one feeling when she took the photo, and another when she examined it more closely. This shifting interpretation is an example of the multiple, fluid meanings of a constructive postmodern view.

The central feature of this photo was the clock. Coral commented that the clock counts down time, but “I didn't really get into too much detail.” Daisey said the clock reminded her that it was time to start taking care of herself, and that “when you have diabetes, you live by the clock.” Emily said she wanted to make the most of her time, because time keeps ticking. Because the time on the clock was 5:05, I said that it reminded me of when I had to eat dinner at the same time, and that I've always had to abide by that clock, the clock that rules us all. Camilla wrote, “It's time for me to check my pump. It's time for me to check my sugar again.” The point at the top of the clock represented the laser beam that entered her eye during recent diabetic retinopathy surgery. She said it hurt so much that, “You know, when I was sitting in the chair, my hand was at testicle level, and I just wanted to squeeze.” The group laughed, but I sensed



that we all feared the pain of laser surgery, and a greater fear of blindness. Whether we realized it or not, we were talking about the “eye,” which was the initial image that the clock represented. Sophie said the clock reminded her that it was always time to test or do something, and it was not fun having to be time-sensitive.

### *Friends*

Coral chose the kite because of the bright colors and the “group has become closer as friends.” Before participating in this study, she didn't know anyone with diabetes, and no one in her family had it or understood the disease, so it was “nice” for her to talk with the other participants and hear what is “normal.”



*Figure 3.* Friends (Coral).

Daisey said she “got a positive feeling” from this photo, because she thought of friends helping her grow and looking at the bright side of things. Emily said the kite helped her appreciate all her friends who try to understand, and then named those friends. I wrote that:

Friends keep us together, and they keep us alive and yellow. My purple friend gives hope, the blue gives faith, my pink friend fills my life with energy, and the orange one brings inspiration. I know I can do it.

Daisey wished that she “had even a yellow friend,” followed by more laughter from the group. Camilla commented that she doesn't have friends that look “this happy.” Daisey replied that this was a “nauseating” picture. In this spirit of laughter, Coral, the owner of the picture, apologized. Many of the participants in the group said that the picture reminded them of Coral, who is “Miss Upbeat” and positive. Roberta wrote that the kite reminded her of freedom and flight.

Camilla said that her sister was one of those friends in the kite, but that the photo was like the people in the group to whom she has connected. Sometimes she feels that some of her friends “fly higher” than she does, because she is left behind checking her blood sugar. She feels like something is always weighing her down, so she considers herself the tail of the kite. Sophie said, “My phrase reminds me of Barney, or another children’s show” because she wrote, “Friend’s kite. Nice. Like the people in this group.” Everyone laughed. Agnes called her poem, “The Crayola Kite,” which read, “Happy daisies. Friends. New, fresh colors and old lamppost.” It was interesting that no one noticed that the kite was tied to the post, and was not flying freely. Instead, the focus was on the bright colors and the images of flowers and friends.

### *The Spot*

Daisey took this photo of “The Spot” because it represented her spot of tissue buildup at her injection sites, which is the “only issue I feel every day.” She said, “Every day, 24 hours a day, I make the decision as to whether I want to be healthy and live with

the spot, or be unhealthy and not have the spot.” In the past, she would purposely keep her blood sugar high and not give herself insulin so she could stay thin and not have scar tissue. There is hardly “anything written about it,” but the scar tissue comes as a reaction



*Figure 4.* The spot (Daisey).

to insulin injections. She said, “I don’t know if I’m super sensitive, or I just abused the areas that I’ve had for so long ... or if I didn’t move it [the sites] around enough.”

Pointing to the one-way sign, Daisey then said, “The good news is that there’s only one way, and it is the healthy way.” Agnes asked if Daisey was taking a picture of “The Spot,” or the one-way sign. Daisey said, “It was about the spot, but the one-way sign happened to be there.” Sophie replied, “It is our subconscious at work.”

This photo of “The Spot” is a familiar fast-food restaurant in Harrisburg, most notable for its hot dogs and 24-hour breakfasts. Roberta wrote that “The Spot” was filled with childhood memories, celebrations with food, and happiness. At the same time, it reminded her of grease and carbs. Daisey’s photo gave me a completely different impression, reminding me of the spot where I give myself injections, where the insulin pump enters my skin. I wrote, “It brings me to that spot that I hate. That spot. That dark spot within myself that is cold, clammy and unexplored. Don’t touch that spot.” Coral

commented that she “can't write like that,” but wished she could put her thoughts into words better. I reminded her how well she creates pottery, and that sculpture is not my natural talent.

To Camilla, “The Spot” photo was like time, as in time to check her blood sugar. She thought it was ironic that the word S-P-O-T had four letters in it, because she is “supposed” to check her blood sugar at least four times a day. It also reminded her of the circular marks that remain after pulling out her pump site. The group started to talk about the different types of sets they use in their pump. Sophie said it was “The spot. Sore spot. Shot spot. Testing spot. The spot.” Agnes added:

The spot. The spot. The fish, the subs, the spot. Orange marks the spot. And, they serve breakfast 24 hours a day. Too bad I can't eat 24 hours a day. But wait, with the pump I can eat any time of day, 24 hours perhaps.

Coral's thought was similar, because she commented how much she wants to eat, but she “has to watch her carbohydrate intake.” Coral seemed to always have something positive to say.

### *Dry*

I selected this photo of the blue water pipe because it represented living with diabetes on so many levels: physical thirst, mental fatigue, and spiritual longing. To me, it means:

Dryness, needing water, which is close, but not able to be reached. Knowing that there are dry spells, barren floors, my hope is dried up. Where can I get the water? Friends, a higher power, nature. Maybe I need to rely and have faith in the source. It will come. I am thirsty.



*Figure 5. Dry (Heather).*

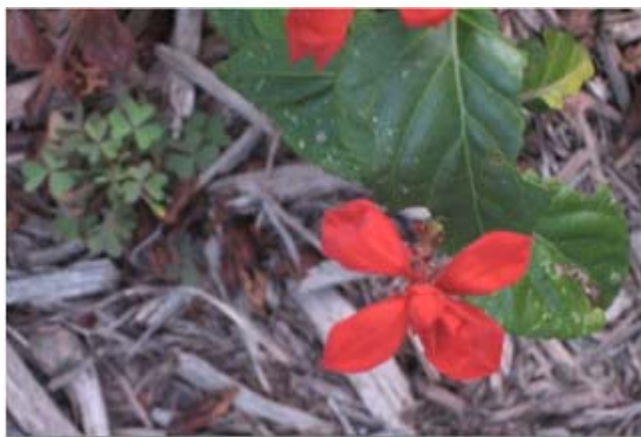
A couple of participants said this photo was the most difficult on which to comment. Camilla said the vibrant color blue reminded her of her pump, and it looked like a blood glucose meter with a drop of blood being inserted. “Unfortunately,” she said, “The blue is covered up with a black case.” It also looked like “Pac-Man,” who needs to eat the dots to stay alive, or a reminder to always drink plenty of water. Lastly, she mentioned that there was water inside the pipe, and she keeps a cap on her feelings and not let them out except, she added, “When I’m in this group.” Sophie focused on the “dried up, dead looking stuff,” and said it was dry around a water marker, but no water was available. Sometimes she feels totally spent, and doesn't have time to deal with bad feelings about diabetes. Sometimes she thinks it is “very trying” to talk about her feelings, but she feels exhausted because she “doesn't deal with things, keeping them internalized and prioritizing everything else.” She feels thirsty for relief, and not just “drinking” thirsty. Then she joked about the negativity of the group, again taking a positive spin and trying to escape her realization.

Agnes wrote, “Water, not blood. A way to get to the pipes, perhaps. What is the way to the blood? Needles, lancets, cannulas.” Coral said she saw water in the picture,

which represented thirst. She was always thirsty, even before she had diabetes, and she is twice as thirsty now. Sophie agreed that she is always thirsty, too. Daisy's interpretation was that the water was necessary for survival, as insulin is for diabetes. She said, "Water is healthy for you, but you don't always want it. We don't always use our natural resources even though they are right in front of us."

### *Danger Flower*

Emily chose the danger flower because it reminded her of her red "X" image and of the many decisions and crossroads that she experiences with diabetes. Although she participated in writing interpretations for everyone else's picture, Emily did not write one for herself. Sophie was surprised by this, as she said, "Emily seemed so compliant" and willing to go along with anything. Sophie thought Emily was showing a bit of defiance, but Camilla explained that Emily wanted to get to all of the other pictures before she had to leave, so she chose not to write about hers. Camilla said she avoided her own photo at first, too, but then came back to it.



*Figure 6.* Danger flower (Emily).

Some participants in the group had similar interpretations of this image, with the red representing blood. In addition to blood, Camilla thought the flower looked like an

“X,” which was Emily's intended image. Camilla said it also looked like a butterfly, if held a certain way. Butterflies represent beauty and a form of new life. Sophie started by writing, “Blood on life,” and then changed it to “Blood of life.” Agnes said it was a red flower, with clover or shamrocks in the background. It was a bright, happy picture for her, as well as for Coral, who thought it represented happiness and regrowth. Sophie commented that, “Some people are just too positive all the time.” Daisey said there was a contrast between trying to have hope among negative feelings at times. For her, the flowers were opening up, symbolizing trying new things. My interpretation was taken from Emily's meaning of the picture, so I wrote about the flower as a warning to keep out, or “X” marks the spot. The red represented danger or anger, yet the flower grows from the earth, and tries to be something else. Roberta wrote that the flower in the photo meant “loneliness, separation, and isolation,” and an overall sense of “survival.”

### *The Key*

Although Roberta could not attend the group meeting, she gave permission to share and discuss her pictures. She took the photo because the kite reminded her of “flight” and “strength,” and the keyhole meant that there “is a key to being whole with diabetes.” The key for her is to be positive.



*Figure 7. The key (Roberta).*

Camilla noticed that the photo of the keyhole did not resemble Roberta's initial image of a rectangle (ticket), so I showed other pictures of Roberta's of an actual parking ticket on a car windshield and rectangular shapes on a crosswalk (included in the following section as Fig. 15). To Camilla, the key photo represented herself, because there is a reflection of someone in the kite, broken in a "million pieces," as well as a faint image of a heart. She wrote:

Me. Inside. Shattered. Surrounded by people who love me. They want to help me, but they haven't found the right key to get me out. There are many keys, and I am shattered over and over.

Around the outer edge of the kite, there are metal keys molded into the sculpture. It was Camilla's favorite, because it represented diabetes and her life "the best." Sophie focused on the hole in the heart, where there are spaces (memories) missing that "make up people's hearts." Agnes came to this picture first, so she said she simply provided a literal description:

A kite with a mosaic heart painted on it and a large keyhole in the center. The keyhole appeared to be reinforced with silver, gold, and metallic rivets. The heart is surrounded with many keys, perhaps to the keyhole in the heart. Upon closer look, the mosaic heart appeared to be made of shards of a mirror and a face is reflected in one of the shards.

Coral was the only one who said she had the key to her diabetes, as she is the one who controls it. Camilla said she liked that Coral had the key, and not the doctors who "tell you what to do." Sophie said that these pictures would be good to use for marketing at the Penn State Diabetes Center. Coral commented:



Think about it. If we had to get a disease, not that we *have* to, thank God it is diabetes. Because you can control it. It's not like it's cancer. You try to do everything you can to control it.

One participant said she guessed we should be glad that we have diabetes, and not cancer.

This reinforced the theme in Chapter Four that focused on diabetes as “not that bad.”

Daisey said the reason we are in this group was to express how we feel about diabetes, and “We never do, because people are always saying, well, at least you don't have cancer.”

Coral said that even during family functions, people notice what she is eating. If she eats green beans, which is a “free” food, her family makes it into a green bean casserole and “totally destroys what is healthy. They just don't get it. Then when you twirk off about it every once in awhile, they think you're in a bad mood.” Sophie added, “Yes, and [if you're in a bad moor] your sugar must be low,” to which Coral responded, “And do you need to test?” Agnes added, “Are you supposed to eat that? Oh, God, how many times have I heard that!” Camilla said, “When they do that, I say ‘yep,’ and I shove a bigger forkful in my mouth. Or ‘nope,” and I just take 15 more units.” In sarcasm, Daisey's response would be, “I don't know. Are you supposed to be fat and eating that?” Coral remembered the first weekend she was diagnosed, and her whole family ordered pizza. She said:

I figured it out, and I could have two slices of the extra Thin-n-Crispy Pizza Hut pizza. Everyone just stared at me. I could have just flipped. Every bite I took, I thought they were looking at me. But, they're over that now.

Camilla said, “All this time, I thought I was the only one who hears this.” Coral said, “When we go off on our ski trips, the group says ... are you going to test your sugar? You’re a little testy right now,” to which she responds, “No, I’m just tired.” Camilla has a similar experience when she is disciplining her children and they ask, “Mom. Is your sugar OK?” Camilla replies, “No, my sugar is just fine. It is you.” Sometimes Coral uses diabetes as an excuse when she wants to be by herself. She says, “I want to go upstairs and test my sugar,” even when she doesn’t. Camilla uses her diabetes as an excuse when “little old ladies” ask whether she would like to buy cookies.

Back to the key, Daisey said “There are many pieces to the puzzle of diabetes, but what really is the key to living with it? Is it within our reach, and we just don't know it?” This was an important comment, because it shows that not *all* people find meaning in diabetes. Emily wrote, “It makes me think of a hole in the heart. A broken heart.” She sees the face in the mirror. I wrote:

This is the key to my diabetes care. I was always told that there is no key (cure).

They are glued to the side of the kite, but none of those keys is for me. There must be one. Maybe it is an illusion. Maybe the key is to look to the other side of the kite, to the sky.

To me, there is hope in looking upward. Hope beyond the key, and hope beyond the sky.

### *Underwater*

Camilla said her underwater photo looked like a heart, with arteries. She was not able to take pictures with us in session two, but took this photo at the Baltimore Aquarium. She chose this photo because “something has always weighed down my heart, which represents the rock.” Camilla saw her face in the rock, “sometimes happy

and sometimes miserable.” The marks in the rock looked like finger pricks. The rock also reminded her of her broken heart, sharing that her son had died after childbirth as a result of an unusual infection, leaving holes in her heart. Camilla said that may be one of



*Figure 8.* Underwater (Camilla).

the reasons she is a negative person because a lot has happened to her. “Maybe,” she reflected:

That is why I like the key and the heart picture, because it is a whole new heart. It has a hole there, but there are many keys to lead me in a new direction and to make better of everything.

She said that nothing could be worse than losing her son. Sophie responded:

Well, don't stay stuck in the shit. In fairness to your son, you'll never get over the pain, but you can't stay stuck there. You've got to move on, or you're going to tear yourself down. You'll be a pancreas with holes, which is what I saw in the photo.

Sophie continued, “You have all this joy and happiness, explaining that even though Camilla's insulin pump was bright blue, she had covered it in a black leather case. “It's time to take off that black and see the blue, because there is beauty there,” she

encouraged. Daisey said to Camilla, “Look at all that ... you’ve been through, but the key is *went through*, and you have survived.” Camilla felt like there is no way out, and that she is constantly crawling. She knows that she can control her diabetes, but the “fix sucks.” Daisey said, “It’s not a *fix*; it’s a management, just like insulin is not a cure.”

At this point, it seemed that others' interpretations of Camilla's broken heart would have diminished the heaviness of the meaning in her own interpretation, and I suggested that we continue to the next photo. However, the group wanted to stay with Camilla's photo and go around the room. Daisey said the photo reminded her of “Saving Nemo.” She feels like she is in another world all alone, trying to stay afloat. Agnes also saw faces in the various shapes and forms of the object underwater: a fern, fish, sponge, maybe even Jabba the Hutt. This comment lightened the tension in the room. Emily also saw faces in the mass. Roberta thought that the photo represented “confusion,” and was a “blob, waiting to be transformed.” Coral noticed that the water was clear and clean, not murky, meaning new advances in the treatment of diabetes are underway. When Coral was diagnosed in 1994, the insulin pump was a new advancement. Although the best time to get diabetes would be when there is a cure, she felt fortunate that she could take advantage of the insulin pump technology, and the research done with islet cell transplants.

As it was approaching our ending time, I asked the group if we could extend the session for another 15 minutes. All participants agreed, and we continued with the final photo below.

*Metal Kite*

Sophie took this picture because it struck her as totally indecisive. She said, “There's a lot of stuff going on here, and it is undecided. There are happy shapes like the swirls, and scary shapes, like falling.” She reiterated that she doesn't have time to think about her diabetes, and now “Heather is making me do all this thinking about it.” But, the face on the TV reminded her of people always watching “you,” or “you” are looking



*Figure 9.* Metal kite (Sophie).

out at people. The eyes are big, like when she is having a low blood sugar. The face is a startled look. When Sophie took the picture, she did not notice the steeple in the background. But, the fact that it was sharp and pointy reminded her of diabetes, where there are always sharp things sticking “you.” The steeple was a subconscious image that she did not see in her picture initially. The colors, like blue, attracted her to ideas of freedom and life. Agnes wrote about this photo in a poem:

Modern Art versus old church steeple

What's of the future, what's of the past?

Where did they join? Why did they last?

Will I have the metal? Will I be made like stone?

The face in the kite reminded Coral of a spaceship, so she interpreted the picture as being onward and upward, with all of us together. One participant said, “I don't know what kind of insulin she (Coral) uses, but I want some. It must be laced.” Daisey said she felt like people were always watching her, keeping her in line. She feels like she was always on TV, like the “Truman Show” and that nothing is ever a straight line with diabetes. It is always asymmetrical. Emily felt as though she were watching someone on TV, and the girl looked sad. I wrote:

Here I am, looking out from the kite, flying to the world. There are metal plates holding me down, yet blue sky calling me forward. Spirals of energy, taking me to Earth. I want to see the world through the many eyes of the kite. Through the metal, I see light. But, here I am in the box. At the bottom. Wanting to go up.

Camilla said it reminded her of her pump site. Because the kite is abstract, she asked, “Which direction am I going?” The girl in the kite looked like she was lying in bed with her head on the pillow and the covers pulled around her face. That led to Camilla wondering whether the woman was sick. It reminded her of the insulin pump picture shown earlier that evening (Fig. 1), because the facial expressions were similar. The cathedral reminded her of the piercing pain going through her eyes, and the swirls in the kite made her feel like she was going in circles. She wondered whether the doorknob represented her being trapped inside. The holes in the kite reminded her of her infected pump sites. Agnes asked how infected the sites could get, and both Camilla and Daisey answered, “Very. Stuff (like goo) can come out.” Roberta wrote that the photo looked

like it was “directional,” and going in multiple ways, which was the reason Sophie was drawn to the picture in the first place.

*Learning/Reflections of the Third Creative Session*

When everyone had a chance to share the meaning of the images, I explained the next steps of the final interview, and that it would include questions regarding what people have learned from the creative process, how they made meaning, and how it might have influenced their view of diabetes. We agreed that I would be in touch over e-mail regarding times of final meetings. The group wanted to hear *Dry Bones*, so I read the essay in its entirety. Immediately after reading, there was silence, and then clapping. Agnes said, “That was pretty neat.” Daisey said I might have been Medusa in another life form, because the snakes reappeared in *Dry Bones*. I explained that when I wrote *Dry Bones*, it was the first time I had expressed my feelings of diabetes, and the images were strong, harsh. My spirit believed that Yahweh, a higher power, is able to bring life. Through the use of metaphor and imagery, I was able to find *meaning* in my diabetes and communicate to others what diabetes felt like. Although I have presented portions of the essay at conferences, I had never read it to other people who had diabetes. Feeling as though my words were *understood* and *experienced* by others was more powerful than I expected. It felt like a force greater than myself, connecting the experiences of the group.

After *Dry Bones*, participants completed the anonymous *Reflections on Learning* page. Camilla was visibly upset, and she asked if she could complete the page at a later time. Before she left, I asked whether she was alright, and she said she wanted some time to be alone to think about her son and her diabetes. The evening appeared to have opened up those wounds for her. From the four *Reflections* sheets I received from participants,

everyone enjoyed being together, and the release of feelings facilitated by the creative process. One woman said:

What was good about the session, what has been good about them all – the comraderie (sic), the release, the friendship growing from the oneness the group members share from having diabetes. Diabetes is what brought this group together, but the uniqueness of each member has brought hope, release, sharing, laughter, joy and overwhelmingly, hope.

Another expressed that she liked sharing what others wrote and thought about the images of diabetes. One added that she liked to see others' photos, because it reminded her that "I am not the only one with anger and hurt." Because "all the walls were down," one woman added, "Everyone was open, honest and showed their emotions." She also commented on how descriptive and deep others were regarding the photos. These four responses focused on the importance of sharing emotions with others through this creative process.

For some it was challenging to share (or hold back) emotions. One woman wrote that it was difficult to share her photo and explain why she took it, because her photo represents an issue that she "keeps telling people is resolved, but it never is." It was hard for one participant to get started on writing about the pictures, and for another to know what to say about each image. My assumption is that the feelings of the image were more powerful than the literal words themselves. One participant found it challenging to not say what she thought to Camilla. She "needs to move on from her loss and pain or it will certainly kill her." Through the use of imagery, during the session, Camilla did



move from the image of the underwater, sunken heart to an image where there are keys to help in the healing process of her heart.

One participant said she is wondering if the issue of body image and anger over it hides other feelings about diabetes. She said:

I am still not healed from my bout with scar tissue in 7<sup>th</sup> grade and being called ‘tennis balls.’ I remember at camp that all the girls on pumps were fat, so I refused to go on one [pump] due to this.

This evening, she learned that the self-conscious says “a lot about which we are not aware.” Another woman mentioned that she has

Come a long way since I was 15 and first found out I was diabetic. I never thought at that time that I would live this long, but I’m still here and so far in ‘OK’ kind of health. Maybe I’ll make it until there is a cure and then *be* cured.

She enjoyed being with the group again and talking about the images together. These eight photos represented the feelings and powerful experiences of diabetes through group interaction and meaning making.

#### *Further Construction of Meaning through Images*

The ten photos below were not chosen by the group as their “selected” image, but they deserved attention for their metaphorical power and further construction of meaning. As Dirx (2001) said, “Images are gateways to the unconscious, and our emotional, feeling selves” (p. 66). As clay is molded for an art form, or sound is cultivated in the production of music, these photos elicit a visual response to bring further meaning and interpretation through the dynamic relationship between the photo taker and the photo itself. The photos, listed on Table 4, generate further discussion, powerful feelings, and

new images of the experience of diabetes, which cultivate the construction of meanings. Because these images were not chosen by the participants as their “first” or “favorite” choice, the descriptions which follow are my interpretations of the photos.

**Table 4.**

**Summary of Additional Images and Photographs**

Participant	Figure #	Title of Photograph
Agnes	10	Chained
Daisey	11	Feeling Dammed
Daisey	12	Hiding Behind Shades
Roberta	13	Caged
Heather	14	Unnatural
Roberta	15	End of the Road
Coral	16	Lancet
Heather	17	Range of Blood Sugars
Roberta	18	Running out of Time
Heather	19	Snake Bookmark

As there is not one, *right* interpretation, or even *one*, singular interpretation to these images, I invite you to actively construct your own interpretations of the photos. The photos are listed in random order.



*Figure 10.* Chained (Agnes)

This photo represented Agnes's circle image, a bicycle chained to a tree. The bicycle tire was once free to roam wherever and whenever it chose; now it is chained to an insulin pump, and a regimen of diet, exercise and food. The tree is trapped in the ground, wanting to grow and explore, but it must think always of where to get blood sugar supplies, insulin, and must not wander too far from a doctor or from medical benefits. Having diabetes makes me feel like I need to take the "safe" road and be responsible, planted firmly in the ground. From the experience of having diabetes, I have learned to grow strong, yet within the boundaries of what I can and cannot do



*Figure 11.* Feeling dammed (Daisey).

Although difficult to see in this photo, there are a number of branches stuck at the foundation of the bridge. This dam along the Susquehanna River describes the feeling of being closed or congested. One moment, life seems to be flowing easily and smoothly, and the next, there is a feeling of being blocked. Not only does Daisey feel dammed with her feelings of self-image and scar tissue, but perhaps also dammed with a life of insulin injections and complications.



*Figure 12.* Hiding behind the shades (Daisey).

Daisey had mentioned that she hides behind shades, and wants others to think that she is alright. This was also a feeling expressed by Sophie and Camilla. She has a difficult time expressing her feelings to others and finds it hard to let people in, free to see who she is, without the mask of sunglasses or a costume.



*Figure 13.* Caged (Roberta).

While in meditation, the image that came to Roberta was that of a rectangle, a box or a ticket. This caged box on the side of a house describes what life with diabetes can feel like, caged with no escape. Once a diabetic, always a diabetic. Life with a chronic illness can be limiting. There are metal bars guarding us from the cure, unable to be reached or accessed. We are caged.



*Figure 14.* Unnatural (Heather).

This is a picture which I took, and it represents the day of my diagnosis. I labeled it “Unnatural,” because having diabetes meant I would need to take some form of insulin injection every day for the rest of my life. I must avoid sugar. I might go blind when I grow older, or lose my kidney function. These things are unnatural, especially as a young child, represented by the bright orange slash of death.



*Figure 15.* End of the road (Roberta).

This is a path, taken by Roberta, which is unfinished. Its path is uncertain, but it leads us step by step on the journey of living with diabetes. This is one of the pictures which was briefly shared with the group (refer to p. 33). Camilla had said that the crosswalk could have represented a path or a journey. The photo reminded Daisey of Kelly Clarkson’s song, “Because of you (I never stray too far from the sidewalk).”



*Figure 16.* Lancet (Sophie).

Sophie took this picture as a symbol of her image, the wedge. It could also represent a lancet, used many times a day to pierce blood from the fingers. The lancet is larger than its normal size, towering with the trees. Taking blood sugars can become overwhelming, and seem to be a “bigger deal” than what they actually are.



*Figure 17.* Range of blood sugars (Heather).

This was a comedic photo I took from the office numbers of a building in Harrisburg. The reason it relates to diabetes is that these are the range of blood sugars on a “bad” day when diabetes is uncontrolled. Numbers can range anywhere from 205 to 401 in a short period of time.



*Figure 18.* Running out of time (Roberta).

All of us with diabetes had the fear of death, as a theme in Chapter Four. This photo demonstrates that fear of running out of time, as there are seven minutes left on the parking meter before it “expires.” We continue to give ourselves insulin as coins to keep the meter fed.



*Figure 19.* Snake bookmark.

This is the only photo which was not taken with the others during the second session. While keeping occupied in the checkout line at Borders bookstore, I paged through bookmarks. One that immediately caught my attention was a light purple bookmark, in the shape of a wave, exactly like the image I have previously drawn. I shared this bookmark with the group. Daisey said, “Wow,” and Agnes said that it was even the same color purple. Inscribed on the bookmark was the word, *faith*, which held a

message for me. Daisey mentioned that my shape looked like a pathway. Since this study, I have been noticing that I am drawn to the shape. Approximately one year ago, I designed a stained-glass window, which had a light purple ribbon through it. Ironically, it is also in the shape of a wave. The participants in the study said the shape held a religious symbolic meaning of *resurrection*. At Easter, Camilla, Sophie and Daisey said the ribbon symbolizes a new beginning.

### *Individual Expressions of Creativity*

In this action research process, the participants were given the option to express themselves not only in a group, but also individually. They were not pressured or required to create something, but it was an opportunity for individual expression. During the initial interview, some of the women said they enjoyed creative activities such as quilting, pottery, writing, beading, kayaking, and singing, and they were invited to bring these, or other, individual expressions of their diabetes to this study. They had the choice to share them during the final group session, or with me, during our last interview. Two women chose to participate, by sharing the following forms of creative expression with me: (a) a beaded bracelet from Emily and (b) a pottery vase from Coral.

Emily enjoys creating beaded bracelets and necklaces for her friends, and selling them at local art shows. She made this bracelet specifically for this study, and it expresses her experience of diabetes. Emily's beaded bracelet is pictured below (see Figure 20). Emily described the bracelet to me as, "Ugly. I just don't like it." She said, "Usually I like to have things in a pattern, but this doesn't. I put that [the believe pendant] on there, because it's for diabetes." She chose a pendant with the inscription, *believe*, because "you want to believe in a cure."





*Figure 20.* Beaded “believe” diabetes bracelet.

Emily showed me another bracelet that was patterned two large beads, two small beads, symmetrical and colorful. However, the colors in her “diabetes” bracelet didn’t “go together.” When she created the bracelet, she said “I didn’t like how these two colors didn’t match, so I kept putting ones together that didn’t match ... and I never put two of the same ones together.” I told her that the colors reminded me of diabetes, because she could have chosen brighter colors, like red or bright blue. Instead, she said, “they’re boring, plain colors.” The colors reminded me of those someone might find in a hospital. She said, “Uh-huh. Like a waiting room. It kind of even matches the carpet.” Based upon the meaning of her beaded bracelet, Emily’s diabetes is unbalanced and irregular, and feels boring and plain.

Coral owns a pottery shop, and often displays her artwork at craft shows. “One day,” she said, “You can mold the clay, and everything works out perfectly. The next time, it could all fall apart.” The same is true of diabetes. As Coral said in her initial interview, “You can’t force the issue. You just have to roll with it.” The vase is not molded in perfect symmetry, with one side unequal to the others (see Figure 21). The



*Figure 21.* Diabetes pottery vase

wavy edges represent the “ups and downs” of diabetes, and Coral glazed the vase purple, which is my favorite color. The vase was both a gift to me, and an expression of her diabetes.

#### Chapter Summary

In summary, the images included in this research demonstrated the many ways in which adults with insulin-dependent diabetes express their experience and meaning of living with a chronic illness. Through the use of photography and social interaction, we were able to communicate images, and reflect upon those subconscious parts of our selves of which we were previously unaware. Words alone cannot tell the story of diabetes. Through the use of creative expression through imagery, we will begin to find greater meaning in the experience of diabetes and help others understand the difficulties, and positive experiences, in our meaning-making process. The next chapter describes the findings of the final interviews with individual participants.

## CHAPTER 6

### FINDINGS FROM THE FINAL INTERVIEW

During the final individual interviews, participants reviewed the five themes of the initial interview and their introductions. They also responded to several guided questions about the creative action research process. What did they learn about their diabetes by using images and photographs? What did they learn from each other? This chapter is organized around three main findings of the final interview: (a) their glucose numbers as a part of diabetes care, but not the whole; (b) further meaning making of images and photographs over time, and (c) the multifaceted aspects of learning and meaning making. My own learning experiences are primarily included in the conclusion to Chapter Seven, although I discuss some of my meaning making experience through image over time in the discussion of the second category to set the context.

Although not a theme in itself, one interesting finding was that none of the participants said they wrote down their blood glucose numbers for better diabetes management, even though they knew their glucose control was an important part of their overall health. The section below describes our conversation related to this finding and helps to answer the question “why?” by discussing blood glucose numbers as a part of diabetes care, but not the whole of the experience with diabetes.

#### Numbers as a Part of Diabetes Care, but Not the Whole

Knowing why participants are reluctant to record their blood sugar results for diabetes management is an important question for practitioners to answer, as improving blood sugar control reduces the risk of complications and improves overall health. The

findings are listed below under two separate categories, although they are interrelated:

(a) “They’re just numbers:” Looking at the part; and (b) “There’s more to diabetes care than numbers:” A holistic approach.

*“They’re Just Numbers:” Looking at the Part*

Measuring blood sugar regularly can prevent low blood sugar at night and help people with diabetes make informed decisions about the amount of insulin to calculate for injection. Writing down blood sugar results helps them understand the effects of certain foods, exercise and stress on the body. Using the blood sugar results to keep levels balanced and normal can help determine patterns of fluctuation in blood sugar and reduce the risk of eye, kidney, blood vessel and nerve complications). In a medical visit, patients typically are asked to share their blood sugar record sheets, like the one below in Figure 22, to detect trends in high and low blood sugars and make recommendations for adjustments to insulin or diet (Diabetes Center of Excellence at the University of Florida, 2006).

<u>Date</u>	Medication	Before Breakfast	After Breakfast	Before Lunch	After Lunch	Before Dinner	After Dinner	Bedtime

*Figure 22.* Blood sugar record sheet.

All of the participants expressed difficulty with writing down blood sugar results, as mentioned in Chapter Four, ranging from just being “tired” to “hating” to do it.

Although they recognized that checking and recording blood sugars was part of their diabetes management, it did not constitute the whole of who they were as a person or the whole of their care. From a constructive postmodern perspective, their relationship with

diabetes was constantly shifting from the foreground to the background with the monitoring of blood sugars being a part of that shift. Numbers within the range signify better glucose control and lower risk of complications, but Camilla said “they’re just numbers” to her, and her whole life consists of numbers:

How many kids do you have? What’s your Social Security number? What’s your driver’s license number? I need your telephone number. What was your blood glucose? What’s your license plate number? How many years have you been married?

Sophie realized that “numbers are so important to being a diabetic,” but, she asked, “Who has time to write down the numbers?” She said she just has to “live and adjust as she goes.” If she’s trying to be “diligent” and reach a certain goal, she will write down her numbers. She commented that her goal is “to stay alive with the least amount of impediments possible.” She realizes that living with diabetes is an ongoing disease, and writing down her numbers is not part of her usual routine. Later in the interview, Sophie said that although she doesn’t write down blood sugars, “I feel darn guilty about it. I should.”

When physicians and educators ask Emily for her numbers, she feels like they are grading her. This makes her feel younger than she is because “they have to check my numbers.” She said:

You know, part of it makes me feel like it’s one of those homework assignments that you get, but you don’t really want to do. Then if you don’t do it, they’re even more disappointed. ... I hate writing the numbers down ... When I was in college, it felt like an extra essay. You know, now it feels like an extra job.

Specifically, she remembers when she was in grade school and she would be disappointed every time she would write down a 300 or 400 read. She felt like she did something wrong. To avoid getting into trouble, she would “round down the numbers, so 301 turned into 210.” The numbers became the focus. She said, “It’s not like they [medical professionals] didn’t know. My A1C was 10.5.” They would tell her that her blood sugar records didn’t match her A1C, and would ask her why. Emily would reply, “I don’t know.” Despite that she “hated” writing down her blood sugar results, she always wanted to give the physicians something, so she would do it. Now that she can upload her numbers to the computer, she said, “I will never write it down again, ever.”

Camilla resented physicians’ focusing on her numbers. When Camilla was younger, she would “make them up,” writing down the results in the exam room. She said she got to the point where she didn’t care if she had her numbers, because at least she showed up for her appointment. Daisey also said she didn’t write down her blood sugars. Sometimes she didn’t even test or she “made up her blood sugars” when she did give them to the doctor. Her reason for not writing them down was that:

If you don't write it down, it doesn't exist, and you don't have to mentally deal with it. You don't have to feel anger; you don't have to feel guilt. You know.

You don't have to get scared because you're like 400.

She said that she was never allowed to forget she had diabetes, because her parents were always asking her if she checked her blood sugar. She would make up her blood sugar numbers for her parents and her doctors, even though this didn’t help her own glucose control. When her physicians or educators made adjustments based upon her numbers, Daisey just “didn’t follow their advice” because she knew that her results were false, and

“if I really followed them, I would get further screwed up.” She also wrote down her blood sugars because she didn't want to feel guilty, and she didn't want to hear that she didn't do it. She said:

I was like, here you go. They would say, ‘Gosh, these don't make sense at all. I don't see a pattern at all.’ A lot of times when I feel like my blood sugar is high, I just crank it in and I don't even test. Of course, they don't make sense.

By just looking at the numbers, without considering the spiritual, imaginal, somatic and creative aspects of the experience of diabetes, attention is placed on the rational side of self. When we open up the space of our spirit-body-mind to incorporate multiple ways of knowing, we can begin to express more fully who we are, and how we know and learn. In the next section, participants made recommendations for practice, including attention to the affective and creative ways of knowing as a holistic approach to diabetes care.

*“There's More to Diabetes Care than Numbers:” A Holistic Approach*

A holistic perspective does not contradict the medical view in bringing emotional, somatic, artistic and spiritual dimensions to learning. Rather, it complements the biomedical view by focusing on not only the sickness and the symptoms themselves, but the whole of the person. Overall, participants were pleased with their diabetes educator and care which they were receiving, but thought the affective component was missing in general in diabetes care. Daisey said, “it's the emotional component that is being missed.” Sophie added that there was “more to diabetes care than numbers,” and, like Daisey, she thought the “emotional component is lacking in diabetes care.”

More compassion and personalization are ways to incorporate more of the affective dimension of diabetes to clinical appointments. However, there is a larger systemic issue of how to devote more time to patients' emotional and psychological needs when there is a demand on the physicians and educators to see more patients in less time. These two areas are discussed below.

#### *More Compassion and Personalization at Appointments*

Rather than just asking, "How are you today?" Agnes prefers medical staff who are more inquisitive and compassionate. She likes the current diabetes educator's method of interview, because the educator takes time to explain things and "goes through a list of questions to remind me if there is a problem." Agnes said:

You end up thinking more about what you really *feel* like, because she [the educator] goes to that point in her questioning. I think about it. I like that. I think she ... makes me feel less guilty ... than many doctors in my past experience ... Many of them just kind of yell at you almost, but she gives you the tools rather than just getting on you.

For Daisey, it is also important for medical professionals to "just give an aura of understanding, be nonjudgmental." She gave an example of how this might look in practice:

The patient comes to you and says, 'You know what, I'm making up all my numbers. I really don't care right now about myself. I lost my job, and I'm not testing.' It's important for them [the medical staff] to not be like, 'Well, that's totally wrong. You need to test' and [instead] they would say, 'Wow. I could really understand the stress you must be under right now. Is there anything I can



do to help you to get back on track?' ... not that finger-pointing, because that's what really makes us make up our numbers. Let's face it. It's being afraid of getting yelled at, or having someone look at us going, 'Why are you doing this?' The whole judgment of it all.

Daisey also thought that personalization in diabetes care is important. In reflecting on her experience in the study, she suggested using creative expression is one way. She said, "To personalize the definition for people. It makes diabetes personal. Even though there are common themes, there is still going to be something different about everyone's experience and definition of diabetes." We discussed how breast cancer and other chronic illnesses are personalized with pink ribbons and pink bagels (like Panera Bread's bagel to commemorate National Breast Cancer Awareness Month), but Daisey has only seen:

One or two posters about the diabetes walk. They don't think it's a big deal, because it can be something that is physically managed. They figure if you can live with diabetes, then it's not that big of a deal. They allow that [breast cancer] to be a personal story, a personal journey, but yet diabetes is just cut and dry. Just manage the physical symptoms, and that's all you have to do. Other diseases, like HIV and congestive heart failure, have a huge emotional component, but diabetes never seems to have that emotional, personal side.

To bring in the personal side and include more of the affective ways of knowing in practice, Coral, probably because of her experience in the study, suggested she would use creative expression to communicate the experience of diabetes. She also thought the

use of creative expression by the nurse or educator might help the physician focus more clearly on what is important to the patient. She described the process like this:

I mean, could you imagine going into the diabetes clinic and the nurse would say, 'Now, I want you to draw a picture of where the pain is.' And [the doctor] comes in and says, 'What did you draw?' That could expound things, too. It really could. A lot of times, and I love them [the medical professionals] to death, they're like, "How are you feeling? How are your sugars?" And they're out the door. He's a fabulous doctor, but their time is limited. But, maybe by having the patient doing something like that, maybe that would help.

At each appointment, Camilla recommended that medical professionals "focus more on the positive," and attend to the way she knows and learns by "explaining things more." She said:

The big thing is try to be compassionate. Try to remember that they [the patients] are normal people with feelings, also. Don't tell them they can't have something. Explain to them that it's probably not best for them to have it, but if you feel like you need that piece of pie, it's okay. Just take three or 3.5 units for it.

She said if she ever walked out of her medical appointment "more positive or better, that would be ... wow!" She went to appointments, thinking that her A1C would be "so good," because she was feeling great, and then she realized that she wasn't "doing as good of a job as they want us to do." Camilla said:

It is always up to *us*. *We* have to test our sugars. *We* have to give our insulin. *We* have to give our bolus. *We* have to make ourselves feel better.

In an ideal appointment, patients would leave feeling more motivated to take care of themselves and better about their diabetes because they visited their physician, nurse, or educator. Rather than being labeled “uncontrolled” or “non-compliant,” Camilla hoped that the medical professionals would take the time to say “good job” and focus on one thing she is doing right.

### *Systemic Need for More Time*

Lying underneath the surface of these recommendations is the need for more time, which is a larger, systemic issue within medical care. Daisey was not sure the current system is set up for addressing larger issues than just diabetes numbers, because it “would take a lot of time. It’s not something you just mention at a visit, talk about, and go on your merry way.” Emily also said that there were limitations to the current system. She is a special education teacher, and understands her role as a teacher is to teach the children. She related this to the role of the physician, whose job is to keep her healthy. She said:

It’s not that I don’t care about my kids, but I’m there to teach them, whether it be about making friends, because some of my kids aren’t socially like their peers, or whether it’s to teach them math skills and language arts skills. I’m there for them to be their teacher, which doesn’t mean that I don’t care about them, because there are things that come up and they’re having a bad day, and I will talk to them, because they know I care. But I can only care so much because I have 11 kids. If I’m there to teach them, and I’m the constant in their life to teach them, that should be enough to make them feel good about me being their teacher. And they know I care because I’m there all the time. And I’m there to teach them.

This was an excellent and challenging point. I asked Emily, “If a child is having a problem, or is not dealing well emotionally with school, where should he or she go?” Emily said “they could go to their guidance counselor, or the nurse, even if they don’t feel sick ... parents, if they have both or one. Siblings. Friends.” In diabetes care, we have similar models of support, but many medical offices do not have someone to fill the role of guidance counselor or emotional support. There is a teacher (the physician) and often a nurse, but there is not a supportive role within the diabetes system — a person who can take the time to ask deeper questions and has the skill to listen and walk through the patient’s emotional and psychosocial concerns. Daisey said that she “would not expect them [physicians] to be a counselor, or anything, because there’s not enough time to do both that and work on the diabetes numbers.”

Before this study, Sophie didn’t “think about the mental component of dealing with diabetes,” but emotions are important. She said it is important to engage her body, make time to take a deep breath, and:

Just breathe with this. Just take a deep breath and just relax. How do you feel about it? It's like you're always, do this, do that, do this, OK, do this. Once we’re done with those things, OK, quick, tell me how you feel.

From the participants’ comments, it was clear that diabetes is more than just a focus on the numbers, but it also involves a deeper, emotional component which is currently not addressed. The medical profession’s role is a balance between attending to a patient’s medical needs as well as psychological needs. Patients are seen, at most, four times a year for their diabetes care. Between visits, patients need to remain motivated and diligent in trying to take care of their diabetes in the best ways they know how. *Both*

education/knowledge to manage their disease *and* the motivation/meaning to sustain better health are needed in a holistic view of patient care.

There is a systemic issue of not having the resources to provide enough time to fully address emotional issues of diabetes during clinical appointments, as well as a lack of attention to the affective experiences of patients with diabetes that are not integrated into current practice. These are important concerns to discuss, and recommendations for practice are included in the final chapter. To continue with the findings of the final interview, the next section moves into the further analysis of the meaning making process of the actual images and photographs, and the ways in which meaning can be constructed and reconstructed.

#### Further Meaning Making of Images over Time

As discussed in Chapter Two, one of the ways knowledge is constructed and reconstructed is based on learning through the search of personal meaning making as well as in the social construction of meaning. Because I construct meaning through the use of metaphor, as in *Dry Bones*, I wanted to use a metaphor that would help structure this chapter and communicate the findings of the meaning making process.

As I was visiting a co-worker's (Becky's) office, I noticed a framed picture of multi-colored stones on her wall. Immediately, I saw the multiples layers and ranges of colors in the stones and the different meanings the word, "stone," could have. At the time, it struck me as a way to talk about levels of meanings through metaphor, and I asked if I could borrow her picture for a few days to include it in this dissertation. What caught Becky's attention were the different veins throughout the stones, which I did not see initially. I explained how her comment related to the metaphor of meaning and

understanding shifting over time, and how multiple levels of meaning are embedded within contexts.

After working with the findings of the data in this study and trying to work with other metaphors, this one (see Figure 23) seemed to most relate to the way meaning is constructed through images and how that meaning shifts over time. The meaning of the images and photos to the participants also continued to develop, deepen and expand, particularly as they interacted with each other in a social process.

As both a researcher a participant in the study, my constructive postmodern and feminist poststructural perspective emphasizes the social construction of knowing, and that the knowing cannot be separated from the knower. The researcher affects the data, and the data affects the researcher. Through that process, meaning and identity are constantly shifting, deepening, and being challenged by multiple interpretations of what is “right” and “true.” Although the study primarily focused on the other participants, rather than my meaning and construction of knowledge, I am going to begin by using an image of my own process of making meaning of these findings over time, and then move into a discussion of the participants’ meaning of their own images. The following two themes were developed using the metaphor of stones to further illustrate the construction of meaning and knowledge.



*Figure 23.* Multiple layers of meaning

When first looking at the photo, I noticed the vibrant colors of the stones. On further reflection, the shapes become visible; then, the frosty glare that touches each edge, and the positioning of each of the stones in reference to the others. I noticed how they are embedded and cuddled together, and how some stones are buried or hidden. I then became aware of both the differences in the rocks and the shadows that unite them. When I began talking with Becky about the image, I noticed things which I had not seen before, such as the range of the palette, the stones that continued outside the frame, and the fine lines spinning through the rocks. Some viewers may focus on each stone as an individual part, where others may see the whole pattern in the picture. Through dialogue, I understood more about the image, and how the process related to meaning construction for the participants.

When we look past the literal stone(s) and think abstractly, using our imagination, the *meaning* of the photo emerges. One viewer might interpret the stones as being developmental milestones of a child's life, or another might say that the colors represent shades of feelings. The stones could be hard circumstances and steps that someone might have had to take, in AA, for example. They might remind you of skipping stones with your brothers along the lake in Milwaukee, or the colors at an art deco exhibit in San Francisco. From a constructive postmodern view, each interpretation is “true,” and we begin to see a greater picture of the possibilities of meanings when we are able to discuss them with others. Social interaction and support is an important part of making meaning as illustrated through the image of the stones.

During the final interview, the participants and I spent time processing and analyzing the initial images and the photographs that came from the images during the

action research sessions. Using the analysis of the stones as an example, the two findings below represent the participants meaning making process, which included: (a) the layered processes of meaning, which is also a social process, and (b) the image embedded in other life contexts. This process of analysis is not *complete*, or *done*, as construction of meaning is ongoing and happens over time. The cyclical process of self-exploration often involves several ways of knowing (i.e. imaginal and somatic) simultaneously, and the process is open and inductive (Malchiodi, 2005). The finding of the layered process of meaning is discussed first.

*The Layered Process of Meaning as both Individual and Social*

The way the layered process of meaning as both individual and social relates to the images of the participants is that each person began creating meaning with the simple shape, much like the stones in Figure 23, more or less on their own, but with an invitation from me. The more the participants reflected on the meaning of their image, new interpretations begin to form. When they begin talking with each other about their photographs, they understood various levels of meaning in ways in which they hadn't thought of before; thus, there was also a social dimension to their creation of meaning.

In Agnes's image of the eye, she noticed the jagged edges of movement in her round circle, which was “how my eyes felt that night. They just felt like sandpaper. I didn't know how else to show that.” She started with the image of the eye, and then said this related to diabetes, because “Any kind of problem, almost any problem I've ever had, they always say, ‘Oh, yeah. Diabetics have that more.’” She said, “I want to tell them, ‘Forget I have diabetes,’” but:



Ev-er-y-thing relates. I have to laugh, because I can just picture myself in a casket. And people are saying, 'You know, too bad she didn't take better care for diabetes. She could've lived another 10 or 20 years.'"

She said, "I don't want them to say that!" She told her daughters that at her wake, she wants them to have cookies and ice cream. Although she said, "It's kind of silly to talk about, but I mean . . . that whole image of people in general putting a person down, which is basically what they're doing, 'They weren't perfect, so they died.'"

When Sophie first drew her pointed image, she wanted to change it to a tornado, rather than identify it as a wedge. In talking about it again, she first commented on the color of her image. She said, "If it was a bright red, that's an alarm. This is just a gray background, potentially nagging in the background." Before, she hadn't noticed the color of her picture. The wedge of Sophie's image reminded her that diabetes:

Always creates the potential for a pitfall. It's always there. There is always the potential for things to go wrong. It never creates the potential for things to go right. If you could get rid of it, it would be great because diabetes is never a positive thing in terms of helping you to get to a better place.

She continued to say that diabetes is, "God's way of making me humble. Insulin reactions, low blood sugars, are ways of keeping me humble because that's always a battle." After talking about the meaning of the wedge, Sophie started to open up about how low blood sugars have taken away her word ability. She said:

Or it could be my age, but I need to blame it on diabetes when I can't remember those words. Sometimes, I feel like a person from a foreign country trying to

think of that word I want to use, and I can't grab it anymore, because it destroyed that part of my brain. And I really believe that.

Further meaning of the wedge for Sophie was that diabetes was causing her to lose some of her word finding ability because of her low blood sugars.

Coral noticed that her initial image of steps also looked like a windkite in the airfields, like "we're going to fly somewhere," and constructed another meaning for her image. She said the "image I was visualizing was a green/blue. I made it as close to it as I could. My favorite colors are pinks, yellows, corals, bright, vibrant, for some reason, it was a greenish/blue." Although we did not have an explanation for that, it was interesting that she subconsciously chose a color that was darker than her "favorites."

I initiated a discussion about the brick wall which she drew on the back of her picture (see Appendix L), and she said, "I made a mistake, and I drew a brick wall." After pushing her slightly further, she repeated, "I made a mistake, covered it up, and made a brick wall. End of story. I don't know." She said, "I didn't draw a brick wall, thinking I'm putting walls up, I'm not talking to anyone. I had no idea." I told her that was why I found the process so fascinating, and maybe someday, a year or two from now, she might say, "Oh, I know why I drew that."

Emily's red "X" had several different levels of meanings, the first of which was her infusion site that had hurt her that day. It also represented a crossroads, because many things can happen along the road of having diabetes. Emily said:

I feel like if I cut my finger, I could get an infection and lose my fingers. I feel like every time I go to my eye doctor, I might have glaucoma. Also, I got the pump, and that's new, so that changes things. It changes things with my

insurance. I feel like diabetes is ... there are so many different parts to it, to learn about, to take care of, to try to make it better.

She said the crossroads represented both “good” and “bad.” The pump was a “good thing” for her, but the complications of diabetes were “bad.” She said, “My foot ... my whole body has potential to have something wrong, because my pancreas doesn't work.” The positive side is that she “always tries hard with whatever I do, and I think I also try very hard with diabetes ... I always try to look toward the positive side.” After thinking about it further, Emily said that the red “X” could also be negative, meaning “danger” or “keep out” because of all the complications. In her words:

It means I don't want anything else. Keep out. Like this is enough for me to handle, and I don't want to have to deal with any other problem. So, maybe it means keep out in that way ... Like, this is enough to deal with.

This related to her danger “X” flower photograph, but also the *weeds* in her picture. In fact, the weeds were how she said she would rather describe her diabetes. Emily said, “It's the weeds that you keep pulling out, and they keep coming back.” After talking about trying to use weedkiller, Emily added: “Weeds. It doesn't go away. You can make it try to go away, but it doesn't go away.”

Roberta drew her rectangular image as black on white paper. When asked whether she thought about her color selection consciously, Roberta said, “I don't think so. I just thought black would go on white. Yeah. I didn't really put much thought into it.” Since the most striking element of the image was a lack of color, I asked if it had any meaning for her, to which she replied, “Maybe subconsciously, but not consciously.” Since we were reflecting on the colors of the image, I asked if she saw anything new now

that it was brought to her attention. She said, “I was just trying to keep things simple ... and uncomplicated.” Roberta’s image of a ticket or box came to her “at that experience and that time.” She said the image was “abstract” as opposed to a concrete image of “needles, and glucometers, and low blood sugars, high blood sugars, passing out.”

I asked Roberta about her photos, which were different from her initial image. When we were reviewing the photo of her “Key to Diabetes” kite (see Figure 7), Roberta said she didn’t notice there were a heart and other keys in the photo, and then, “Look, there’s my reflection!” One of her photos included stones, and she commented that “the rocks were parts of diabetes ... . doctor visits, eyes, medical equipment, all that stuff. Testing my blood sugar, eating right, exercising.” In one photo of a parking ticket on a car, Roberta was “thinking about the ticket thing, literally. You don’t put enough money in the meter, and you get a ticket.” To me, that meant that the meter was running out of time with her diabetes, and I asked if that was true for her. She said:

Sometimes I think, you know, I’m going to die, and it’s going to be because of diabetes. I didn’t think that when I took the picture. I mean, I just assumed that.

That can be very inaccurate. I could just be hit by a car, or something, you know. Roberta said the road crossing photo (see Figure 15) looked like her shape of a ticket, so she took the photo. She was “trying not to get cars in it, so that is why it’s not straight.” Her image of a ticket represented a “part” of how she felt about diabetes, but was not the sum of the experience. She said:

Like I could say, this is what it's like to have a low. This is what it's like to have a high. This is what it's like to take an injection. This is what it's like to do all this

... but to try to put that all together, and say, this is what diabetes is like for me ... would be hard.

In constructing meaning with Roberta about this image, I was again reminded that all these images were really parts, snapshots, of fleeting moments in time. Parts can be explained or expressed, but not the whole. The whole is greater than the sum of the parts, and the more parts (or stones) we have, in the form of images, photographs, and stories, the closer we are to understanding the richer and deeper experience of diabetes.

### *The Image Embedded in Other Life Contexts*

The meaning of the image for the participants was embedded in not just their experience with diabetes, but other life contexts as well. When we look at the stones in the photo, we begin to see the relationship between them. If we focused on only one of the green stones, for example, out of context from the rest of the picture, we might not know it is a stone at all. It might look like a piece of an apple, a rhubarb leaf, or the tip of an alligator's tail, but when placed in relationship with the other stones, the part takes on the meaning in relationship to the whole. This relates to the participants' images, because the images held multiple meanings, many of which were embedded in larger parts of their lives. The images related to diabetes, but they also related to other parts of their lives.

For instance, the image of Agnes's eye reminded her not only of the pain she felt that evening, but also related to the way she always felt like the "oddball" and an introvert. When she was a teenager, she was self conscience, being the only one who had to take insulin in high school. She said, "It was a small high school, but, it was just ... that's an oddball. Out of 100 people, and you're the one who's different." She said this study helped her "feel like I am much more in the norm."

Sophie said, “Wedge, to me, is a small piece. Again, it's something you need to get around, or deal with. But we tend to push it to the back.” She was talking about diabetes, but also her relationship with her husband. She said, “I’ve been married for 20 years, and at times, we always had periods of driving each other nuts. He’s Type B, and I’m a Type A person.” She related this back to diabetes when she said to him, “You don't know how hard this is to deal with low blood sugars.” Diabetes is embedded in the greater context of her relationship with her husband and family.

Daisey’s image of Mr. Potato Head held meaning for her because he has a smile, “and doesn’t have any other faces,” which related to diabetes but other life experiences with her family, and her self-esteem and body-image issues. She explained:

If you open the dam, you have to be sure you can close it in a reasonable ... I mean, the time factor, too ... You know, it was just one of those things. You had to keep it together. I think a lot of people did that. There were one or two people who actually expressed their emotions during the study, but I think a lot were fighting them. Watching faces and stuff.

One of Daisey’s pictures was a dam made of sticks against a bridge along the Susquehanna River (see Figure 11). Since my role in the study was an educator, facilitator, researcher, and participant, but not that of psychotherapist, my intent during the study was to raise awareness that there was a dam, but not necessarily to “fix” it. There was time to look at the dam, embedded in other life circumstances, that diabetes potentially created and perhaps remove one or two outer sticks, but to largely leave the participants’ world view intact during the short period of time available. Daisey said:

Yeah, it's like you're trying to be fair to the study, yet you don't have enough time with these people. I mean, a lot of feelings that people have, including myself, about diabetes are very deep-rooted. It's not even something that you talk to your best friend, or your parents, about a lot of times.

However, Daisey said that *not* talking about feelings was being like Ms. Potato Head, where people “pretend nothing is wrong, or you talk like diabetes is somebody else's disease ... But the face never matched the words.” She said that “it was a time thing,” and she needed more time to express. This is true of diabetes, but other deep-rooted feelings that are embedded in the stones of life experience.

Coral's image of the “Friends” kite reminded her of the friends and family who were in her circle. She said they were her support group in life, and “if they're not there for you, what do you have? Not much.” The flowers in the kites were the people who support her. She said:

You can be having a horrible day, and you might not want to relate to them, your sugars are going up and down, and this is happening, but they're there to cheer you up. I don't know about you, but they all can tell when I'm not feeling 100%. They can tell when I'm pale. They'll say, ‘Are you feeling stressed today?’ That's very important to me.

Although her “Friends” image seemed positive, upbeat and possibly superficial to the outsider, at this point in the study, I realized her friends and family are a large part of who she *is*, and they are tightly interwoven and molded with her spirit. To illustrate, Coral shared a personal story about her one friend, which helped me see this significance:

Benjamin and I, my coworker, were known as the Republicans. In January 05, when Bush got inaugurated, Benjamin committed suicide. His wife is still my friend. But, they really only interacted with themselves. They kept people more at an acquaintance level. She is starting to struggle with getting some new groups of friends. You can't limit yourself.

Then, Coral related Benjamin's story to her life by saying:

I want to make sure I have more than one person to rely on. I mean, everyone has that one person they can rely on, but they didn't have that big group of people. Now, it's her. It's tough. If one friend goes, you're up the creek without a paddle, and I need paddles [laughter].

After realizing how her friends and family are embedded in her life and constructing meaning of the kite with Coral, I had a new understanding of the depth and significance of the photo. Her friends and family are the paddles and the kitewings of not only her life with diabetes, but many areas of her "self."

In Camilla's photo of the underwater heart, she focused more on the broken heart than in the fact that it was submerged. She knew that her image was not only about diabetes but "everything else." She said:

When I started off with a broken heart, it was everything else. I felt so depressed. My heart felt like it was breaking in so many pieces. I couldn't keep my kids happy, I couldn't keep my husband happy. Here I am with this frickin' diabetes, and my eyes are acting up. Sometimes, I just get into this thing where it's like, why bother?



She shared a poem with me called the “Broken Heart, which is how she perceived her experiences of life. Diabetes is embedded with other parts. She said:

It’s cut into several little pieces. This is the part for my husband, and my kids, my diabetes, my extended family, my job. At any given time, one of these pieces can be broken, but it still fits in the overall picture to make it a whole. I have friends. And even these friends can be a hundred little pieces. I gave this piece of my heart to this friend. I gave them part of me, and they gave me a part of them, that replaced it and put it back in there. So it's not just my heart. It’s everything about me. It's everything that's fun, wild, crazy, sad, loving, giving. It’s everything. So, even though this is my husband’s piece, there are a million pieces even there. I don’t know if this makes sense.

My response was, “Things always make sense for me in images.” Her heart is broken because of diabetes because it has restricted her life. She feels like people are restricting her because of her diabetes, because she lives in a “what if” world, where “I can’t believe you would go out of the country. What if you would wind up in a hospital there?” Camilla said she doesn’t worry about it. It was evident to me that Camilla’s heart has been broken in multiple places, many times, and for reasons both related and unrelated to diabetes. The underwater image gave me the sense of the weight of her burdens, and degree to which her pain reaches the depth of her soul.

Roberta described her photo of “Caged” (Figure 13) as how she thought of “life in general, not just diabetes. There's so many things you want to do that you don't do, or wish you could do, and ... said or didn't say. You know. You're stuck inside the box.” After asking what she meant by that, she expressed some of her life difficulties to me, but

preferred that they remain confidential. Diabetes was only one of the ways in which she felt stuck inside the cage.

In summary, this section discussed the ways that participants made further meaning of their images and photographs through the social construction of meaning and the way that diabetes was embedded in other life contexts. The process of meaning making does not occur instantaneously, but it takes time to connect with images and symbolic representations. As the participants reflected further on their images, additional layers of meaning were formed through dialogue and social interaction. Although the image represented their feelings about diabetes, it also represented their life experiences in other contexts. Participants learned about other aspects of the creative process, as described in the following section.

#### The Multidimensional Aspects of Learning and Meaning Making

Learning is not only a rational, cognitive process, but also a multi-faceted one that involves emotions, experience, and creativity. Neither is diabetes only a “mind” or “rational” disease, but it also affects emotions, the experience of things, and aspects of people that are usually not expressed. The purpose of this study was to raise an awareness of those feelings through multiple ways of knowing, such as the use of images and metaphor, and discover how those images could communicate the experience of having diabetes. This section summarized our learning process and experiences of diabetes through creative expression and dialogue with each other. Specific areas include the participants’: (a) learning about feelings through creative expression; (b) learning through group interaction; and (c) expanding the meaning of diabetes.

*Learning about Feelings through Creative Expression*

The purpose of the study was not to change the behavior of participants nor have specific outcomes on blood sugars, but to discover how creative expression can be used a way of knowing about the experience of diabetes. Roberta explained the study like this:

It's like dealing with diabetes from a non-medical perspective in a way that most programs, and methodologies, don't deal with. You know, you deal with how to take insulin, how to count carbohydrates, how to test your blood sugar and everything, but no one ever says, 'How do you feel?'

No one in the study had ever thought about how diabetes feels, particularly in a metaphorical way. Before participating in the study, the women had never completed the statement, *Diabetes is like ...*” It was a new, positive experience for them. They did learn about themselves and their diabetes by becoming more aware of their feelings, creating a new avenue for expression, and realizing they are not alone with diabetes.

Sophie said:

I took the time to think about it emotionally. I guess I don't have the time to think too much about diabetes, or allow myself the time to focus on the emotions of diabetes. Emotions, not in an active sense, but emotions of what having this disease means to me. By being in this group, it allowed me to do that, to put words and images to it.

Had Sophie not been in the group, she “never would've taken the time.” Her participation allowed her to think about the feelings she has about having diabetes, and go, “aahh, and just take a breath and breathe, and just relax ... Take time to say, 'How do

I feel about this?’ and ‘How am I?’” Sophie shared her experiences of participating in this group with her mother. Sophie said:

‘Mom, oh, my gosh.’ She was basically like, ‘OK. That’s nice.’ Then, ‘Mom, listen,’ and there was no time to just ... no, mom, do you hear what I’m saying? I realized all these things about how I might have felt about this or not felt about this. And, ‘Isn’t this wonderful?’ She was like, ‘Yeah. How are you doing? Are you doing OK?’ I’m like, ‘Yeah, yeah. OK. Fine. I’ll talk to you later,’ because we aren’t on the same wavelength. I think it really is important to take time to focus on it.

Emily learned a new way of expressing her feelings about diabetes through the use of expression. She had never thought about “diabetes is like ...” before this study, but now she views having diabetes as weeds in her garden. Emily said:

If someone asked me how I felt about diabetes, I could say, ‘I really hate it, or it’s OK’. But if someone said, ‘What does it feel like to have diabetes?’ they could understand it if I said, ‘It feels like you’re a gardener and you take pride in your garden, and you have weeds that just keep coming up, that you pull out, that won’t ever go away.’ So, if they ask me how it feels, and I say, ‘I hate it,’ they won’t feel anything from that. But, if I say, ‘Well, what’s your job?’ And then I try to make something really annoying out of their job that happens every day, then that’s what it feels like.

Neither had Roberta “ever associated it [diabetes] with one particular thing before ...I don’t know if I would have done something like that all my own. You know, to think of,

‘Oh, what can I associate an image of what diabetes looks like.’” Coral summarized the benefits of the body focusing process like this:

Everyone drew their object, or what they were thinking and feeling, and that opened the door for that [first] night. We could have sat around and talked about it, but by drawing an object, you’re able to see how other people are, and expound, and then that allows more interaction, than if we would have sat there, ‘How do you feel?’ Instead, draw an object. Well ... you can do a couple of things with what I did.

As was discussed in the earlier section on “The Layered Process of Meaning,” the social construction and deconstruction of meaning was an important part of the learning process. Participants expanded on what they learned from each other through group interaction.

#### *Learning through Group Interaction*

Agnes, Camilla and Coral did not comment on the learning experience by using creative expression specifically, but they did mention what they learned about themselves by being part of the group. Agnes said she learned that she was not alone as an “oddball” with diabetes. During the study, she was comparing herself against what others thought about themselves or their diabetes. She said, “We had different ideas, but they boiled down to being the same in a sense. We just had different ways of expressing it.” After I asked how they were similar, Agnes replied:

Roberta was sitting next to me, and she had the feeling of having a weight on her shoulders. It seems to me that there were others who had a similar experience ... we all felt the weight or whatever, the burden.

When explaining to her husband what the study was about, Agnes said “It’s hard to explain to somebody else outside of the group who’s not within the group. I think there’s a lot of undercurrent, or something, that I can’t even explain.” She said it was like trying to tell someone who is not diabetic about diabetes. Participation in the group helped her feel like she wasn’t alone.

Camilla felt like she was “outspoken” in the group, but she hoped that her participation in the study would help someone “down the road who was my age and didn’t know what to do.” She learned that being overweight was never an issue for her, and she thought that was “a neat thing to see.” Like Agnes, she was glad to have met other people who have diabetes. Camilla said, “I met people that are outlets to me now that I didn’t have before. Like, it was meant to happen.”

Coral said she realized that “I’m not the only one who has these feelings. For me, that was the key.” She also said the study “really opened up a lot of things you think about, but don’t really say.” It was great for her to “meet everybody” and learn that “Everyone has a lot of the same feelings. I might not have some of the negative feelings, but it was just nice to see that you’re not the only one.” She said that support groups might do the same thing, “but there are so many people there and it’s really not for people to connect ... it’s more for people to find out about the new things going on, and no one is as open. This was great.”

Daisey said that although her body issues were not “something I didn’t know ... it [this study] made it clearer as to the degree at which it still is an issue.” Her body issue was the “one major thing” about her diabetes that she can’t quite shake. She said:

I mean, I can deal with putting a needle in, the needle doesn't bother me, pricking my finger, but I always have that self-esteem, that childhood teasing, that made diabetes an issue. That's pretty much the only thing I'm aware of. You know, consciously, that bothers me about it. Is what it does to the whole body image and physical appearance.

During the course of the study, it was difficult for her to open up the issue of body image with the group, but she learned internally what she was feeling and thinking about it. The downside of using a group process to relate to diabetes in terms of feelings, imagery, and emotions is that participants may not be comfortable sharing personal stories. Roberta said she felt uncomfortable expressing herself in a group of strangers. She said, "You don't want to tell strangers, you know, intimate parts of your life. But, after a while it got easier." For Camilla, she said that she was "enjoying the moment ... enjoying life. Enjoying meeting other people and hearing what they had to say." At the same time, she was aware of an uncomfortable feeling, because:

I don't feel like I'm as good as the other girls [sic]. I watched them all that night, and it was so funny, because their machines were beeping, and they're testing their sugar. I sat there like ... My pump's on, I'm good to go.

Agnes also compared herself "against what others thought about themselves." Coral talked about the compassion and sympathy she felt for others in the study, because she thought they felt "angry." Her response made sense, because her focus was relationships with other people. When I asked how *she* felt by participating in the study, when she focused inside, she could not answer. For all the participants, it was easier to express "past" feelings about diabetes than present; and participants were more open with me

during the individual interviews than they were in the group setting. When the study was completed, however, participants expressed an interest in continuing with the group or meeting for dinner from time to time to keep the relationships going.

### *Expanding the Meaning of Diabetes*

In Chapter One, I referred to making meaning in a chronic illness experience as a search for understanding that assists individuals in finding a sense of purpose in their lives (Dirksen, 1995). Making meaning was also defined as a way for individuals to regain a “sense of mastery and well-being over an otherwise chaotic and disordered environment” (Bard, as cited in Dirksen, 1995, p. 629) and “changes in self awareness” (p. 631). These definitions were found in the literature, but I wanted to know how the *participants* defined meaning making. The findings of the study indicate that they had expanded the meaning they made of diabetes as a result of their participation in the study. They used the following phrases, as summarized below: being accepting, interacting with others, changing faces or perspectives, discovering what diabetes feels like, and listening to rhythmic sounds which escaped literal translation of meaning through words. Meaning making is difficult to conceptualize and define, so I asked the question of meaning making in this way:

This statement may or may not be true for you, but I would like to focus on how you might define meaning making in this sentence. If I said, ‘Participants made meaning of their diabetes by using creative expression or imagery,’ how would you interpret or define making meaning?

Agnes said she might answer that question, “Why do I have diabetes? Why me? And I don't think there is an answer, in this life, anyway.” She continued that finding



meaning would be to “Just accept it. But I don't know if I could ever really, 100%, accept it. I'm always wanting to kind of fight it. Maybe that's the meaning, to be accepting.” Coral said she was able to make meaning out of her images and photos, but “sometimes people don't know the meaning [of diabetes]. They think diabetes is a sugar disease. You know, sugar. With us, we all know it is not just a sugar disease.” It is more than just sugar and medical attention. She said it “changes your life.” Coral spoke of others frequently, and made a comment at the end of the interview, which described her socially constructed meaning making process:

It was interesting to hear about others' complications. Even the one person who asked whether anyone else took an antidepressant, and that threw me for a loop, because I didn't think about that with diabetes. You can get depressed with it. Surgeries on your eyes, and stuff like that. Again, it is still new to me, but I never thought about, ‘This is what I look forward to in the future’ ... It all comes back to ‘it was great to meet everybody.’

Both Daisey and Roberta defined meaning making as “changing faces.” Daisey said she would “interpret it as discovering how they were feeling about it. It would be like giving it a different name or giving it a face.” Roberta also said meaning making would be giving diabetes “another face so that you could operate with it differently than you have in the past.” She did find meaning through her participation because “we came up with another shape or image and tried to describe it, or qualify it, and apply it to diabetes.” After thinking about the question for a few minutes, Roberta added that meaning making meant “transforming it, so that you feel comfortable with it.” Roberta

said that coping with diabetes has negative connotations, because “usually you think of something tragic, and you have to cope with it,” but transforming was positive.

Emily said meaning making is understanding what diabetes *feels like*, which she distinguished from understanding *feelings*. She said her friends understand when her sugar is high, and they won’t let her drive because they are concerned about her; or, it’s low, and they say, “Let’s sit down and eat.” But they don’t understand what diabetes feels like. Emily said:

So if I were to talk to them about it sometime and say, ‘Can I try to make you understand what it feels like?’ and explain it to them in the way that we all sat around and talked about, with what we drew, or how it felt to everybody, I think my friends might understand it a little bit better. Even though they know me really well, and they are with me when I experience high blood sugars and low blood sugars, I think just telling them what I came up with the weeds and stuff like that, would help them understand it even more. Yeah. Because I had never had to think like this.

Although she had written about her diagnosis before, and tried to write how she felt about it, she never thought about diabetes as a metaphor. It helped her give *meaning*.

As Sophie and I were seated at a dinner café for our interview, I asked, “How would you define meaning making?” A song, “Ms. Wilson,” by New Cool Collective (2005), came over the sound system, and both of us stopped to listen to the rhythmic, soothing tone of the jazz. Sophie said, “Just listen, and sit back,” to which I replied, “Exactly.” The whole tone of the conversation had shifted from cognitive thought, explained through words to body knowing, filled with music. This is what both of us

meant by making meaning. We lost the ability to form words, but just listened until the song was complete. After the interview, Sophie sent me another song, “Samba Pa Ti,” by Santana (Santana’s Greatest Hits, 1990), which also reminded her of the meaning making process. Sophie added, “By using some of the things we've done in the group, by taking time to stop and feel, just like listening now, is how to make meaning. It’s been wonderful.” In summary, all the participants had expanded their meaning of diabetes as a result of the process.

### Chapter Summary

This chapter focused on the findings of the final interviews, which included looking at diabetes from a holistic view, further meaning making of images over time, and the multidimensional aspects of learning and meaning making. The participants discussed recording their blood sugar numbers as a part of diabetes care, but not the whole of the experience. They desired a holistic perspective on care, which included attention to creative and affective ways of knowing about diabetes. In addition, more compassion at appointments and a less judgmental outlook from medical providers was important. They realized that paying attention to the psychological needs of patients takes time, which is a systemic issue that needs to be resolved within medical care.

When further analyzing the images and photos, participants discussed both the layered process of meanings within the photos and the ways the images of diabetes were embedded in other life contexts. They summarized what they learned through the use of creative expression and group interaction and their definitions of meaning making. Prior to this study, no one had ever thought about how diabetes feels, particularly in a metaphorical way, and they learned about themselves and their diabetes by becoming

more aware of their feelings, discovering a metaphor for diabetes, creating a new avenue for expression, and realizing they are not alone. They defined meaning making as being accepting, interacting with others, changing faces or perspectives, discovering what diabetes feels like, and listening to rhythmic sounds which escaped literal translation of meaning through words. The last, and final, chapter will provide a discussion of the findings, implications for both adult education and medical practice, the strengths and limitations of the study, as well as recommendations for further research and my final, personal reflections.

## CHAPTER 7

### DISCUSSION AND RECOMMENDATIONS FOR PRACTICE

We all have dry bones in our life: the losses through death and loneliness, feelings of guilt, anger and rage at systems of intolerance and injustice. But we also have creativity and breath of hope that enters our spirit to bring life to the dry parts of ourselves. The purpose of this action research study was to understand the dry bones of living with diabetes and to explore creative and alternative ways that adults make meaning of their diabetes. Through a narrative approach in interviews and three cycles of action research with eight individuals who are insulin-dependent, we explored multiple ways of finding meaning and “knowing” about diabetes. In this chapter, I first provide a summary of the study as it relates to the research literature, followed by a discussion of the study in light of the constructive postmodern perspective, informed by feminist poststructuralism. Next, I consider implications for the field of adult and patient education, followed by the limitations and strengths of the study, adding questions for further research. Lastly, I offer conclusions and final reflections on the research process.

#### The Study in Light of the Research Literature

Following the work of many who write in adult education about the multiple ways adults construct knowledge (for instance, Belenky, Clinchy, Goldberger, & Tarule, 1986; Clark, 2001; Dirks, 2001; Yorks & Kasl, 2002), this action research design incorporated several creative ways of knowing into the experience and meaning-making process of diabetes. The two research questions which formed the basis of this study were: “How do adults experience and make meaning of their Type 1 diabetes?” and “What are the

ways in which adults with diabetes could engage in creative expression to find greater meaning and wellness?” In the practice of adult education, another question which this study addressed was “How can educators and clinicians incorporate multiple ways of knowing into their practice?” The primary focus was to understand how adults make meaning of their disease, and to use creative ways of knowing in the integration of diabetes care.

### *Summary in Focus*

The findings of the initial narrative interviews were that adults with diabetes have the common experience of: (a) experiencing a range of negative feelings about diabetes; (b) resisting against diabetes and medical approach; (c) taking a positive spin on the negative as a way to cope; (d) constantly shifting awareness of diabetes; and (e) living for others. Although the participants experienced fears of death, anxiety and worry about complications, many of them took a positive spin on their disease as a way to cope. Thoughts about diabetes were usually in the background of their day-to-day activities, but came to the forefront during hypoglycemic events or while testing their blood sugar, exercising or eating. Some resisted their own diabetes care through not testing their blood sugar or “cheating” on their diets. When a significant other or a child entered their life, each participant seemed to want to improve their blood sugar to have a healthier life so they could “be around” for that other person. These findings were important in planning the next cycles of the action research process.

During the three sessions of creative expression, involving the emergence of images, photography related to the experience of diabetes, and social construction of knowledge, participants were able to express their feelings and the experience of diabetes

in ways not explored before. In addition to the meanings of the photographs themselves, findings from the creative process and final interview included: (a) glucose numbers as a part of diabetes care, but not the whole; (b) further meaning making of images and photographs over time; and (c) multidimensional aspects of learning and meaning making. Although the participants recognized that checking and recording blood sugars was part of their diabetes management, it did not constitute the whole of who they were as a person or the whole of their care. They enjoyed discussing their experiences with other people who had diabetes, and the more the participants reflected on the meaning of their image with others, new interpretations begin to form. Because learning and knowledge does not only come from cognitive, rational thought but is formed in multiple ways (Flannery & Hayes, 2001), participants used creative expression to put an image and a voice to the feeling and experience of diabetes.

These examples of multidimensional ways of knowing begin to inform the practice of adult education and make way for other methods of inquiry into understanding the teaching and learning process in patient education. Prior to this study, these types of ways of knowing and meaning making in the context of a chronic illness (specifically diabetes) were not addressed in the adult education and medical literature. Additionally, the research is important to those who work with chronically ill patients by providing specific recommendations for practice, attending to the multiple ways adults know and learn.

Rather than the clinician's, the caregiver's, or the family's understanding of illness, this action research study addressed the *patient's* experience of having diabetes. Ravenscroft (2005) stressed that that the patient's perspective is needed, for "without the

inclusion of the affected individual's perspective, it is possible that the information [from the provider's perspective] is incomplete or misleading" (p. 502). This action research process grew out of my own reflections on what diabetes means to me, expressed through the metaphor of *Dry Bones*, and through my observations as the patient who understood that attention to the affective and other ways of knowing were not integrated into diabetes care. In taking a constructive postmodern view, my immersion in the research process assumed the interconnection of the experience of the researcher and the participants in some ways (Bloom, 2002). My own interest in the imagination connected with this need to discover how those with diabetes understand and experience their illness, and how *meaning* can be discovered and rediscovered through creative expression.

#### *Comparing and Contrasting the Research Literature*

In general, most of the research literature was consistent with the findings of this action research study, including diabetes as an ongoing struggle, the quest for a positive outlook, and the use of imagery leading to insight and potential healing. One area of difference was the resistance against diabetes and medical providers, which was a strong theme of this action research study but not the literature. These comparisons between the literature and this study are listed below.

#### *Diabetes, Ongoing Struggle, and Positive Outlook*

Participants felt negative emotions toward their diabetes, including a fear of death, anger and frustration, feelings of difference, depression and moodiness, guilt, and uncomfortable, physical pain. It was difficult to hear about the struggles of the women in the study because, as one said, "it is real for us to die." Where most people might think about death after hearing of trauma, suicide, or a death in the family, those with diabetes



live with the reality that complications could come, as Sophie said, “like a thief in the night.”

In describing the meaning of diabetes, participants in Hartrick’s (1998) study used metaphors to describe their negative feelings, such as “the envelope of diabetes, the walls of diabetes, unknown terrain, a cloud looming, a ball and chain that you drag around, and a noose around your neck” (p. 81). For all people living with diabetes, it is an ongoing struggle. Hartrick’s participants described diabetes as something they lived with every minute; similarly, in my study Agnes commented about living with diabetes “every minute of every day. In my opinion, it is a choice all day long.” Emily and Sophie worried about complications and viewed diabetes as a struggle, which related to this comment in another study: “I’m anxious, worry about late complications. It’s like a running enemy. I fight with it every day” (Tak-Ying Shiu & Yee-Man Wong, 2002, p. 158).

Despite the ongoing struggle, participants in both this and earlier studies tried to maintain a positive attitude. Coral said, “You try to turn a negative into a positive,” and Roberta said she took diabetes in stride, realizing that there's not much she can do about it to make it go away. This sense of optimism and looking to the positive relates back to the study of one woman who was diagnosed with HIV/AIDS, and said that her disease gave her a way to make a difference and said “everything happens for a reason” (Baumgartner, 2002, ¶ 30). A woman from another study said, “The illness has made you stronger in some respects” (Kralik, 2002, p. 151).

Camilla, Amber and Sophie took a positive spin by focusing on their faith in God, which was similar to the findings in a few studies (Lyons et al., 2002; Narayanasamy,

2002), where meaning making included a spiritual awareness of needing someone or something greater than themselves to see them through. Having a positive outlook is important, because the more positive the meaning attached to the illness, the more positive the mental and physical health (McFarland, Rhoades, Campbell & Finch, 2001).

### *Resistance, Imagery, and Potential Healing*

In the study, a theme which emerged was resisting against diabetes and the medical approach. Participants in other studies also made comments indicating similar feelings. For example, a patient in the Hartrick (1998) study reported, “You were just dehumanized; you were just a pincushion to regulate.” However, this theme of resisting the medical approach was generally not an ongoing or recurring theme in the literature as it was in this action research study. In fact, in another study one patient said, “You know the doctor is right and all will be well if you don’t struggle ...” (Kralik, Brown & Koch, 2001, p. 598). In this action research study, the participants made comments like, “I could count on two fingers the number of times that I brought in my blood sugars to the doctor’s,” and “cheating” on diets. They were also honest about not following prescribed medical advice and not taking care of themselves as well as they knew they could.

This difference may be explained by the divergent philosophical views. Most of the medical research literature that examined meaning-making issues was based more on a humanist viewpoint, but my approach was a constructive postmodern perspective on diabetes care, where I encouraged participants to deconstruct and reconstruct meaning and to express their feelings and the experience of diabetes. Not everything had to be fine, only “real” and “true” to their understanding. Because I have diabetes myself, I was

able to understand the participant's experience (at least, in part) and ask in-depth questions about feelings and thoughts of diabetes which may intersect with my own.

The education literature that I have drawn upon does not discuss postmodernism and creativity or imagination. This is the first study in adult education that takes a postmodern and poststructural perspective in discussing creative aspects of knowing and learning, which relate to practical applications in teaching. Taken from the arts therapy literature, the use of creative expression in this study was a therapeutic intervention “of visual images and art-making for self expression, insight and healing” (Bien, 2005, p. 284) to assist people in finding “meaning in making art with intention” (Schroder, 2005, p. 9).

Through the action research process, we used imagery and photography to understand and connect with our experiences and meanings about diabetes. One example was Emily's photo, which pictured her red “X” and weeds. The interpretation was a dance between the bright color and the symbols of the flower, flowing back to her understanding, then to the weeds growing out of the earth, and back to the music of the connection between it all, unable to be expressed fully in words. In connecting with ourselves through images and symbolic representations, we discovered a new creative source and developed new connections for understanding and knowing our selves (Payne, 1996). The more we reflected on the meaning of the images, new interpretations began to form. When we begin talking with each other about their photographs, we understood various levels of meaning in ways in which we hadn't thought of before. The social connection was another note in the music of the dance of knowing, and added its sounds to the meaning of the photos.

The arts and therapy literature showed that artistic and creative therapies can bring healing, literal words alone can be restrictive and limiting when communicating soul and emotions, and image and symbol assist in the meaning-making and healing process through imaginative and creative expression. These themes also extended to the findings of the action research study. The participants used creativity, which lies in images being constantly formed and projected into symbolic meaning, where the “inner creative force serves as a backdrop for healing” (Spring, as cited in Bien, 2005, p. 284). At times it was difficult for participants to express their feelings through words, because words alone could not communicate the experience of diabetes. One woman said that it was challenging to put diabetes in words, and another woman felt “less creative” than others in the group, whom she perceived to be able to express themselves in words better than she. The connections that we made between our images and the experience of diabetes, and with each other, encouraged us to know and come to understanding in multiple ways.

In summary, despite these differences in philosophical perspectives, most of the literature was consistent with the findings of this action research study. But some of these differences are likely rooted in the philosophical framework that informed this study, which is explored next.

### Revisiting the Philosophical Framework

Although there has been some debate about the significance and practical relevance of postmodernism in adult education, at the very least, postmodernism provides space for a multiplicity and diversity of meanings and possibilities through which to make sense or meaning (Edwards & Usher, 2001) Constructive postmodernism,

informed by the works of Foucault (1988, 1980, 1972) and feminist poststructuralism (St. Pierre, 2000; Tisdell, 1998) challenges the dominant culture in deconstructing and questioning what has typically been valued in the construction of knowledge and the role of power in shaping what has counted as knowledge (Foucault, 1980). One strength of postmodernism in this study is that the framework makes space for multidimensional ways of knowing, learning and meaning making by deconstructing the notion that rationality is the only way one comes to understand the world. The frameworks also focus on enabling the ways people can reconstruct their identity through the development of voice by examining the positionality and power of the teacher and the students, as well as the differences in the cultural identities of the students and their access to power (Elias & Merriam, 2005; Merriam & Caffarella, 1999; Tisdell, 2003). Five philosophical underpinnings of the feminist poststructural framework in particular include the recognition of fluid, shifting and multiple identities; the ongoing construction of knowledge; deconstruction of binary categories; differing views about “truth” and certainty; and power relations and voice (Tisdell, 1998). The first four areas are described below under the category of “Shifting Identities and Ways of Constructing Knowledge,” and the final area of power relations and voice is described as “Issues of Positionality.”

### *Shifting Identities and Ways of Constructing Knowledge*

Even as I write from my assumptions as a female, middle-class, white, single mother of one, my identities are shifting from researcher to writer and back again. Given another day, I may disclose to you another aspect of my identity and choose other labels

to describe myself. The sections below further describe what is meant by shifting identities and the multiple ways the participants' construct knowledge within our world.

*Shifting Identities and Awareness of Diabetes*

Because postmodernism assumes uncertainty, doubt and ambiguity, the idea of shifting identities in constructive postmodernism points to the idea that there is not one, stable identity, or even "core self" to be known, but a multiplicity of selves from which we can begin to make meaning (Witcombe, 2000). From a feminist poststructural view, these shifting identities are discussed in relation to positionality, shifting the understanding of what it means to be a person of a particular race, gender, sexual orientation or class. In this study, the shifting identity in relation to the positionality of the doctor-patient relationship also was explored, with patients shifting between the desire to be compliant and please their physicians, and engaging in multiple forms of resistance, perhaps as a way of activating power.

The participants in this study were all women, who interact with primarily male physicians within a patriarchal medical system that is directed by a means-end rationality (Hendricks & Paterson, 1995). Although the participants did not talk about resistance to a male-dominated or patriarchal system of power directly, in light of the feminist poststructural framework, it is important to note that women have a limited history in medicine, and medicine has traditionally been considered a masculine pursuit (Nicholson, 2002). Since the Enlightenment, the medical system was built upon science- and evidence-based medicine, and women were invited to attend medical school in only the past 150 years (Candib, 2006). Scientific, rational thought in medicine makes little room

for affective, spiritual or imaginative processes, but *all* ways of knowing need to be incorporated in holistic care.

Along with others who know that the biomedical perspective is not enough to explain the experiences of chronic illness (for example, Brown & Williams, 1995; Ironside et al., 2003), the participants recognized that numbers and rational, logical reasoning are only a part of their diabetes care, and it does not represent the whole of their identity or experience. The emotional component of diabetes is also an important part of who they are and the way that they make meaning of diabetes. Because these were strong women who had endured a great deal of hardship, both related and non-related to diabetes, many of them were beginning to raise their voices in this study to express their discontent with the way they were treated as numbers by the medical system. Many shifted between wanting to do the “right” thing as a patient and the inner desire to resist compliance by not showing at appointments, faking numbers, and telling the physician what he or she wanted to hear.

Also, another finding in this study was that the participants “lived for others,” particularly a child or significant other, which Gilligan (1982), based on her well-known study of women’s moral development, suggests is a gendered phenomenon. Although this connection with others may cross gender lines, and the theme may have developed even if there were men in this study, more women than men define their identity in terms of their relationship and connection to others (Chodorow, 1978; Lyons, 1983). Although the women did not talk about the importance of taking care of themselves for their own well-being, they did mention that their relationship with others affected the attention they gave to themselves and served as their motivation to adopt more healthy patterns of

diabetes self care. Here, their identities of mother or family support connected and directly influenced their identity as a woman with diabetes.

Viewing identities as fluid, multiple, and unstable presents more possibilities for the understanding of differences within individuals, and allows for multiple understandings of what is “true” and “real” (Mann & Huffman, 2005; St. Pierre, 2000). As Foucault said, “Truth is a thing of this world” (1980, p. 131). The “truth” of our own identities does not remain static, but shifts over time through new learning experiences, contexts and dialogue with others. In addition to gendered identities, there was a constantly shifting identity around diabetes itself. Participants in this action research study were aware of shifts in their experience with diabetes fading from the foreground to the background and back again. Emily described her awareness as “going in waves,” where sometimes she did not even think about her diabetes, but writing her blood sugars down made her think about her disease “all the time.” Camilla said that “half the time, I don't feel like I have diabetes. I just go and do my everyday thing.” Living with diabetes is a constant shift of awareness of “truths” about the experience of chronic illness and the “truths” of other identities within the world.

The theme of constantly shifting awareness related to the Shifting Perspectives Model of Chronic Illness as discussed by Paterson (2001) in her consideration of chronic illness. The model shows living with chronic illness as an “ongoing, continually shifting process in which people experience a complex dialectic between themselves and their ‘world’” (¶ 7). From this perspective, the experience of chronic illness was either in the foreground or in the background, and adults moved between periods of illness and



wellness. Diabetes was just one of those identities that shifted, embedded within the context of other dimensions of life.

### *Construction of Power-Knowledge*

In postmodernism, one assumption is that there is more than one “truth” about what is known as reality (Foucault, 1988) and what passes as reality is typically determined by those with power. Foucault (1980) discusses this point in his consideration of how power-knowledge intersects. Typically “knowledge” about diabetes is determined by those with power, usually the medical establishment from a cognitive rational perspective, as opposed to those who actually have diabetes. Rational thought processes reflect only a part of the experience of diabetes, and are often not adequate to communicate the affective, spiritual, somatic, and imaginal experiences of it.

While doctors and medical technology play an important role in health care, they do not hold the ultimate secrets to health and wellness (Robbins, 1998). Largely, the participants held the knowledge of the experience of diabetes expressed through imagery and creative expression. By allowing space for the participants to explore these multiple ways of knowing, they were able to make meaning of their diabetes in a new way. Sophie said she, “never would’ve taken the time,” because she had other shifting identities of employee, spouse, and mother, yet her participation was valuable by allowing her to think about the emotions she had about diabetes, which leads to greater awareness and healing.

Part of this healing process comes from not only viewing the images represented in this research, but feeling pierced by its significance and meaning to the point where we become the image. Not only are we looking at the image, but the image is staring back at

us. The working of these images through our bodies “inaugurates depths which are weavings and re-turnings in which the continuous movement opens ‘the circle of the touching and the touched ... of the visible and the seeing.’” (Mazis, 1993, p. 106). Within the dawning of this sense, the past comes to new significance and meaning and we come to view our situation differently. To explain through the use of Agnes’s metaphor, diabetes is not only a rational clock, keeping time on when to eat and when to exercise, although that was part of it. But after she explored the meaning of her image further, she had the intuitive sense that diabetes was watching her – other people or even God was watching to make sure she didn’t “cheat.” Each of these interpretations forms a part of the greater understanding of the experience. Within these experiences, there were both commonalities and multiplicities of interpretations, most notably in the range of photos which described the multiple meanings of diabetes. Just as there was not one photo that was the same, there is not one “truth” that describes the experience of diabetes, but multiple truths floating to the surface of consciousness and back again.

Postmodernists also challenge and deconstruct binary categories such as good/bad, right/wrong or all/nothing, normal/abnormal (specifically Foucault, 1972). One finding of this study was that the experience of having diabetes is not a binary affective/rational process, but constructed through multidimensional aspects of knowledge, which comes from many aspects of the spirit-body-mind. Many adult or higher educators have discussed the mind, body and spirit connection, some who identify with postmodernism and poststructuralism (Somerville, 2004, Tisdell, 2003a) and some who do not (Apps, 1996; Dirkx, 2001). Although a humanist and not a postmodernist, Apps said that to learn as a whole person, we must “listen for the whispers from our

hearts and the messages from our bodies. Of course we involve our minds, but we avoid concluding that thought and thinking are the beginning and end of learning” (p. 2). Our emotions, and our imaginative thoughts of them, assist in the meaning-making process and the ways we interpret and experience ourselves (Campbell, Chodorow, Denzin & Jaggar, as cited in Dirx, 2001). In deconstructing the thought that rationality is at the center of all knowledge (Foucault, 1988), educators can attend to the multiple ways adults know and learn.

*Deconstruction and Reconstruction: Postmodern Action Research in Metaphor*

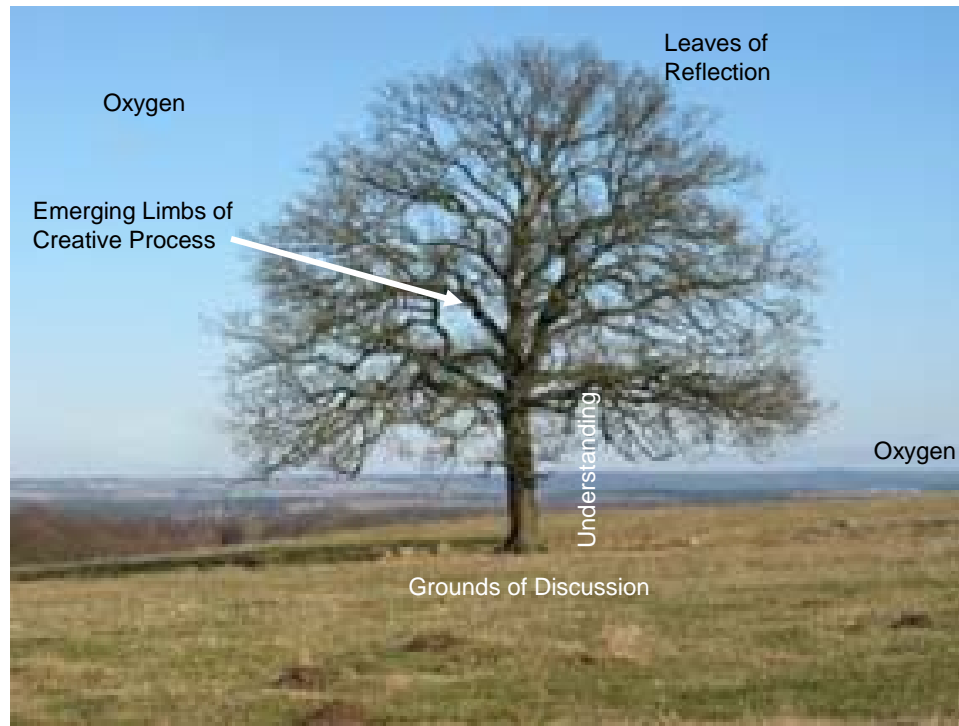
Although patients were able to express their knowledge of what diabetes means to them through metaphors, imagery and photography, the action research cycle was also a constantly shifting process, and somewhat problematic from a postmodern perspective. In claiming my own voice, one issue with using action research is that the cycles of planning, acting, observing, and reflecting as Kuhne & Quigley (1997) suggest are not as neatly tied as they might appear. When does acting stop and reflecting begin, for instance? Are they not simultaneous and connected? In this action research the process was not laid out in categories or stages of planning, acting, observing and reflecting, but rather these areas were webbed tightly together.

The creative process in this study did not follow a linear cycle of planning, acting, observing, and reflecting, but the process involved more of a simultaneous and nested cycle of understanding the participant’s narrative, bypassing cognitive understanding, developing metaphors, reflecting on the meaning making process, and discussing with each other to make new meaning and metaphors. This too, occurred not sequentially in a linear or even cyclical order, but moved between these parts and the whole of the process.

The action research in this study formed multi-trajectory, simultaneous patterns of understandings, emerging developments, reflections, and discussion, which I might name “postmodern action research in metaphor.”

Using the metaphorical example of a pear tree to illustrate (see Figure 24), the roots are the socially constructed grounds of discussion in action research, from which a conversation typically both begins and ends. The trunk of new understandings grows from the discussion, from which the activity, or the “action,” is channeled. Limbs and branches of emerging developments are formed from the action of creative processes and multiple forms of knowledge that develop from our source of understanding. The leaves and fruit of the tree represent the new reflections that have shown themselves to the tree, and the oxygen produced by the leaves is the knowledge not known or seen, yet present, giving life to the tree and all life forms. As the leaves fall to the ground, they again meet with discussion in the organic process of knowing and learning and return to the tree. This is my deconstruction of the current action research model and a beginning reconstruction of a “postmodern action research” dynamic model of my understanding of the process in action research.

In looking at the findings through the lens of postmodernity, I was intending to deconstruct the notion that the only knowledge of value was the dominant position of cognitive rationality, and reconstruct a way of integration that values multiple ways of knowing in adult and health care education. Based upon the findings and observations in Chapter 5 specifically, I also deconstructed the cycle of action research in order to form a new way of looking at the process. It is important to question, to learn from multiple



*Figure 24. Postmodern action research in metaphor*

ways of knowing, and to use our new understandings and reflections to help ourselves become more meaningful educators and learners.

#### *Issues of Positionality*

Given my philosophical perspective of constructive postmodernism informed by feminist poststructuralism, it is also important to recognize issues of positionality regarding the way that people are “positioned” relative to the dominant culture, which connects to whose voices are heard and represented in the research (Mann & Huffman, 2005; St. Pierre, 2000; Tisdell, 1998). In this section, issues of positionality related to the interviewing and recruitment process, my own position of power, and interpretation of the data are discussed.

### *Importance of Voice*

There was the opportunity for each person to talk about her experience of diabetes. As described throughout this dissertation, voice is an important philosophical underpinning of both constructive postmodernism and feminist poststructuralism, because it is through voice that we can express our desires and thoughts and have our interests heard. As noted earlier, the purpose of this study was to hear the *patient's* voice because so much of the medical literature does not include their voices, instead privileging the voices of “experts” and physicians. In the research, there were times when the participants resisted taking care of themselves because they felt like they were not being heard by the physicians or the dominant patriarchal system of medicine. For instance, Camilla said that she did not really want to take calcium pills or an aspirin as recommended, because the (male) doctors assumed that she wanted to do it. After meeting with one medical professional, Daisey said he was "a complete jerk. I went out [of that visit] feeling like I was old, fat, and 'Sorry, we can't help you.'" One woman smoked, and the doctor said, "You might as well build yourself a graveyard plot right here." Although the participants didn't feel heard by the medical professionals, perhaps the women did not raise their voices to speak. They were used to being silent about their diabetes, so the conditions weren't created for them to come to voice. Their speaking out in this study was an opportunity to find their voices, and to come to learn about themselves and their responses to their diabetes and the medical system.

Another possibility for their not being able to come to voice is that medical professionals are not (or do not know that they are not) listening to the silence. An initial recommendation from participants is that physicians and other medical professionals

should ask questions that might break the silence, indicating more acceptance rather than making pronouncements such as, "You've got to check four times a day," and more like, "Just think about what you're doing." The medical community and patients would benefit from establishing connection and conversation. The importance of relationship and connection for women as learners is a theme of most of the feminist discourse, and most feminist theoretical frames (Hayes & Flannery, 2000; Tisdell, 1998). By feeling a sense of compassion and asking questions that promote interest and connection rather than statements of judgments, participants felt like they were heard and treated as another person, not only a disease or a Cartesian object that can be ordered and controlled. These are just suggestions about ways of facilitating connection, which might enable these women and other patients to come to voice.

#### *Gender in the Recruitment Process*

The fact that there were only women in the study, though not necessarily my initial intent, was likely the result of some gender dynamics that are a part of the gendered dynamics of society as a whole. The criteria for the study were that the participants were age 21 or older, they have insulin-dependent diabetes for 10 years or more, and they have difficulty managing their diabetes ( $A1C > 7$ ). In the recruitment brochure, both men and women with Type 1 diabetes were invited to participate, but the participants in the study were all women who happened to have insulin pumps. In light of the research perspective, this issue raised concerns as to whether only women were asked to participate, or only women were interested in participating in creative research.

The primary recruiter, a white woman in her 50s, said that she went "through the list of potential participants in her head," and wanted to give the brochure to people who

had time and were willing to participate in the study (personal communication, August 30, 2006). She said that most of the men she could think of “had jobs, which would make it difficult for them to get together.” In addition, many of the men weren’t local, one being 50 miles away from the study site. Yet, three of the women in the study held full-time jobs, two were teachers, and four were either retired or held part-time positions. From a feminist poststructural view, I questioned whether the recruiter assumed that women would be more interested in a qualitative study using creative expression than men. Although creativity is a trait desirable in both men and women, according to a survey that characterized the contents of prescriptive gender stereotypes (n = 208), it was more desirable for a woman to be helpful, optimistic and creative than it was for a man (Prentice & Carranza, 2002). In addition, it was a stereotype that men could be warm and creative, as long as they held the more “masculine” qualities of being goal-oriented and decisive. Perhaps this social construction of creative expression appealing to women was a factor in the recruitment process.

Another possible reason that only women were included in the study is that there were more women patients in the practice. On average, this practitioner sees three men to nine women per day; therefore, there is a 2:3 likelihood that she would come in contact with women. She works exclusively with patients who have an insulin pump, so all the women in the study had the shared experience of living with that particular method of insulin delivery. In the end, having all women in the group on insulin pumps, as opposed to mixed genders, likely contributed to the openness in the group. From a feminist perspective, one explanation for the cohesiveness is that there was not a male physician leading the study, because as some researchers have suggested (Butler, 1999; Gilligan,



1993), a white male presence can inhibit some women's freedom to speak. The women may have felt more comfortable sharing their personal thoughts and experiences with me as a woman, an insider with diabetes, rather than a male who did not have diabetes. However, even though I presented myself as a non-judgmental peer, I was perceived as the researcher, the expert and the one with the "knowledge," and participants may have been reluctant to share their personal thoughts with me.

### *The Researcher as "Expert"*

During the course of the study, my positionality as a researcher was not questioned as the "expert" or "authority." I was an educated, white, middle-class researcher, the one who "led" the study and was viewed as the facilitator and teacher. An example of my unquestioned authority was the lack of discussion surrounding the themes of the research discussed during the final interviews, as well as the fact that all of the participants journeyed with me in the creative process without resistance. There was disagreement and sarcasm among several of the participants, such as when Sophie told Camilla to "not stay stuck," and Daisey said Coral's picture was "nauseating," but none toward me as the facilitator.

From a feminist view, one explanation for my unquestioned authority can be the notion that "good girls" listen to their teacher, and they respect authority, not wanting to disrupt the status quo. In the adult education classroom, the ability to speak in class is referred to as voice. One study in particular (Johnson-Bailey & Cervero, 1998) addressed the positive and important feeling of being free to speak out in class and express opinions. The positionality of race, class, gender, and sexual orientation of each adult learner affects the freedom of voice (Sheared, 1994) and this is played out in the

classroom. For instance, two of the participants in the study were bi-sexual, but they made no comment about their partners or relationships during the group sessions. In other words, their voices were silenced, although other participants felt comfortable talking about their spouse or male significant other without a second thought. Perhaps participants were also silenced to some degree by my positionality as a teacher, and that they were women who learned to hold their voice in a group rather than speak against those in perceived positions of authority.

From an adult learning view, unquestioned authority may also be attributed to the study of group dynamics (Tuckman & Jensen, 1977), where there are four basic patterns of group development. Although it is a linear interpretation of stages in group dynamics (and my preference is more of a non-linear one given my philosophical perspective), looking at the general characteristics of group dynamics may assist in the ways in which the group interacted toward me as their perceived leader. During the beginning formation of groups, it is common for participants to be anxious, guarded and dependent upon the leader. As the group becomes more comfortable with each other, informal smaller groups begin to form and interact. When participants in the group become even more familiar with one another, some disagreements among members or toward the leader might come to the surface, but a group will eventually try to work through the conflict.

It was my observation that participants in the group were beginning to connect with one another; however, they still regarded me as the “expert.” At the end of the study, Daisey said she was still “feeling uncomfortable with the group,” and this would lead me to believe that the group was not fully trusting of one another. Even so, the

participants were willing to share their parts of their lives with me and each other, and trusted not only the process, but me, as their guide. In emotional and other ways of knowing, trusting is the “heightened loosening or letting be into dispersion within the enmeshment with the world and others” (Mazis, 1993, p. 132). Trust is different from the rational, Cartesian world view, where there are regimens and rules to follow rather than a letting go of what is known, a falling into the air, to awake from the spiral and find a part of self caught by the new knowledge of becoming. Like postmodern thought, there is an uncertainty, an unpredictability and opening to things unknown and unaware. Trust takes time and an openness to multiple ways of knowing. The participants in the study were somewhat dissatisfied with the current medical system and wanted things to change, and they formed a degree of trust with me as their leader to help facilitate that change and action.

While I didn’t embrace the role of research as “expert,” there were times when I felt the desire to interpret the images and photos for the participants, but often held back because I wanted the images to be *their* meanings and interpretations. There was a certain degree of wanting to control the direction of the conversation, yet an even stronger awareness of a presence that released my control over the process. There was also a tension between knowing what to say, and what to hold back so that the meaning making process was about the participants. For instance, Daisey’s image was on red paper, which to me represented anger, hatred, and fiery emotions. There was not a period at the end of her description of “Diabetes is like,” as if there were more to be said about the meaning of her image. The combination of these two components in her images led

me to believe there was more that she was holding back, and I wrestled with pushing her on the issue or letting it go at that moment.

The same was true with Coral, who drew a brick wall on the back of her image. I wanted to tell her that the brick wall could have meant she was blocking her negative feelings about diabetes, and didn't want to think about them. At times like these, I remembered Foucault's (1980) discussion on power-knowledge, and the need for *her* voice and "truth" to be heard, not mine. After all, the role of the facilitator, as in educational or creative activities, is to be minimally directive with choices emanating from the participant rather than imposed by the therapist (Abraham, 2005). As an educator and facilitator of action research, my focus was to not put the attention on myself and my intentions, but to allow the process to emerge in powerful ways, which I could not plan nor predict.

#### Implications for Adult and Patient Education in Practice

Although there is literature written on the affective dimensions of teaching and learning (Dirkx, 2001; English & Gillen, 2000; hooks, 2003), the literature in adult and patient education related to the artistic or imaginative domains was limited (Clover, 2006; Donoho, 2005; Lawrence, 2005; Olson, 2005). No research studies existed in the medical education literature in implementing creative expression or multidimensional ways of knowing in medical care during clinical appointments, and there were no action research studies in adult education that related to creative expression and patient education. The philosophical underpinnings of constructive postmodern and feminist poststructural perspectives opened the space for deconstruction of previous assumptions of diabetes care and management and the reconstruction and emergence of additional

ways of thinking which previously were drowned in the seas of rational thought and medical protocol. It might seem contrary to postmodernism to offer some specific suggestions for practice that could seem instrumental, since postmodernism would generally see reality and practice as constantly changing and impossible to pin down. Nevertheless, as a constructive postmodernist, I see the importance of both recognizing the context as shifting as well as introducing specific implications to offer in practice.

*Attending to the Affective and Imaginative Dimensions of Meaning Making*

When we meet students or patients, a conversation begins. During that initial dialogue, it is important to establish a connection and sense of trust. In all educational settings, students bring their own personal experiences, emotions, and assumptions when entering the classroom or office. The identity of learners or patients is part of who they are, but it is not the whole of their identity. With the participants in this study, I encouraged conversation that focused on the affective and imaginative dimensions of meaning making and understanding -- not just the medical aspects of their lives. In order to develop a dialogue and resist the traditionally male dominated medical model, it was important to establish a sense of trust with the women.

One way to facilitate trust is to attend to the affective dimensions of learning by discovering why the students are interesting in attending the class (or appointment), what they expect from the time spent with the educator, and what would make an “ideal” learning experience for them in the time available. As in the action research study, learners can be co-creators of the curriculum or the appointment and be asked what they expect to do during the time available. Educators tend to miss the importance of this initial dialogue to uncover the learner’s intentions and expectations of the time together.

From a constructive postmodern view, this connection is not made in order to make everything “OK,” but in order to promote a sense of trust that later leads to a questioning of previous assumptions and new understandings.

Attending to the affective dimensions of adults is an important part of learning (Apps, 1996; Yorks & Kasl, 2006). In medical education, if physicians and patients do not recognize the psychological, emotional and affective aspects of having diabetes, patients may miss appointments, resist disclosure about diabetes to some health care professionals, or be unable to initiate diabetes self-management processes (Nair, Dolovich, Ciliska & Lee, 2005). Diabetes is both a psychological and physiological disease, and participants in this study said the affective dimensions of understanding the disease were lacking in diabetes care. Daisey said, “it’s the emotional component that is being missed.” Sophie added that there was “more to diabetes care than numbers,” and, like Daisey, she thought the “emotional component is lacking.” This is also true of adult education, where the traditional approach was based on the rational transference of information from teacher to learner, which has resulted in passive students who can regurgitate facts, but have little emotional connection to the subject (O’Connell, 1991). Emotion has its own sense of power, not of coercion, but of suspension and interconnection (Mazis, 1993). It has the power to hold us, to compel us to stay with the emotion, to learn about our inner selves and understand our thoughts and feelings about diabetes.

Some educators are concerned that it takes too much time to think about feelings and multidimensional ways of knowing. Incorporating creative aspects into the classroom or clinical appointments does take time, but time is not the only issue. By

altering current educational practices, the educator may actually *gain* time, rather than *lose* time at each meeting (Gordon & Duffy, 1998). No matter what the educational setting, time is always limited, and adult educators want to find ways to use interventions or strategies that are useful to learners during the limited time available. One way the interactions during classroom time or clinical appointments may become more meaningful for both educator and learner is by attending to the multidimensional ways adults learn. There are multiple ways in which educators may incorporate affective dimensions of care into practice, two of which are reflecting on the educator's *own* meaning of teaching and assumptions about the learners and the subject; and incorporating a narrative structure of interviewing. These recommendations for practice are described below.

#### *Reflect on One's Own Meaning Making Processes*

During this study, participants reflected on their own meaning making processes and what the experience of diabetes was like, and it was important for me as the researcher to reflect on my own assumptions and feelings about teaching, learning and diabetes. From my philosophical perspective, I also considered what these reflections mean to me as a cultural being, one who lives within a Western society that values rationality, and how my actions may be perceived as divergent or deviant from the norm. Before entering a classroom or a patient visit, educators need to take an introspective and reflective look at their *own* assumptions about teaching, the subject, and the beliefs, cultural understandings, and meaning making processes of their students. Although Palmer (1998) takes a humanist approach to teaching and learning, I agree with his statement that we need to understand ourselves so that “we can serve our students more

faithfully, enhance our own well-being, make common cause with colleagues, and help education bring more light and life to the world” (p. 7). From there, we can raise awareness of where we feel oppression and when we experience freedom from our own internal and external forces that disconnect us from our sense of meaning.

Although it is important for educators to help students create a functional and rational meaning of the subject being taught, where they learn the content coursework or know what to do medically in order to take care of their disease, it is also important to consider the psychological or symbolic meanings of the learning experience. Each educator will have a different comfort level in dealing with the emotional side of teaching, the subject being taught, and with each student. It takes courage to stand back from educational pedagogy and the way “things have been done,” to let go and allow the imagination, emotion and creativity flow. Like Plato, many educators and clinicians may object to the increased flow of emotions because they can move us and take us into a world that is not under rational control (Mazis, 1993), but just as we expect our learners to be open to what is to be learned, so must we as educators be open to the multiple ways in which students come to know and learn.

In a traditional approach to adult education, the role of the teacher is to provide knowledge to the student, and the student absorbs information from the teacher, in order for learning to occur (Bounous, 2001; Elias & Merriam, 2005). Objectives are set for the student to reach, and the behaviors are reinforced if the objectives are met. In diabetes education, this relates to medical professionals who are used to adjusting insulin regimens, recommending diet and exercise, and dealing with medical questions. This takes me back to the photo of *Dry*, where there are patients thirsty for more than what the



medical establishment is providing. They search for water, but all they find are prescriptions, medications, and solutions to their diabetes. What they need is not a cure for diabetes, but a need for healing, meaning, and respect for the whole of their being. From a feminist perspective, perhaps they feel dry because they are tired of patriarchal systems of power. They may work all day under oppressive dominant powers, and then come home and experience the same with their spouse or significant other. They go to the physician's office, and find that health care is also reflective of the larger society, which therefore mirrors the inequalities within it. Although built on a masculine system of humanitarianism, health care is also under the arm of capitalist terms which can commoditize patients and their illnesses (Jiwani, 2000). We are dry, and it takes courage to replenish the water of our spirits, to find the energy to say, "I will continue. I will help to make the world whole again."

It does take courage, but the challenge exists for educators to begin by reflecting inwardly to discover more about themselves and their meaning making processes. Although there are many ways in which educators may do this, some of which may involve creative expression through painting, modeling, or gardening, for example, there are also ways in which this could be explored through open-ended questioning. Some examples include: (a) Why is it important for me to attend to the affective component in education; (b) What is my comfort level in dealing with deeper issues other than functional, technical, rational and/or medical questions; (c) How would I feel if I were in the learner's position (for example, if I were the student, or the patient with diabetes); (d) What would be some changes that I would need to make if I were a student (or if I

had diabetes); (e) What do I like and dislike about working with students or patients with diabetes; and (f) What does being an educator or clinician mean to me?

Responses to these types of questions can help educators begin to understand their own meanings associated with teaching, their students, and the subject at hand in order to create an environment supportive and flowing with multidimensional knowing, meaning and learning. This is not the only way to engage affective dimensions of knowing, but it is a way to begin the process of meaning. To complement this approach, practitioners can use a narrative approach to interviewing as a pedagogical methodology to attend to the affective dimensions of learning and focus on the person in front of them in a holistic way.

#### *Incorporate a Narrative Approach*

The initial interviews in this study were valuable in many ways, not only for planning the action research and analyzing the themes of the participants' previous experience with diabetes, but for helping the participants feel heard and understood. By taking a narrative approach to interviewing and asking, "Tell me about your diagnosis," I was able to discover more about the context surrounding the participant's meaning of diabetes than by simply asking, "How are your blood sugars?" For instance, knowing that Camilla's son had died helped me to understand her resistance toward medical care. In hearing about Daisey's issue with body image, her previous decisions to not want to take care of her diabetes were contextualized within other identities of gender and societal's demands for women to look "perfect." If she were a male, for instance, would the scarring on her body be as much of an issue for her? This is somewhat rhetorical, but thinness and investment in appearance are feminine norms in society (Mahalik, Morray,

Coonerly-Femiano, Ludlow, Slattery & Smiler, 2005), which are exacerbated by diabetes. This theme of gendered non-perfection because of diabetes was displayed through Daisey's images, photos, and narrative interviews.

Narrative is not necessarily a postmodern, nor a gendered, way of knowing. However, the narrative interviews were a way to establish a connection, which is also an affective way in which women come to know and learn about their selves (Belenky et al., 1986; Gilligan, 1982) and it allows for multiple directions of conversation to flow. Although it is not practical to hold two-hour interviews with each student or participant (as in the initial interviews), practicing a narrative approach to interviewing does not need to take a great deal of time. One focused question that connects to the heart of the issue, rather than a dozen that do not, can save time and introduce important matters that otherwise would have taken years to disclose (Charon, 2004b). If a student or patient appears to be having trouble in class or at their appointment, educators could ask a question during a one-on-one meeting such as, "Tell me about your struggles with this class (or with your diabetes)?" and then write the student's response. In turn, the educator would repeat back portions of the story, and ask, "Did I get it right?" This helps educators to know that they have heard the learner correctly, and that they are using the learner's words to communicate the meaning of the narrative and better assist in the learner's situation.

To bring affective dimensions of knowing into adult education contexts does not necessarily mean talking about feelings directly. In fact, some of the examples that follow do not include a "feeling" word. Educators in nearly any setting from informal to clinical could pose questions that expose the affective dimensions of knowing and allow

thoughts to rise to the surface, which may have been repressed or unknown for many years. Educators can ask learners to show them, through words, journals or artwork, for instance: (a) How does this course (or diabetes) impact your life, both negatively and positively; (b) What are some things that motivate you to do better and what are the barriers; (c) What is important to you in your life, besides this class (or your diabetes); (d) What could I do differently to help you; (e) What scares (concerns, frustrates, makes you angry) you about being a learner (or having diabetes)? Exploring questions such as these often encourages dialogue and affective ways of knowing, and deepens the sense of mutual commitment and investment in the learning experience. This narrative approach helps to break down the dichotomy of patient/teacher, good/bad learner, and compliant/non-compliant patients. The power is established through an emotional connection between educator and learner. In this way, learners can feel comfortable expressing their thoughts and feelings about their experiences inside and outside of the classroom or appointment, not just the academic or medical reasons of how they should be acting or behaving as a “good” student or patient.

Reflecting on assumptions about practice and introducing a narrative approach opens the space for affective ways of knowing, but sometimes words are not enough to express an experience. Questioning assumptions and talking about our meaning making processes can take us only so far. Then it is up to the wings of imagination and creativity to allow us to fly. An introductory look into implications of creative expression and multidimensional ways of knowing in practice is described below.

### *Incorporating Creativity in Practice*

In patient education, much of the traditional approach to diabetes care primarily comes from a cognitive-behavioral perspective (for example, Berkel, Poston, Reeves, & Forey, 2005; Bodenheimer, 2003; Fox & Kilvert, 2003; Gottlieb, 2004; Graves & Miller, 2003; Hall, Joseph, & Schwartz-Barcott, 2002), but not a creative one. The diabetes literature relating to creative and artistic expression was minimal, and that which was included was either in the form of a recipe book (Kerr & Kerr, 2004) or seemingly juvenile activities (Graham-Pole, 2000). Likewise, in adult education, the cerebral and the objective tend to dominate practice (Michelson, as cited in Yorks & Kasl, 2002), although several educators have begun to write about and research the creative dimensions of learning in practice (for example, Armstrong, 2005; Lawrence, 2005; Olson, 2005). This action research study used creative expression (particularly body knowing, metaphor, imagery and photography) with adults who had diabetes, but creativity in adult education can be used in nearly an infinite number of ways. This section focuses on two ways in particular; first, the imagination as a way of knowing in practice and then the use of metaphor and image to describe concepts in teaching.

#### *The Imagination as Knowing*

The use of the imagination is a powerful way to communicate meanings of an experience, as displayed through the images of the participants' photos of diabetes. One example was Roberta's additional photo of a parking meter, running out of time (Figure 18), which held multiple meanings of physical and spiritual death. Parks (as cited in Tisdell, 2005) talked about the role of the imagination in spiritual experience. She explained that when there is some type of conscious or unconscious conflict, one pauses

or moves away from consciously dealing with it. There is some type of image or insight where the conflict is removed and recast, a repatterning, and then an interpretation or testimony about the experience. To relate this to the adult education learning environment requires, well, the imagination.

In research, for instance, ideas are generated from the world of the imagination. Parts of a research idea may come from literature, parts from discussions with others, but it also comes from deep within. Research does not begin in a clinical laboratory, but emerges from the imagination in a place where personal experience meets with the possible. There is an intuition or an idea that is sparked and the learner begins asking, “What if?” or “I wonder how?” From that curiosity comes a research question.

In a graduate research class, for example, where students are beginning to think about topics, this is a wonderful opportunity to use the imagination and creative expression in practice. The professor could ask students to write down or discuss their many possible research ideas, then pause and change the direction of the conversation by using a creative intervention. The professor simply asks, “What color makes you feel the best?” and then learners may decide whether any of those potential research ideas match that color. If there is one that feels more “purple,” for instance, then students can begin working with that idea until it matches the intensity of the color. In other words, the color which appears in the visual mind is the learner’s passion, the feeling, the affective dimensions that flow through that research topic. One could do the same thing with music, or smell, or other sense of image.

In patient education, a similar intervention could be used that relates to the use of color, sight, smell, or sound. Instead of asking, “How are you feeling today?”

practitioners could ask, “If you could pick a color of how you are feeling today, what would it be?” Although not all educators may feel comfortable using color per se, they might feel more comfortable using other aspects of imagination by drawing on music, dance, story, etc. in their practice. The point is to find a creative way of understanding the world and getting at meanings that are deeper than what appear on the surface, and this is helpful in any educational setting.

### *Metaphor and Image to Describe Concepts*

There is a lack of research using the imagination, symbol, or creative expression in order to make meaning of feelings about diabetes. Yet, people frequently use metaphorical language, similes and images to describe concepts, such as, “It was colder than ice -- He drove like a bat out of hell -- I nearly fell off my chair.” Wright-St. Clair (2003) said, “People often use metaphors when it is hard to depict the subjective meaning of things in everyday words” (p. 46). Metaphors and images are similar in this way, in that they may have multiple interpretations of meanings by the use of one word or photo. For instance, if I am a professor in an organizational development class trying to explain the concept of linear and non-linear systems, using words or lecture alone would take quite some time and would probably not generate much class interaction. Using a metaphor of a baking recipe for a linear system, or a cooking recipe for a non-linear one could lead to a meaningful discussion of how these two metaphors are similar and different, and how this relates to the subject at hand. Learners could be encouraged to develop their own metaphor, based on their own understanding, as a class portfolio assignment. The professor could have given a written examination of the material, but

using metaphor as a description is one way to check for knowledge and understanding, as well as incorporate creativity and multidimensional ways of knowing in adult education.

Although lengthy to include in this section, specific recommendations for including creativity in patient education are listed in Appendix M, and include:

(a) Engage patients upon arrival; (b) Use imagery to help patients who are “stuck;” (c) Address multiple ways of knowing in small groups; and (d) Add creative educator and/or counselor role to facilitate creative aspects to diabetes care. These recommendations will help patients be more comfortable during their visit, use imagery as a way of understanding the meaning making process of patients, and use creativity in small groups, facilitated by an adult educator.

#### Limitations, Strengths, and Suggestions for Further Research

Although this action research study addressed an important need for more understanding of the meaning making process and experience of those with diabetes, and the ways in which creative expression may contribute to that meaning, every study has its strengths, limitations, and suggests implications for further research. At this point, it is important to remember that results are not necessarily generalizable in qualitative research, which is neither a strength, nor a limitation, but the nature of the research. Rather, it is up to the reader to determine if the results can be applied in similar situations. With regard to this study, the limitations are considered first, then the strengths, followed by suggestions for further research .

#### *Limitations of the Study*

Listed below are five limitations recognized in this action research study. Some emerged during the action research process, and others were realized after the study was



completed. Although the research was a beginning look into the experience of diabetes, which added to the literature on meaning making through creative processes, it had several limitations. They included: limited time for repetition of action research cycles; lack of internal and external controls; relative lack of diversity of the participant group; exclusion of those with limited access to health care; and the recording process itself. The limitations are discussed below in that order.

First, incorporating creative expression requires a significant amount of time and trust on the part of both the teacher and learner. The amount of time spent in action research in this study was somewhat limited (three sessions of two hours each). Additional findings may emerge through more opportunities to discuss the meanings of the images and more repetitions in the action research cycle. Also, more cycles would increase the interaction and the comfort level among participants, which would further enhance the co-construction of knowledge. Agnes wished we could have had more time, and Emily said the only thing she would change about the study was “maybe we could do more.” Time also limited us from testing the “postmodern action research in metaphor” process at this point to see if this revised way of thinking of action research is helpful in other situations.

Second, the emerging nature of action research lacks in internal and external controls (Merriam & Simpson, 2000) and its design, though flexible, is also tenuous because there is not a specific plan initially. In the recruitment process, for example, participants wanted to know what they were going to *do*, and I told them it would depend upon the interests of the group. If there is not an amount of trust and confidence in the instructor, this could lead people to be reluctant to participate. Coral said, “I had no

expectations for this. I can't see anything [to change]. One thing is that you really got all of us to open up and talk. Yeah, I had no clue what to expect." Although the design is fluid and unpredictable, all the participants who began the creative cycle in action research followed through to the end. Neither did any one say that they did not want to participate because there was not a solid plan; rather, they enjoyed the participant-led approach.

Third, the diversity of the participant group was a limitation. In the literature, one critique was that the majority of studies focused on white participants and they were not inclusive of other ethnic identities and socio-cultural dynamics. If they would have been, perhaps other forms of making meaning would have emerged. This is true for my study as well. Although I attempted to recruit both men and women with diabetes of diverse ethnicities, the population who seeks medical attention at the Penn State Hershey Diabetes Center is largely white and middle-to-upper class. Further studies could include diverse socio-economic groups for example, to determine how financial issues affect meaning making processes. Only Camilla mentioned her being "dirt poor" and having difficulties as a child. The fact that we all owned digital cameras spoke somewhat of our economic status. The experiences of varied and diverse groups would add to the richness of the data.

Fourth, this study is based upon a group of women who have access to medical care, but diabetes mellitus (Type 1) and its complications disproportionately affect minority citizens in rural communities, many of whom have limited access to comprehensive diabetes management services (Bray, Thompson, Wynn, Cummings & Whetstone, 2005). This study is limited to recommendations for family practice and/or

organizations that deliver specialty care. It does not attempt to resolve issues of inequality between those who do or do not have access to care, which is so critical, particularly considering that this study is informed by a feminist poststructural perspective. However, the purpose of this study was to understand the experiences of a select, purposeful sample, and introduce creative expression as a way of improving diabetes care by attending to other ways of knowing.

Lastly, the recording process and the knowledge that the participants' words would be used in a written dissertation changes the level of candidness of the interviews to some degree. Participants were limited by what they wished to have recorded on the digital voice recorder. Explicitly, Roberta spoke more openly with me after the recorder was turned off. This brings the limitation of myself as a researcher in the ability to know how much the participants chose to keep silent, and how much they chose to share. In this way, words themselves can be limiting, which is one reason to encourage the use of creative expression and imagery in tapping into the subconscious, and unknown, parts of our selves.

#### *Strengths of the Study*

The study clearly has many strengths. Participants had not previously engaged in creative expression as a way of making meaning of chronic illness, and few thought about feelings and the experience of having diabetes prior to the study. A discussion of this strength, and others, are listed below. They include the appropriateness of the action research methodology to the study's purpose; the inclusion of multifaceted ways of knowing in diabetes care; contribution to improved practice; and the experiences of those with diabetes were written and heard.

First, the action research methodology was appropriate to the purpose of the dissertation, which was the use of creative expression in diabetes care. In the planning cycle of narrative interviewing, the participants were able to discuss their experience and meaning making processes, which were used in the development of other cycles that used creative expression and multifaceted ways of knowing. Eight participants was an appropriate number for this type of methodology, and each contributed to the construction of knowledge and meaning making in the cyclical phases of the research. The methodology also allowed for my dual role as both participant and researcher, which was a strength in the study.

Second, the inclusion of multidimensional ways of knowing questioned existing medical care and what is considered “knowledge.” The creative sessions in this research attended to the psychosocial aspects of having diabetes and highlighted the value of the emotions and the imagination to help people with diabetes find healing. By using imagery and photography, the participants thought cognitively and reflected affectively on the experience of diabetes, and added our narratives and experiences to the literature on meaning making and chronic illness

Third, the findings in the study are a contribution to improved practice and attention to many ways of knowing. Hartrick (1998) recommended further consideration of the relevance of personal meaning for holistic diabetes care. Hartrick believed that a greater understanding of what it means to live with diabetes can serve to “inform and expand the existing perspectives of diabetes and perhaps contribute to the development of more holistic models of diabetes care” (p. 77). This action research study incorporated a

whole-person approach to diabetes care through the use of narrative and creative expression.

Fourth, the experiences of the participants were recorded and heard. Anderson and Hernandez (as cited in Hartrick, 1998) said that “practitioners’ perspectives, and the diabetes care that emerges from them, fail to address aspects that are meaningful to people with diabetes” (p. 76). All of the participants in the study benefited from their involvement including myself. We were given the opportunity to talk candidly, some for the first time, about what having diabetes means. It was a privilege to be one voice among many who have diabetes and to speak on behalf of millions of others who are struggling with the disease. We realized we are not alone, and there are other ways of knowing and multiple paths to meaning making.

#### *Suggestions for Further Research*

In conducting this action research, perhaps more questions have been raised than answered. The purpose of this action research study was to understand how adults experience, and make meaning of, diabetes and to use multifaceted ways of knowing in the integration of diabetes care. The questions below are beginning points in the search for more knowledge about the personal experience of diabetes and the meaning making process. There are multiple ways in which this study could be expanded, one of which could include research with other chronic illnesses and diseases. Thorne and Paterson (2000) said the:

The commonalities and variations within chronic illness experience make it apparent that neither a disease-specific nor a generic approach alone creates an

understanding of the phenomenon of what it is like to live with a chronic condition. (p. 9)

It would be interesting to research how creative expression could be used in care for those with epilepsy, for example, or chronic fatigue syndrome. Would similar patterns, colors and shapes emerge for other illnesses, or is there something in particular about insulin-dependent diabetes that creates an image of a wedge, for example? Another group to include in this study would be those with non-insulin dependent diabetes, as even the word “diabetes” is not an umbrella term and there are differences between those with insulin and non-insulin dependent diabetes. By expanding the research to include other chronic illnesses, as well as non-insulin dependent diabetes, the findings could be compared to see how the meaning making experiences and the expressions which come from different illnesses connect and where they may diverge.

This action research contributed to the study of the experience of diabetes, but these results are not necessarily generalizable to *all* people with diabetes or *all* chronic illnesses. It is up to the reader to determine what is generalizable. Robert Gabbay, Endocrinologist and PhD, stated that the themes and the participants’ comments in this dissertation were similar to most of the patients he sees in the clinic, so although the results may not be generalizable, they mirror the comments he receives from patients (personal communication, February 26, 2007). From a feminist poststructural view, it would be important to research the ways in which men and women, those of different ethnic groups, and social class respond differently to creative expression. It is my belief that adult educators and learners benefit from partnerships that value perspectives of both those within and outside the group during knowledge construction (Deshler & Grudens-

Schuck, 2000). Because of my positionality as an insider with diabetes, it would also be beneficial to have the perspective of a researcher without diabetes to conduct similar research. I welcome more voices to come together to paint more strokes of the brush on the canvas.

One of the findings in this study suggested that participants tried to maintain a positive outlook in their experience with diabetes. A question which was raised for me is to what extent having a positive outlook contributes toward meaning making and overall health? In what ways does having a chronic illness relate to having a more positive philosophy of life, more or less? And what about faith or a person's connection to spirituality and a sense of hope in chronic illness? Because all of the participants in this study expressed a faith in a Christian God, how would those of other spiritual or religious traditions facilitate meaning making? These are all questions that relate to positive outlooks on life and spiritual expressions of greater healing and meaning.

While conducting the action research, I wondered how different personality traits (such as extrovert and introvert) affected the experience of diabetes. From those in the group, Camilla and Coral were mostly extroverted, and Emily and Roberta were more introverted. Are there commonalities between introverts and extroverts in their meaning making processes? From an adult education perspective, it would be important for physicians to know the learning styles and personalities of the patient in order to suggest treatment plans that would be more in line with the patient's needs. Along the same line, Coral's support system appeared to be very strong. It would be interesting to research how those who are alone in their diabetes care and those who have a strong system of support make meaning.

Another question for research is the ways in which developing a chronic illness as a child changes the perception and experience of the disease. Coral, for instance, was the most positive person in the study. Agnes said that Coral was “completely different altogether.” What contributes to that? In addition to her having a strong support system, she was the only one in the study who was diagnosed after adolescence. In what ways are the meaning-making processes different from children and adults? Although this was a study specific to adult education, it is important for other researchers to understand the meaning making processes of children, who eventually grow into adult learners.

In this study, participants used body imagery, shapes, and photographs to communicate their experience with diabetes. It would be interesting to research other forms of creative expression, and how participants respond to different medium. What happens when the type of creative expression is familiar to the participant and how does it matter in the meaning making process? These questions relate to the trial of other approaches in creative expression and add to the findings of this study.

Although this qualitative action research study was not intended to measure the longitudinal effects of diabetes on medical health, this is where research is not exclusively either qualitative or quantitative, but a blending of the two to help in the understanding of creative expression in diabetes. Since many traditional approaches to diabetes care are not effective in improving health, to what extent does introducing creative expression in diabetes care improve blood glucose over time and how does that help with the perception of greater meaning and wellness? Continuing research in this area would have significant implications for both medical and adult education practice.



These types of questions will add a greater understanding to the themes found in this study, as there was little (to no) research conducted prior to this one. My hope is that my work, and the work of other researchers, can continue to improve the lives of those with diabetes and the way many ways of knowing are incorporated into a holistic approach to diabetes care.

### Conclusions

This is how I write it, moving with the spirit, the soul, the energy of those with diabetes who have gone both before and after me. Diabetes is not just a physical disease. It has a psychological, spiritual impact, which is greater than the way it has been discussed in the adult education and medical literature. I see how diabetes has impacted lives spiritually, emotionally, somatically. There is a burning need to call the creative component forward to express a spirit of meaning and purpose. As a summary, I have included my own personal learning and experiences as a participant, responding to the findings and the feelings of the other participants.

Today, as I am writing this section of the dissertation, my blood sugar has gone from 109 to 422 back to 85 in a few hours of time. I am reminded how fragile life with diabetes is, and I cannot change that. What gives me meaning is to be able to use the creative processes of my imagination, and help others see those aspects within themselves. Communicating those images, and having people understand themselves, or life, in a new and transforming way, gives birth to healing. As a participant, I wanted to share parts of my own narrative, and personal thoughts about the learning and meaning making journey.

As *Dry Bones* speaks of anxiety, worry, and fear of complications, these emotions have been with me throughout most of my life. I have been constantly on the lookout, for things like "What's that twinge?" and "Should I be worried?" In part, this research was a way to explore others' emotions surrounding diabetes, as well as finding more meaning in having diabetes myself. As I take a look under the cover of other people's experiences with diabetes, I have come to know and learn that looking for meaning is constantly shifting, always changing, and can be discovered through narrative and creative expression. As I told one participant, "It's a personal journey, but is also really great to hear other people, who are not perfect with their diabetes, and they are part of the journey with me." The comments below reflect the conversations I had with participants during the initial interviews, and some additions, based upon insight gained through the evaluation of the themes.

### *Reflections on the Interviews*

The theme of resisting against diabetes and medical staff reminded me of the first time the A1C test was done in doctor's offices. I was frantic, because I had just been fudging my numbers until that date, and I remember the doctor saying, "Can you test your sugar for me?" I thought, "I am caught. *They* are going to know I'm not taking care of myself." There was not as much a concern for my own well-being and blood sugar control, as a concern over what my doctors would think of me. I would no longer be a "good" patient.

This thinking can be traced back to my German heritage and family dynamics, where it was more important to be good than to share feelings of negativity. In a way, having diabetes was a catastrophic event for me, and on another level, I treated it as a

bump in a road. Was it a bump, or was it a volcano forming? The more something looked like it was fine on the surface, then I reasoned that meant that things were OK. But, things were far from fine, and I spent several visits in the hospital with DKA (high blood sugar). Physicians tried to get me to write down my blood glucose numbers and determine patterns to improve my risk for complications, but I simply wasn't interested.

I have had a few complications related to diabetes, of which the most life-changing was proliferative diabetic retinopathy. Even as I was conducting the initial interviews, I had a large body of fluid in my right eye, which came out of nowhere. I told one participant:

You think that it would have been caused by something big, like a football hitting my head, but I was just sitting there watching TV and all at once I saw it. It was bigger than I've ever seen before. So I went back to [my ophthalmologist] who did my laser surgery, and I saw this pool of blood. I thought that it wasn't quite normal. I can handle a little floater now and then. I don't get freaked out, but this is big.

Retinal surgery was not pleasant, and I wrote about the experience in *Diabetes Forecast* (1996). In that article, I talked about how my left eye had hemorrhaged. On the day of my appointment with the ophthalmologist, I entered a small room with bright cinderblock walls. Humming sounds and drips from the laser cooling system disturbed me as I waited for the unknown. The ophthalmologist encouraged me to be strong as he glued a round stabilizer to my eyelids. With my chin and forehead trapped against steel, the doctor aimed the first laser shot. At first, I did not feel pain. Two, three, still nothing. Twenty, thirty, forty: the back of my eye pinched. Two hundred, three hundred. My eye

ached from the sharpness. As the doctor consoled me with, "You're doing fine," and "Hang in there," only one emotion surfaced: anger. Anger at the doctor for giving me the treatments; anger at my eyes for being imperfect; anger at myself for not keeping my diabetes in control; and anger at my diabetes for being so cruel.

Although having diabetic retinopathy changed my behavior for a time, the transformational moment in taking care of my diabetes was the birth of my son in 1996. As pregnancy was a motivation for many of the women in the study, I also said, "I do think about how I want to be around for him [my son] when he gets to the older." I want to see him grow through middle school, and high school, and off to college or to work. Although I want to keep things stable for my own health and well-being, he is my inspiration for taking care of my blood sugars even when they fluctuate. It is hard to explain how difficult it is to achieve average numbers and how unpredictable this can be.

One time I was teaching, and I had a low blood sugar. I didn't announce to the class, "I'm having a low blood sugar." Of course, I needed something to eat, but there can be such a mixed reaction in the classroom to a medical issue. There are people who become frantic and say, "She's having a low blood sugar!" And there are some people who just don't know what to do, and there are some who get worried. I could feel it coming on, because it takes a little bit of time. As I was telling the class about an idea, I thought:

OK. I'm good. Quick, move them into an exercise with groups, go and take care of your blood sugar without this becoming an event, and return to class the way you were. No one will think anything of it.

I just didn't feel like announcing it or making it public. Having a low blood sugar is a private experience, and it can come to the foreground at the most inappropriate times.

Like the others in the group, I generally take a positive spin on diabetes. This doesn't mean that I think it's wonderful, and I still don't like wearing the insulin pump. After several years, it is still difficult to figure out where to put it on a swimsuit. Or when I'm taking a shower. Let's just say I would rather not have it, but, the pump does make my life easier and maybe better. I don't have to like it. That's the way that I think about the insulin pump. I also think that things could be worse. Having diabetes is not as bad as being ... and I could finish the sentence a thousand ways ... in the intensive care unit, diagnosed with MS or some forms of cancer, dead. And yet, we may have some of the same fears and feelings as those who have a terminal illness. It is frightening. It can be awful, which is why I try to help myself and others make meaning of diabetes, and see how we can find greater strength and wellness with the opportunity for internal healing.

#### *Personal Meaning Making Processes*

Each participant's creative photographs felt like what diabetes is to me, and I bring my own sense of meaning to the images. Diabetes is a broken heart, filled with pieces of diabetes complications, hurt for the way in which I did not take care of myself when I was younger, feelings of being a little girl, afraid and alone. Diabetes is like Ms. Potato Head because my thyroid is not regulated, and there are times when I feel fat and irritable, but I put on a happy face and say, "Everything is fine." Diabetes is like a one-way ticket, not allowing me the freedom to escape from it, or to take a break. It is always there. The eyes represent diabetes because they are the area on my body which has suffered the most surgery and damage from high blood sugars. Floaters and fear of

blindness remind me that I have diabetes. To diabetes, I say, “Keep out! Stay away from me!” The red “X” is a sign that says, “No diabetes!” Diabetes is like a wedge, because it keeps me from feeling healthy. I am not completely healthy, nor entirely ill. If I could remove the wedge, then I would not have to live in this in-between world. And then there is the kite of friends, family and support, for whom I am grateful, and they have allowed me to fly higher than I could on my own.

These images have added to my understanding of diabetes, and the process has strengthened my love for creativity. Although I may have known this on some level before beginning the study, I realized that I make meaning of diabetes by expressing my feelings in images, and communicating those with others. Imagination and creativity is connected to the spiritual feeling that having diabetes has given me resilience, purpose and drive. For one thing, I would not have conducted this research if I did not have diabetes. I call this spiritual feeling a “river,” which takes me from the desert of dry bones to a place of water and rest. I continue to make meaning in this way:

*To become integrated and whole, allow the river to flow through you. Allow the sense of value and great worth to fill your heart. Flow, and open your spirit to the knowing that you have been given diabetes not to harm you. Your body is temporary, but your purpose lives through the searching souls of others. I have not punished you, my child, by giving you this chronic illness, but you are strong, creative, and able to see the hearts of those in suffering. Your throat and lungs respond to the souls of sorrow. Look within. Do you understand the river flows through you to give you the heart to continue? By having diabetes, you have a story to tell, a purpose in helping other people see what they cannot express.*

*You may view your diabetes as a punishment, but it is a way to reach other souls who need to know the river. They are thirsty, they are dry, and you sense the beads of tears in the corner of their eyes. You bring them from the dry land and you show them the flowing water. You have chosen to help those who suffer because you have known suffering and lies, and you have known light. Feel the river travel through your veins and through your heart center. The river is love. Love for yourself. It is a spirit of awareness and meaning. You radiate the love of your keeper and light. She brings the peace that comes to your life; allow the river to flow. Do not resist the river. Do not fight it. The river comes from the Mother of Peace and the Father of Love.*



*Figure 25. The river of love and peace*

The flow of this river is infinite, continuous and shifting. As I was re-reading Chapter Four and the dry bones metaphor, I again felt how difficult diabetes can be, and how focusing on the river helps me to get through the dry land. How close death is to each of us who live, and how the breath of new life is close to each of us who face death. We each have our own river and breath, our own meaning and flow, and my hope is that all people can find a place of restful peace.

Appendix A: RECRUITMENT PAMPHLET

(COVER and INSERT)

**INTERESTED IN A DIABETES RESEARCH STUDY?**



**CREATIVE  
EXPRESSION  
IN  
DIABETES CARE**



**Penn State Milton S. Hershey  
Medical Center  
Penn State College of Medicine  
Penn State Harrisburg**

IRB # 23073  
5/5/06



**The PURPOSE of the research is to:**

- Interview patients to determine how they make meaning of having diabetes; and
- Use creative expression to explore how adults use imagery to understand and make meaning of their diabetes.

Eight PARTICIPANTS are needed, and each must:

- Have Type 1 diabetes for 10 years or more
- Have an A1C greater than 7
- Be age 21 or older

Benefits include an opportunity to explore alternative ways of making meaning and “coping” with diabetes. No medications will be given or adjusted during the research. The study is conducted free of charge to participants.

This study is being conducted at the Penn State Milton S. Hershey Medical Center under the direction of Heather Stuckey, M.Ed., Department of Endocrinology, at the Penn State Diabetes Center.

**Interested participants may contact Heather Stuckey at (717) XXX-XXXX or via e-mail at [HLS119@psu.edu](mailto:HLS119@psu.edu) for more information.**

This research study has been approved by the Institutional Review Board, under federal regulations, at Penn State Milton S. Hershey Medical Center.

## Appendix B: INFORMED CONSENT FORM FOR RESEARCH

IRB Protocol No. 23073EP  
Version Date: 5/5/06

**CONSENT FOR RESEARCH**

Penn State College of Medicine  
The Milton S. Hershey Medical Center

This form is not valid unless this box  
includes an approval stamp by the IRB

(on file)

Title of Project: Healing from Dry Bones: Creative Expression in Diabetes Care

Principal Investigator: Heather L. Stuckey, Doctoral Candidate

Other Investigators: Dr. Robert A. Gabbay, Endocrinology

Participant's Printed Name: \_\_\_\_\_

This is a research study. Research studies include only people who want to take part. This form gives you information about this research, which will be discussed with you. It may contain words or procedures that you don't understand. Please ask questions about anything that is unclear to you. Discuss it with your family and friends and take your time to make your decision.

1. Purpose of the Research:

- The purpose of the research is to explore alternative and creative ways that adults make meaning of their Type 1 diabetes. (Deleted next line).

You are being offered the opportunity to take part in this research because you have Type 1 diabetes and are interested in talking about your feelings about diabetes, and working with creative ways to express what having diabetes means to you.

The purpose of this research is to ask what diabetes means to you and how you can express that. For example, you may be asked to complete the sentence, "Having diabetes is like ..." and then use those images to creatively express your feelings and thoughts.

Approximately eight people will take part in this research conducted out of the Diabetes Center at the Hershey Medical Center.

## 2. Procedures to be Followed:

- You will be asked to participate in five (5) audiotaped interviews/sessions lasting approximately two hours each: two (2) times individually and three (3) times in a small group setting.
- In the first session, you will meet with the PI to discuss your feelings about your diabetes. Next, you will meet three times with the PI and the other participants in this study to explore images, feelings, and thoughts about having diabetes. You will be guided in a way which will help you come up with these images and work through the creative process. Here is an example: You tell me during the first interview that you used to have a garden when you were younger, but now you miss being outdoors and wish you could find time to do that. During the course of the interview, you also tell me that diabetes feels like a flower, always needing tending and care. We will work with both these images during the course of the research in the form of creative expression to express what diabetes means to you. This project is called “action research” because what we do during the course of the three group sessions is mostly decided upon by the group (such as creating artwork, portfolios, journals, etc.). The time that we meet will be convenient for everyone in the group (determined during the initial interview with you). This is NOT a medical appointment, and you will NOT receive any recommendations about adjusting your insulin or other medications as a result of participation in this research.
- During the last session, you will meet individually with the PI to talk about what you learned from using artistic and creative expression.
- You do not have to share any information that you do not want to share with the group.
- You are free to skip any questions you prefer not to answer.
- All interviews/sessions will be audiotape recorded (both individual and group), and your name or any other identifying information will not be disclosed. The cassette tapes will be labeled “Patient #1” (individual interviews) and “Session #1” (group sessions), and the PI will transcribe the tapes. The tapes and transcripts will be destroyed after the research is completed.

## 3. Discomforts and Risks:

- There are no major risks associated with this study.
- You may experience minor stress or discomfort in discussing issues surrounding your diabetes.
- You will also be meeting and talking with seven other participants about your diabetes, so the information you share in the sessions will be known by the members of the group.

4. Possible Benefits:

- Possible benefits to the participant: The possible benefit you may experience from the research is a better understanding of how you make meaning of your diabetes. You will also come to know and learn more about yourself as a person with diabetes through the use of art and creative expression. There is no guarantee that you will benefit from being in this research.
- Possible benefit to others: The results of this research may lead to further understanding of the experience of patients who have diabetes and contribute to the development of more patient-centered models of diabetes care.

5. Other Options that Could be Used Instead of this Research:

- You may decline to participate in the research.

Instead of participating in this research, you could obtain a similar experience through contacting and working with a mental health care provider who specializes in artistic expression and patient education and/or patient therapy. The benefits and the risks would be similar.

6. Time Duration of the Procedures and Study:

- The anticipated total time commitment will be five 2-hour sessions, or 10 hours.
- The individual interviews, group sessions, and follow-up session/interview will be completed during a four to five month period and will be completed no later than December, 2006.

If you agree to take part in this study, your involvement will last approximately four months. You will be asked to meet at the hospital five times. Each meeting/session will take approximately two hours.

7. Statement of Confidentiality:

a. Privacy and confidentiality measures

- All interviews/sessions will be audio recorded. The audio tapes, transcriptions, and interview sheets will be labeled "Patient #1" (individual interviews) and "Session #1" (group sessions).
- The tapes, transcriptions, and interview sheets will be kept in a locked cabinet at my home. The list that matches your name with the code number will be kept in a separate locked cabinet during the course of the study. I will be the only person who has access to the cabinet. The tapes will be destroyed after the research is completed, and the transcriptions and interview sheets will be shredded upon completion of this study.
- Any artwork, portfolios or journaling that is completed will be labeled as "Patient #1," etc. These artistic expressions will remain in my possession until May, 2007, when the study is completed. You will have the choice as to whether you want me to destroy the art, return the art to you or keep the art for further research. This will be your decision.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.

b. The use of private health information:

Health information about you will be collected if you choose to be part of this research study. Health information is protected by law as explained in the HMC Privacy Notice. If you have not received this notice, please request a copy from the researcher. At The Milton S. Hershey Medical Center (HMC) and Penn State College of Medicine (PSU) your information will only be used or shared as explained and authorized in this consent form or when required by law. It is possible that some of the other people/groups who receive your health information may not be required by Federal privacy laws to protect your information and may share it without your permission.

To participate in this research you must allow the research team to use your health information. If you do not want us to use your protected health information, you may not participate in this research.

Your permission for the use, retention, and sharing of your identifiable health information will expire upon completion of the research study. At that time the research information not already in your medical record will be destroyed. Any research information in your medical record will be kept indefinitely.

If you choose to participate, you are free to withdraw your permission for the use and sharing of your health information and your artwork at any time. You must do this in writing. Write to Heather Stuckey and let her know that you are withdrawing from the research study. Her mailing address is Research & Graduate Studies Office, Penn State Harrisburg, Middletown, PA 17057.

If you withdraw your permission:

- We will no longer use or share medical information about you or your artwork, except when the law allows us to do so.
- We are unable to take back anything we have already done or any information we have already shared with your permission.
- We may continue using and sharing the information obtained prior to your withdrawal if it is necessary for the soundness of the overall research.
- We will keep our records of the care that we provided to you as long as the law requires.

The research team may use the following sources of health information

- Initial narrative interview, portfolios, or artwork

Representatives of the following people/groups within HMC/PSU may use your health information and share it with other specific groups in connection with this research.

- The principal investigator, Heather Stuckey
- The HMC/PSU Institutional Review Board
- The HMC/PSU Human Subjects Protection Office

The above people/groups may share your health information with the following people/groups outside HMC/PSU for their use in connection with this research study. These groups, while monitoring the research study, may also review and/or copy your original PSU/HMC records.

- The Office of Human Research Protections in the U. S. Department of Health and Human Services

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people may become aware of your participation in this study. For example, the following people/groups may inspect and copy records pertaining to this research.

- The Office of Human Research Protections in the U. S. Department of Health and Human Services
- The HMC/PSU Institutional Review Board (a committee that reviews and approves research studies) and
- The HMC/PSU Human Subjects Protection Office

Some of these records could contain information that personally identifies you. Reasonable efforts will be made to keep the personal information in your research record private and confidential but absolute confidentiality cannot be guaranteed.

8. Costs for Participation:

- Participants will incur NO extra expense for participation in this study.
- The cost of any art supplies, accessories, or items needed for completion of this study will be the responsibility of the researcher.

9. Compensation for Participation:

You will not receive any compensation for being in this research study.

10. Research Funding:

The institution and investigators are not receiving any funds to support this research study.

### 11. Voluntary Participation:

Taking part in this research is voluntary. If you choose to take part in this research, your major responsibilities are to attend and participate in each of the interviews/sessions. You will also be expected to engage in creative and artistic forms of expression as they relate to your diabetes.

You do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are entitled.

### 12. Contact Information for Questions or Concerns:

You have the right to ask any questions you may have about this research. If you have questions, complaints or concerns or believe you may have developed an injury related to this research, contact Heather Stuckey, Principal Investigator, at 717-948-6347.

If you have questions regarding your rights as a research participant or you have concerns or general questions about the research, contact the research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687. You may also call this number if you cannot reach the research team or wish to talk to someone else.

For more information about participation in a research study and about the Institutional Review Board (IRB), a group of people who review the research to protect your rights, please visit the HMC IRB's Web site at <http://www.hmc.psu.edu/irb>. Included on this web site, under the heading "Participant Info," you can access federal regulations and information about the protection of human research participants. If you do not have access to the internet, copies of these federal regulations are available by calling the HSPO at (717) 531-5687.

### Signature and Consent/Permission to be in the Research

Before making the decision regarding enrollment in this research you should have:

- Discussed this study with an investigator,
- Reviewed the information in this form, and
- Had the opportunity to ask any questions you may have.

Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.

Participant: By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

---

Signature of Participant

---

Date

---

Time

---

Printed Name

Person Explaining the Research: Your signature below means that you have explained the research to the participant/participant representative and have answered any questions he/she has about the research.

---

Signature of Investigator                      Date                      Time                      Printed Name

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In addition to the main part of the research study, there is an optional part of the research after the research is over. You can participate in the main part of the research without agreeing to take part in this optional part.

Optional Storage for Future Use

As part of this study, we are obtaining from you artwork, portfolios, journals, or other forms of creative expression. If you agree, the researchers would like to keep your artwork so that they can be studied in the future after this study is over. These future studies may provide additional information that will be helpful in understanding others' experiences with diabetes, but it is unlikely that these studies will have a direct benefit to you. If you have any questions, you should contact Heather Stuckey at 717-948-6347.

Your creative items created during this study will be labeled with "Patient #1." If you consent to the collection of your creative items for future research, the period for the use of the samples is unknown. If you agree to allow your creative items to be kept for future research, you will be free to change your mind at any time. You should contact Heather Stuckey at 717-948-6347 and let her know you wish to withdraw your permission for your creative items to be used for future research.

You should initial below to indicate your preferences regarding the storage of your creative items after completion of the study for future research:

- a. Your creative items may be kept and stored by the researcher for future research.

\_\_\_\_\_ Yes (Initial)                      \_\_\_\_\_ No (Initial)

If yes, your creative items may be shared with other investigators/groups without any identifying information.

\_\_\_\_\_ Yes (Initial)                      \_\_\_\_\_ No (Initial)



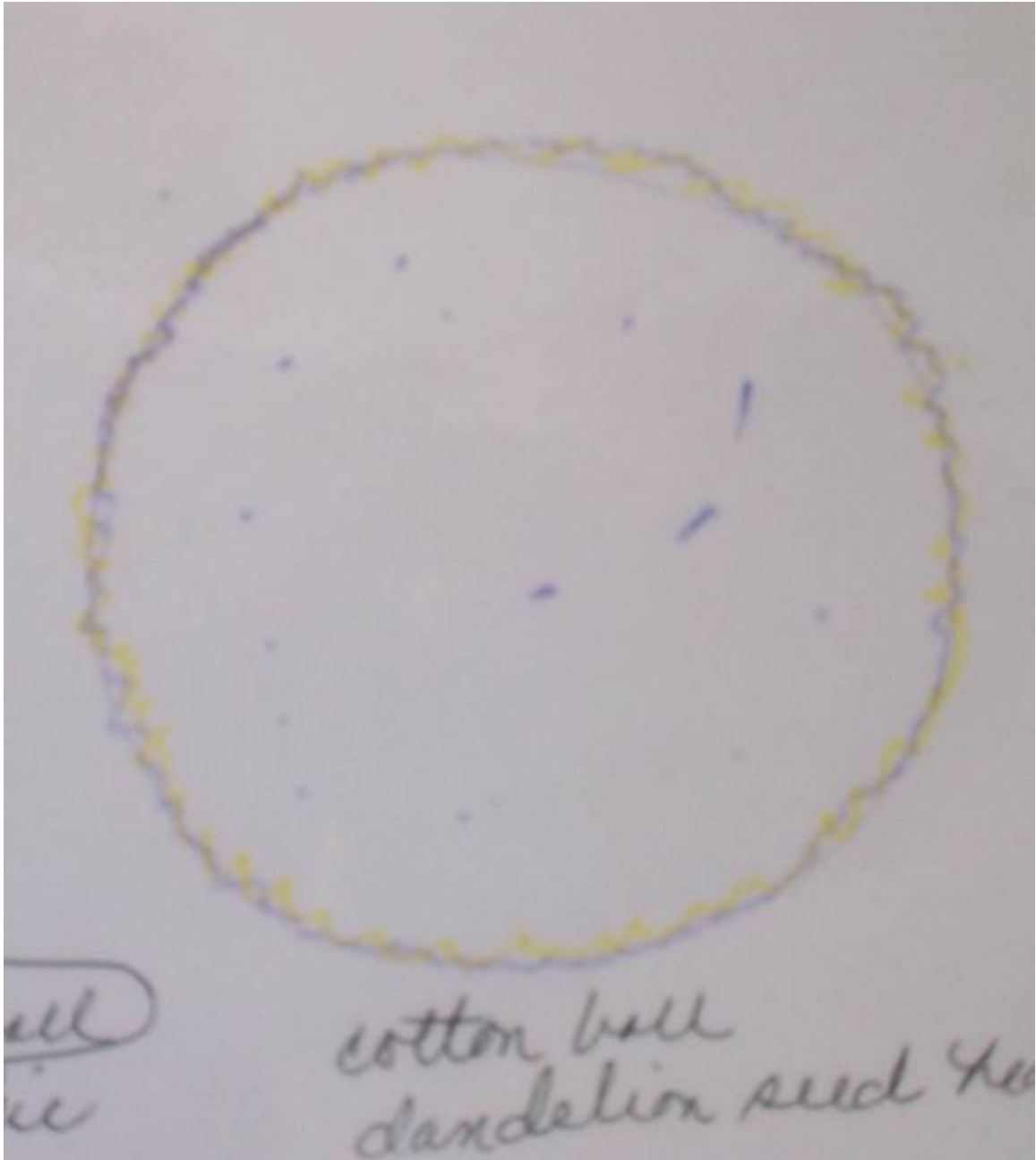




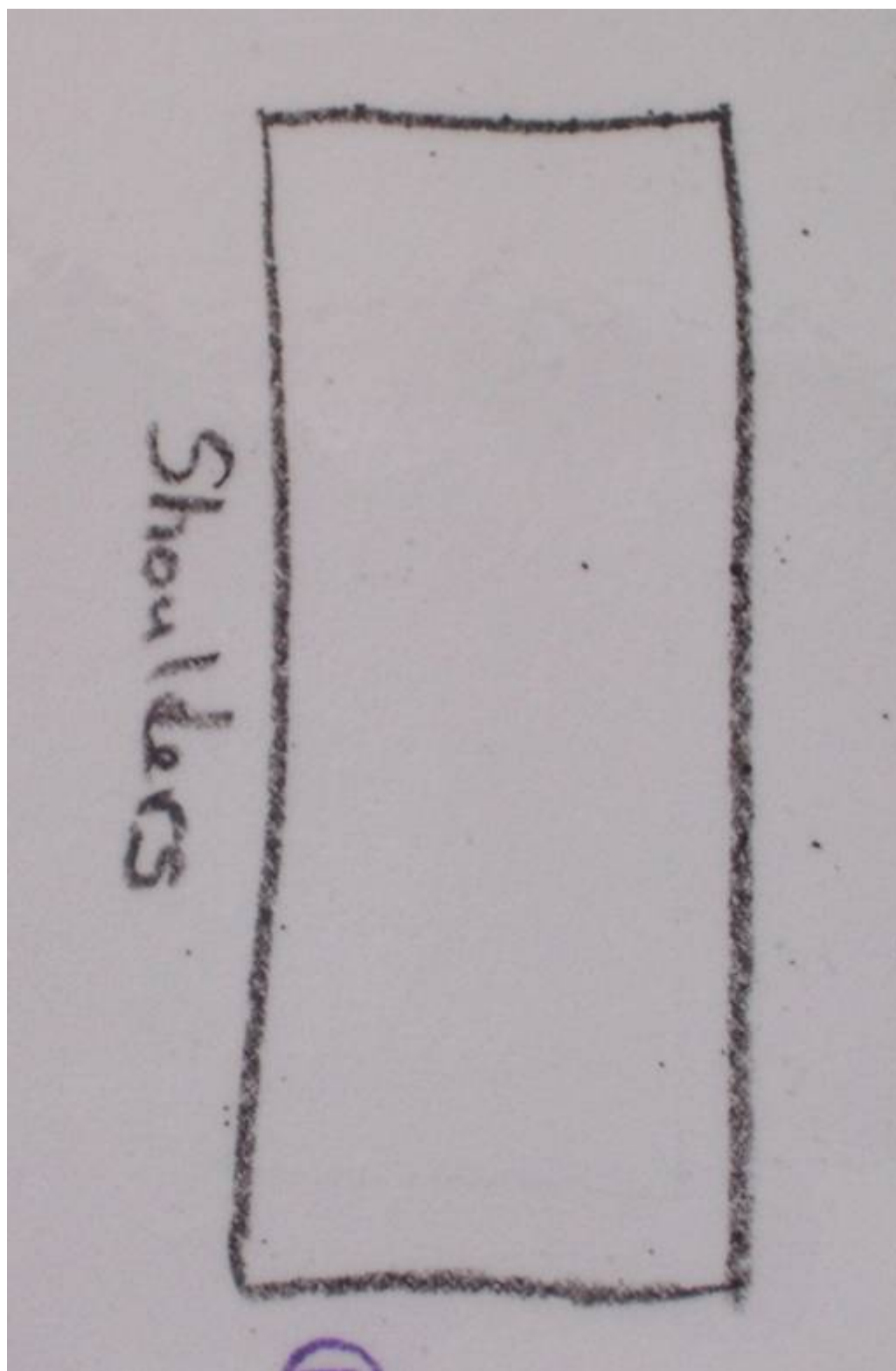
Appendix D: BROKEN HEART (Camilla)



Appendix E: EYE (Agnes)



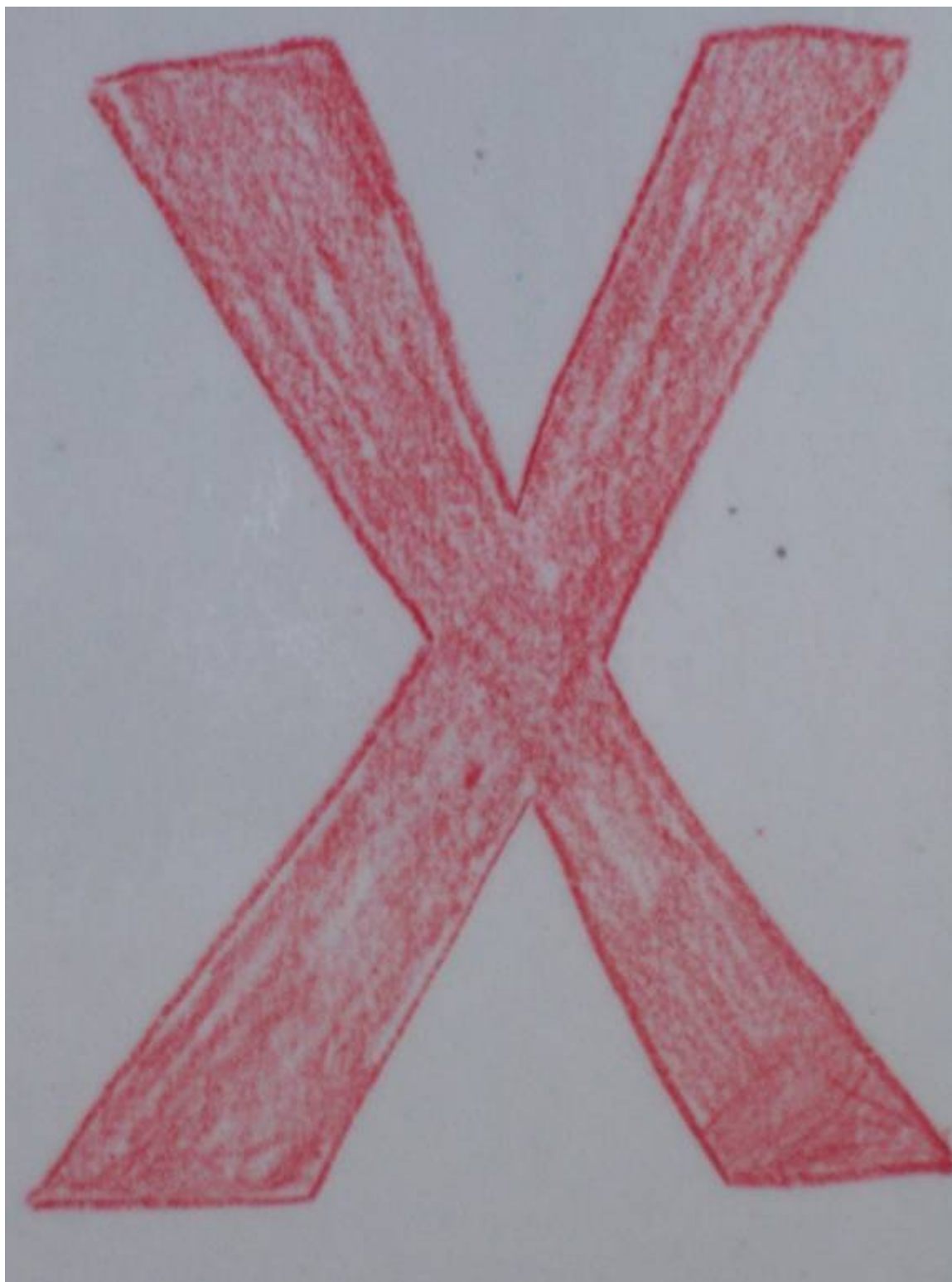
Appendix F: TICKET (Roberta)



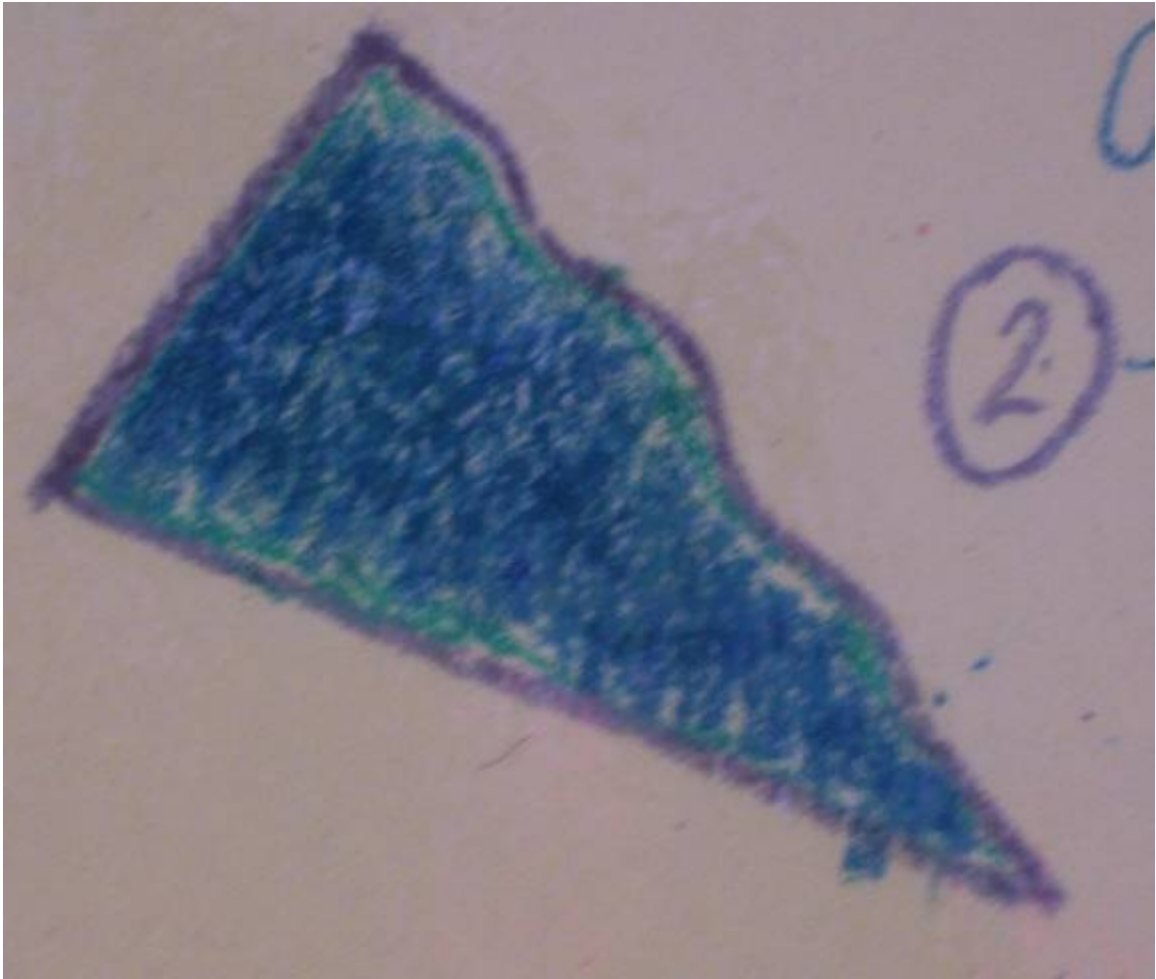
## Appendix G: MR. (OR MRS.) POTATO HEAD (Daisey)



## Appendix H: AN X (Emily)

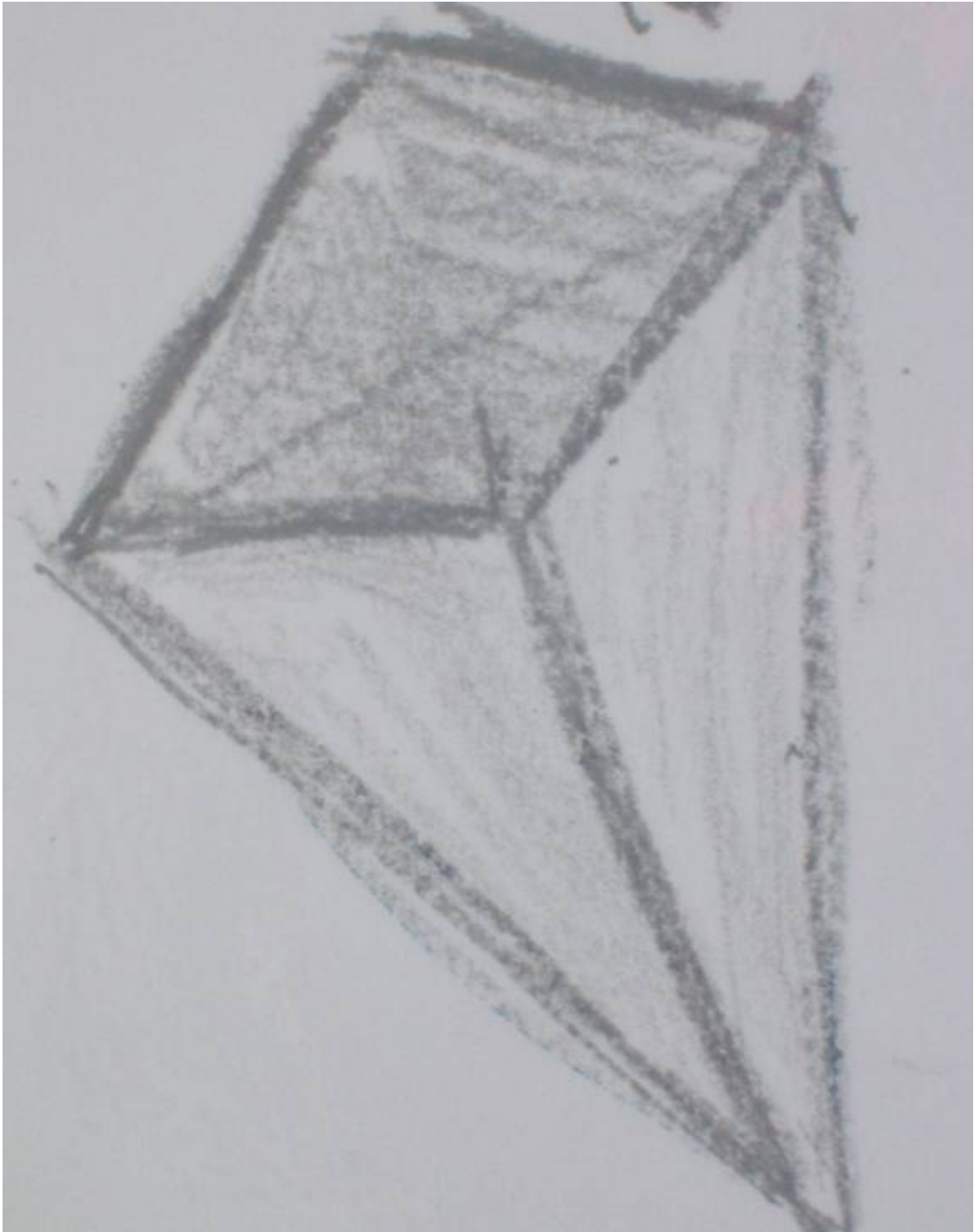


Appendix I: STEPS (Coral)

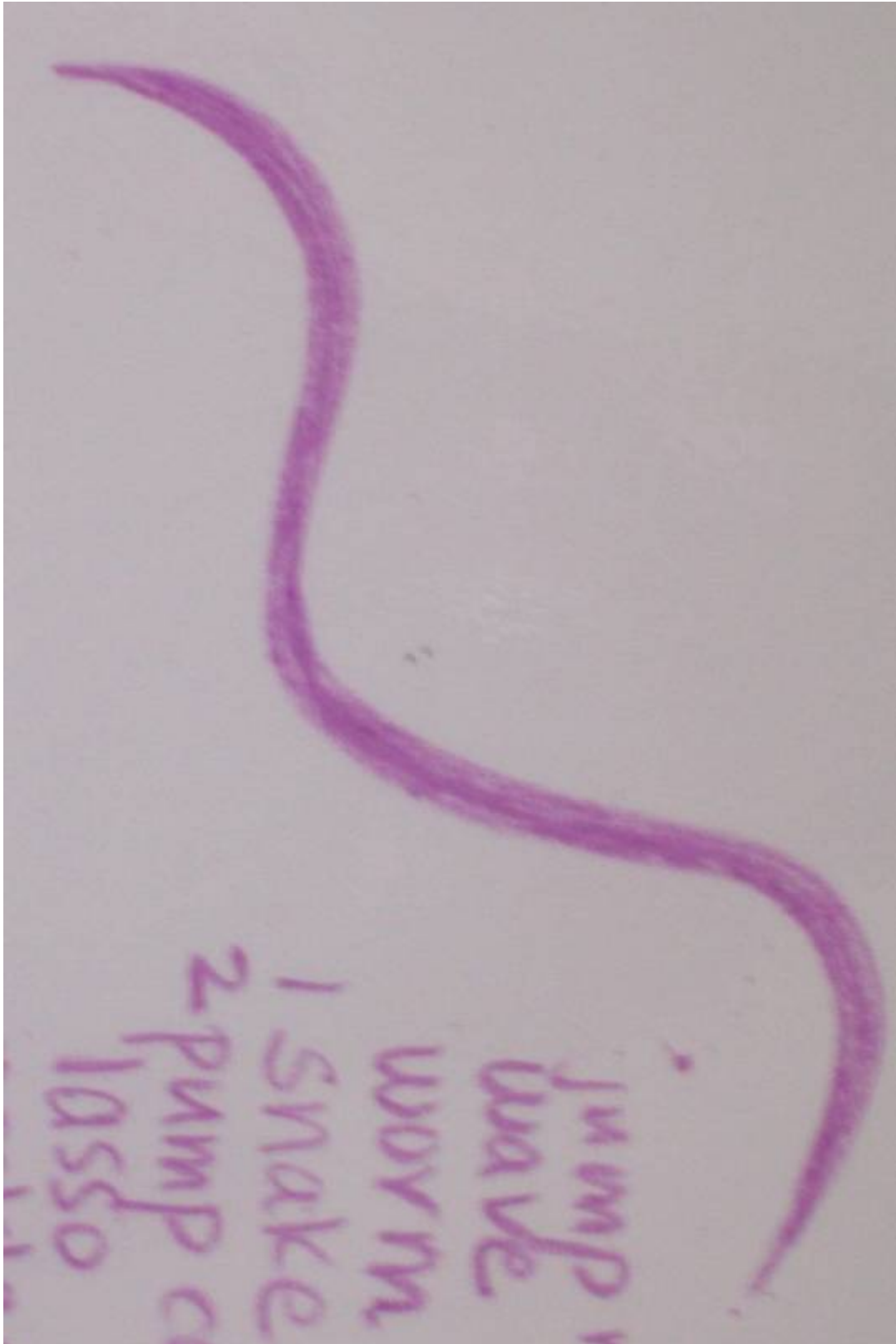




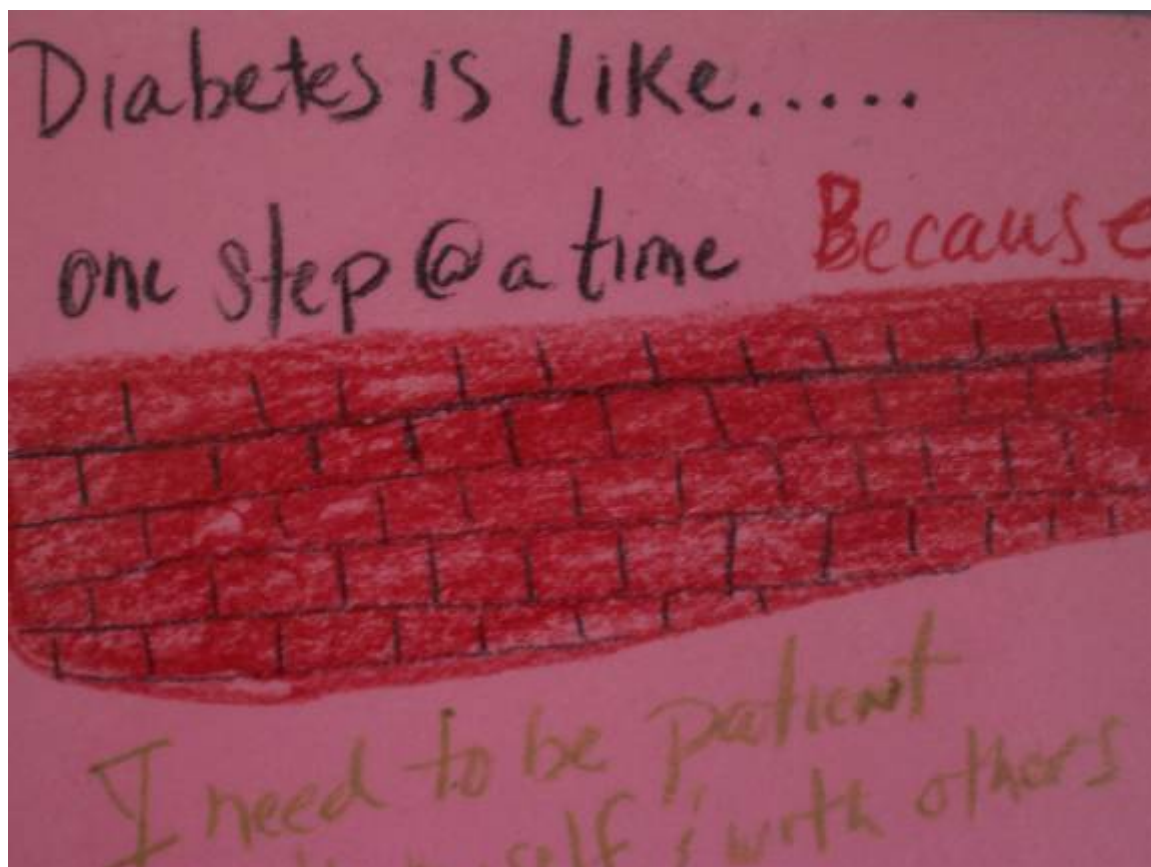
Appendix J: WEDGE (Sophie)



Appendix K: SNAKE (Heather)



## Appendix L: BRICK WALL (Coral)



## Appendix M: INCLUDING CREATIVITY IN PATIENT CARE

Including the creative dimension in patient care at appointments is one way to attend to the multi-faceted ways in which adults know and learn. There are nearly an infinite number of ways to include creative expression in patient care through the use of imagery, gardening, music, cooking, art, or tai kwon do, for example. To integrate creativity into practice is restricted only by the depths of the imagination. The few recommendations below are smaller, yet powerful, ways to improve practice within the current medical system as an appendix to the implications for practice in Chapter Six. These recommendations for practice and examples are listed as: (a) Engage patients upon arrival; (b) Use imagery to help patients who are “stuck;” (c) Address all ways of knowing in small groups; and (d) Add creative educator and/or counselor role to facilitate creative aspects to diabetes care.

### *Engage Patients upon Arrival*

One place to begin using creativity is when participants first walk into the door of the center or clinic. Although the ideal is to eliminate the need for the “waiting” room, the next best thing is to have patients engaged in both educational and creative activities while in the reception area. Hanging colorful, contemporary artwork and comfortable chairs brightens the mood. Providing apples, oranges, water, pretzels and juice with nutritional information listed would be a strategy to help patients learn about healthy eating. An option would include a vending machine in the area, stocked with items in the event of hypoglycemia (low blood sugar). If music in the office is possible, keep the sounds soothing and contemporary (such as the jazz music Sophie described as “meaning making”). Having stretching exercise bands available for participants to take with them,

instructions of simple stretches, a looping demonstration on a television, and a space to move encourages activity. Inviting patients and friends/families to bring their own choice of music to play over the sound system gives a personal touch. The sound of a fountain also adds a relaxing, auditory sensation. Sophie said it was important to take the time to breathe, and this type of environment encourages patients to rest and reflect.

To help patients think creatively and prepare them for visiting with their medical provider, educators could write questions or quotes on slips of paper placed around the reception area. Quotes from people who have diabetes or questions both related and unrelated to diabetes could be included, such as:

- (a) If you were to meet a person who is newly diagnosed with diabetes, what advice would you give her or him?
- (b) What does this quote mean to you: “You don't have to let your life be destroyed by diabetes. You can reclaim your life ... Della Reese.”
- (c) What is your favorite color and why?
- (d) When you were diagnosed, how was it handled well, or what could have been better?
- (e) What is your favorite creative activity? Recreational activity?
- (f) What do you wish you would know about your diabetes, but have not had the courage to ask?
- (g) How do you like to spend your time with family and friends?

Patients are encouraged, but not required, to bring one of their responses into the appointment to discuss with their provider. The practitioner can use these responses as an educational opportunity, a beginning point of discussion, or a chance to learn more about the patient than just their “numbers.” Instead of, or in addition to, responding in writing to a question, patients could also bring photographs of themselves or other family members to a diabetes collage, placed on the wall of the arrival area. This also encourages patients to realize that they are, first of all, people with connections and relationships, and diabetes is a part, but not the whole, of who they are.

*Use Imagery to Help Patients get “Unstuck”*

When a patient comes to the office and his or her A1C is higher than normal, it is judgmental to ask, “Why aren’t you following your diet,” or “Why is your A1C 9.5?” This direct question places a barrier between the clinician and the patient, and is often followed by a response of “I don’t know.” This helps neither the patient nor the provider. By stepping back and asking patients to think of an image, a shape or a color of the experience of diabetes, clinicians and educators might be able to get past the roadblock of “I don’t know.” Because the use of imagery and creativity may be new to medical professionals, a scenario is described below (Educator is “E” and Patient is “P”):

**E:** I see that your A1C is 9.5 today, and we’ve talked about this before. I would like to try something different with you to see if I can understand why your blood sugar is high. What’s one thing that you think you could do better to help you with your diabetes?

**P:** I could exercise more.

**E:** Good. What gets in the way of exercising?

**P:** I don’t like it.

**E:** What don’t you like about it?

**P:** I don’t know.

**E:** OK. When I ask you to think about exercising, what color (or image) comes to mind?

**P:** Black.

**E:** Black. What does black mean to you?

**P:** It means I hate it. I don’t want to do it because I’d rather watch TV.

**E:** OK. And what color does watching TV remind you of?

**P:** Yellow, because it’s fun and it’s not a lot of work.

**E:** Are there any exercises that you could do while watching TV to make it more fun?

The educator could directly ask, “Why aren’t your blood sugars better?” but that creates resistance from the patient, a feeling of judgment from the practitioner. Using imagery through color, shape, texture, or sound (as described in Chapter Five) is a way to help patients get “unstuck” and take on a different perspective about their diabetes. To add to this, physicians and educators could have photos available (such as the ones in the

study), and ask patients to explain if any of the images describe how they are feeling about the medical or emotional concerns presented during the appointment. It is my intent to share the photos of this study with physicians and other health care providers to help them understand the experience of diabetes.

#### *Address Multifaceted Ways of Knowing in Small Groups*

Although support groups are a source of obtaining information of managing diseases (Koch et al., 1999) as well as being an outlet to share feelings and to “unburden on each other” (Bedell, 2000, p. 200), none of the participants in this study were active in current support groups for diabetes care, nor were they in the past. Amber said that support groups didn't help because “it was just old people wanting free cookies or something. You've got to be kidding me. What is this?” Coral said that support groups might be a place for others to meet to talk about their diabetes, “but there are so many people there and it's really not for people to connect ... it's more for people to find out about the new things going on, and no one is as open.” One of the reasons she enjoyed participating in the group creative process is that she was able to connect with a smaller group of people.

One recommendation for practice is to offer a support group that gives medical advice and instruction for the first few minutes, but then moves into “real support” by encouraging small group interaction. To get things started, small group leaders could hand quotes or questions (similar to those posed in previous sections) to generate discussion. Other questions to ask during this time are: (a) What is important to us and out diabetes; (b) What is one struggle that this group might be able to help with; and (c) What kinds of things do we want to discuss or do in this group?

Another suggestion is to open the group with a guided imagery relaxation exercise that focuses on pathways to wellness (Naparstek, 1991). By incorporating guided imagery into practice, it helps relax the participants and also gives them useful images of how to better take care of themselves and their diabetes. According to WebMD Health and the Cleveland Clinic (2004), guided imagery is a proven form of focused relaxation that helps create harmony between the mind and body. Guided imagery can increase the immune system, decrease pain, and overcome stress and anger related to having diabetes. It engages the use of the emotions, body, imagination and spirit to incorporate healing and an alternative way of learning about the body and diabetes. The group leaders may want to ask for assistance from a creative educator in the facilitation of meaning making and diabetes care, whose role is described below.

#### *Add Creative Educator or Counselor Role*

Many physicians and clinicians do not have the *expertise* to facilitate the use of creative expression and multidimensional ways of knowing in diabetes care, even if it is within their circle of *interest*. In those cases, a creative psychologist, educator, counselor, or art therapist can complement the medical approach to diabetes care. Emily said that but there was not a supportive role within the diabetes system — a person who can take the time to ask deeper questions and has the skill to listen and walk through the patient's emotional and psychosocial concerns. Neither did Daisey expect the physician's to fill the role of a counselor, because "there's not enough time to do both that and work on the diabetes numbers."

This educator would facilitate small groups or individuals to include somatic, imaginative, symbolic, and affective ways of knowing. Although it would depend upon



the interest and comfort levels of the group (or the individual), specific ways to incorporate these dimensions of knowing into practice include the use of dramatic elements in engaging somatic knowing; symbols to encourage the imagination; and artistic creations to develop understanding. It is important to remember that members are never forced to participate in the group. Participants always have the choice to observe according to their comfort level and physical ability. The following are examples of ways, but not the only way, to introduce and facilitate creative expression in small groups.

*Dramatic elements to engage somatic knowing.* The use of dramatic elements is one way to introduce somatic ways of knowing in diabetes care. The educator might ask the participants to remember back to when they were diagnosed. How did they feel? They are encouraged to do something with their body that reflects their feelings at that time, as the educator demonstrates. How do they feel about their diabetes now? If it seems appropriate, the educator can go further with the somatic experience. Through the use of imagination in drama, participants are encouraged to show their feelings about diabetes in a circle, as if it were an act (like burying bones, planting a flower, stepping on spiders, for example). In another session, the educator can guide participants to pass around an object with which they are all familiar, such as a closed insulin syringe. As the syringe is handed from one participant to another through several rounds of circles, each participant begins to transform the object; does something different with it. The person might step on it, throw it, whatever comes to mind. At the end of the support group, the participants are encouraged to journal (write, draw) about any feelings that may have

arisen during the activity and have the opportunity to express these thoughts at the end of the session, either as a group or one-on-one with the educator.

*Symbols to encourage the imagination.* Should the groups wish to continue with creative drama during further support sessions, each participant could bring his or her own symbol which relates to the experience with, feelings toward, or thoughts about diabetes. The participants are encouraged to share their symbol with the group. If they choose to try something new, they can talk about a deeper meaning of their symbol with one other person in the room. They can pass the object back and forth. In this way, the participants are getting comfortable with their symbols and what relating to the object does to the feelings in their spirit-body-mind. The educator then asks the pairs, “What does it make us do?” and “How does it make us feel?” The feelings about the object (which relate to feelings about diabetes) will come from the interactions with the object and each other. They are resources to getting the imagination in motion and tapping into somatic ways of knowing. Participants, including the educator, will spend time reflecting again on the use of drama, and how it has helped them come to know something new about themselves and their diabetes.

*Artistic creations to develop understanding.* During other sessions, participants can engage in artistic expression to continue to explore the meanings and experience of diabetes. Many different art forms could be used, such as drawing a card to a loved one explaining and showing feelings of diabetes; building with elements of nature; or using paints and confetti. Another idea may be the use of clay and pottery. All of the participants could attend a pottery class with an instructor, who could teach the participants the basics of molding and using clay. With the creative educator, also in the

roles of facilitator and observer, he or she could help the group make connections to their diabetes and create images from clay that reflect their experiences with diabetes. The idea is not to create art as a *product*, but use art as the *process* toward greater meaning making and discovery.

In summary to this appendix, it is important to address both the medical and psychological needs of patients in diabetes care. *Both* educational knowledge to manage their disease and the emotional and symbolic meaning to sustain better health are needed in a holistic view of meaning making and wellness in patient care.

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2002 **M.A.**, with Honors, Temple University, Adult Education  
1997 **B.A.**, with Distinction, Pennsylvania State University, Humanities

#### Professional Experience: Current

- 6/05 to present **Graduate Research Assistant, Research & Graduate Studies**  
*Penn State Harrisburg (PSH)*  
Determine factors for success and barriers to non-completion of degrees for graduate students at PSH by developing and implementing survey instrument; analyzing and presenting data; and writing results.
- 9/06 to present **Research Assistant, Department of Humanities**  
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#### Professional Experience: Past

- 8/98 to 6/05 **Manager of Staff Development, Hershey Resorts**
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- Spring 2006 **Co-Instructor, Critical Media Literacy/Semiotics, Penn State**
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#### Affiliations

- Society for the Arts in Healthcare**, June 2006 to present  
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