Clara: A Phenomenology of Disability

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A phenomenological approach was used to describe the lived experience of disability of a woman who sustained a head injury 21 years ago. Data were collected through 11 face-to-face interviews and 72 e-mail messages over the period of 11 weeks. An iterative, fluid process of questioning, information-giving, analysis, and verification was characteristic of the whole study, alternating between analysis of the particular and analysis of the general. Through a process of phenomenological reduction, each interview transcript and e-mail message was divided into meaning units that denoted shifts of meaning. Similar meaning units within a transcript or message were then grouped and summarized in a phrase or word. As new meaning units emerged, additional interviews and e-mail exchanges took place in order to obtain an exhaustive description of the experience of disability. All meaning units obtained from this iterative process finally were “horizontalized” into meaning clusters of nonrepetitive themes. The themes of nostalgia, abandonment, and hope emerged through this collaborative process. A shift in view of life was noted in the participant as the reflective process of this study unfolded, suggesting a phenomenological collaboration between patient and therapist may engender a more genuine connection in which personal meaning is authentically the cornerstone of occupation-centered treatment.


"For me it means to embrace a new life that’s so different from the one I knew and loved … it is a frightening choice … one that I keep making and unmaking …” So went Clara’s (not her real name) one-sentence e-mail response to a question I had posed to her a few days earlier at a New Year’s gathering. I had noticed her twisted body and her difficult gait as she wove her way through the tight crowd of guests and struggled to keep her balance as she moved out of the way of a waiter loaded with a tray of drinks. My reflexes as an occupational therapist, who has watched too many people with disabilities fall, took over and I grabbed Clara to stabilize her. As my fingers wrapped around her upper arms I could feel I was too late—she had already managed to balance herself and plant her feet firmly in the ground. She was solid, unmovable like a tree. Somewhat embarrassed, I apologized saying I thought she might fall. With only one half of her face smiling, she moaned something I could not make out. Not wishing to embarrass her, I simply smiled and nodded as though I had understood her perfectly. She then took a deep breath and with visible effort but barely a sound, spoke one word at a time: “You … didn’t… understand … what … I … said, … did … you?” It was my turn to be off balance. “No, not really,” I said. “Good,” she said, “you … can … tell … the … truth.”

Twenty-one years ago, Clara, an energetic recreational therapist in her early twenties, was on her way to a summer camp in the mountains. Clara had worked for over 3 years to raise funds for this camp and her dream had come true: The first wilderness camp in the state for people who used wheelchairs would open the following day. Also, in 3 more days she would be installed as the new, and youngest,
Background of the Project

Occupational therapy is defined as “the art and science of facilitating everyday living through occupation” (American Occupational Therapy Association [AOTA], 1995, p. 1015). The profession was formalized in 1917 by founders who shared a common vision that social concerns such as poverty, ineffective education, and increasing disability could be successfully ameliorated (Bing, 1981; Breines, 1995; Peloquin, 1991a, 1991b; Quiroga, 1995). These founders were united in their humanistic values and hope in the healing processes of occupation and community, and were particularly committed to assisting persons with disabilities with the process of adaptation.

Although over the years efforts have been made to better understand the healing qualities of occupation to legitimize it as an authentic practice of the profession, particularly in the view of medicine, occupational therapy has frequently emphasized an etiological perspective of function and disability. Thus, management of disability is aimed at cure or the individual’s adjustment and behavior change. This view of disability stands in contrast to the profession’s growing understanding of occupation as a social construction (Clark, 1993; Pierce, 2001; Yerxa et al., 1990). Scholars have repeatedly pointed out that a dichotomy is expanding between the positivistic models of occupational therapy treatment and the theoretical and existential understanding of occupation (Christiansen, 1999; Hammell, 2002; Kelly, 1996; McColl, 2000; Whiteford, Townsend, & Hocking, 2000). From the perspective of a positivistic, etiological model, disability is viewed “as a problem in the person, directly caused by disease, trauma, and other health condition, which requires medical care provided in the form of individual treatment by professional experts” (World Health Organization [WHO], 2001, p. 20). In contrast, the existential perspective of occupation emphasizes understanding people for who they are, have come to be, and are in the process of becoming (Fidler, 1997). This perspective considers the complex intersection throughout one’s life of a multiplicity of personal and environmental factors, and is more consistent with a social model of disability. In this view, “disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment” (WHO, p. 20).

An early vision of the founders of the profession was the fullest participation possible in social life on the part of all people, including those with disabilities (Quiroga, 1995). Full participation implies that people have a voice that is heard and that guides which modifications are made for such participation. In other words, participation should be directed by the person experiencing the disability rather than by the objective observers claiming to have an expert understanding of the needs of the person (Illich, 1998; McKnight, 1995).

Although empirical work on the experience of occupation is growing, very little work has been found within the profession that captures an emic perspective of disability itself. Clark (1993) used an autobiographical narrative technique to elicit “wells of meaning” in the story of a patient who had experienced a stroke. These wells of meaning were used to guide the therapist in the design of treatment activities that were likely to engage the patient toward adjusting to her disability and “discovering her new self” (Clark, 1993, p. 1069). Similarly, other researchers have investigated school routines of children with disabilities (Kellegrew & Kroksmark, 1999), the experience of caregivers (Hasselkus, 1992, 1993), the experience of sensory defensiveness (Kinnealey, Oliver, & Wilbarger, 1995), and the experience of people who have disabilities.
of unilateral neglect after a stroke (Tham, Borell, & Gustavsson, 2000) among others. Although in these works a clear effort was made to better understand the patient's perspective, the general view of disability appeared to remain as a problem that resides within the patient.

The Project

I was struck with Clara’s articulate writing in the one-sentence message she sent in response to my New Year’s Eve question. I wrote in return asking if I could meet with her in order to understand her statement better. Her reply to my request again was short, and came in the form of two short questions: “Are you doing some kind of research project? What would it involve?” In this way, Clara herself introduced the idea of formalizing our discussion into a research study.

Before answering Clara’s message I considered the available literature. Although most occupational therapy theoretical models call for attention to be placed on both physical and emotional needs (Kielhofner, 1982), and on meaningfulness of intervention activities for the patient (Mosey, 1992), it was apparent that seldom has our literature considered the “insider” perspective of the person receiving the services. Slowly the conceptualization of the study began to take shape as I articulated my purpose to investigate the meaning and experience of disability from the perspective of a person who has lived with a disability for half her life.

In order to obtain such an “insider” perspective, this study was conducted in the tradition of phenomenology because it is a method suited to describe individuals’ experiences (Creswell, 1998; Stewart & Mickunas, 1990; van Manen, 1990). Based principally on the philosophical movement developed by Husserl in the late 19th century, phenomenology studies phenomena as they appear through consciousness (Varela & Shear, 1999). As Kvale (1996) stated, “Phenomenology is interested in elucidating both that which appears and the manner in which it appears … Phenomenology attempts to get beyond immediately experienced meanings in order to articulate the prereflective level of lived meanings, to make the invisible visible” (p. 53). In other words, the approach can help articulate the deeper sources of meanings we take for granted by bringing to light our way of viewing ourselves, of viewing others, and of viewing all else that comes into contact with our lives (Wagner, 1983). Although theorists have taken phenomenology in different directions, they all aim at discovering the world as it is experienced by focusing on the lifeworld. This life-world, rather than being an objective environment, is what we perceive and experience it to be (Stewart & Mickunas). The person and the world are seen as inextricably intertwined: Humans actively engage in and with their world, and are aware of themselves and the world through their experience in it (Wagner).

Phenomenology places emphasis on discovery and description rather than on speculation or causal explanations (Sokolowski, 1985; van Manen, 1990). In addition, a phenomenological and nonjudgmental attitude on the part of the researcher is necessary in which preconceived ideas are recognized and temporarily set aside to enable the researcher to experience the process of discovering the phenomenon first hand and through direct contact or “intuition” (van Manen, 1997). The researcher must recognize that although he or she is attempting to be nonjudgmental, any and all interpretation is founded on preconception. In other words, the researcher’s cultural-social background is always implicitly present and gives him or her a preunderstanding. Phenomenological knowledge emerges gradually and is built only through a hermeneutic cycle in which “understandings are being continually modified as we move back and forth looking at the whole and parts in a dialectic between preunderstandings, interpretation, sources of information, and what is being revealed. This is then re-examined and re-interpreted” (Vermersh, 1999, p. 22).

In the next e-mail message I sent Clara I explained the project and stated the research question: “What is the lived experience of disability for a woman who sustained a head injury 20 years ago?” My message included an informed consent form that I asked Clara to read carefully and that I promised to review with her in person should she agree to proceed. Within hours, I received a new message from her, in which she stated:

I think I’m ready to think and talk about this. I am not sure what makes now a good time, but I also can’t think why it would be a bad time. Come to my office at 3:30 on Wednesday. Let’s get some formalities out of the way. I work at my family’s printing shop, and am responsible for inventory. I also am the copyeditor. Anything we get to print has to go through me for correction. I have done this for 14 years and expect to be doing it for the next 14 years. I will meet with you, but I prefer writing—speaking takes too much effort and control, and I find I lose concentration on the ideas when I try to also concentrate on controlling my body. I suppose that is something you will want to “watch” me do. Once you get the watching out of the way we can get to the important stuff.

The data utilized in this study were collected from 11 interviews and 72 e-mail message exchanges that took place over the period of 11 weeks between the months of March and May of 2002. Each interview took between 1 and 1 1/2 hours. The first two interviews consisted of open-ended questions focused on obtaining a rough chronology of events in Clara’s life from the time of her accident to the present. Subsequent interviews consisted of open-ended questions.
regarding possible units of meaning contained in the transcripts of the previous interviews or in Clara’s e-mail messages. Each interview began with an invitation for Clara to express any thoughts she had about the project thus far. Probing questions were aimed at obtaining a more detailed description of particular events and the thoughts and emotions associated with them. In addition, in most interviews I asked Clara if the clusters of meaning I had identified fit with her own perceptions. Two interviews took place at Clara’s place of employment, and the remainder at her home. Clara agreed to be tape-recorded during only two face-to-face meetings, and therefore interview notes and my own reflective notes were included in the analysis. Data analysis was conducted in two major phases after the structure recommended by both Moustakas (1994) and Karlsson (1995). Each phase consisted of an iterative process of analytical induction as described below.

During the first phase, each interview transcript or e-mail message was analyzed individually. After the first interview was completed and transcribed, the transcript was divided into smaller meaning units to denote shifts in meaning. In a linear fashion proceeding from the beginning to the end of the transcript or message, each apparent idea or meaning unit was bounded with parentheses and numbered. On the left side of the page each idea or meaning unit was summarized into a word or short phrase and written next to the corresponding number. Later, on a blank sheet of paper, similar or related meaning units were grouped and labeled with a descriptive word or phrase. This process, referred to as “phenomenological reduction” (Moustakas, 1994) required an iterative process of “looking and describing and then looking again and describing again” (Moustakas, p. 90). Therefore, after the initial reduction to meaning units, a follow-up interview with Clara was scheduled in order to verify the accuracy of the reduction. In this phase, I used “imaginative variation” (Moustakas) to seek possible meanings of the experience. According to Moustakas, the aim is “to arrive at structural descriptions of an experience, the underlying and precipitating factors that account for what is being experienced; in other words, the ‘how’ that speaks to conditions that illuminate the ‘what’ of experience” (p. 98). Finally, I considered the universal structures that seemed to precipitate feelings and thoughts in reference to the phenomenon. These included any references Clara made to structures of time, space, bodily concerns, materiality, causality, relation to self, or relation to others as suggested in the relevant literature (Karlsson; Moustakas; Velmans, 2000). Clara read all notes and frequently amplified or corrected meanings after reflecting on them. In addition, Clara had veto power over my naming of themes in an effort to assure I used her words to capture her life-world. In this way, Clara acted just as much as the researcher as I did.

The resulting phenomenological understanding of Clara’s experience is described in the following section as an interactive, collaborative story given plot by human feelings and intentions (Polkinghorne, 1988; Sarbin, 1989). As Holstein and Gubrium (1995) stated, “All interviews are interpretively active, implicating meaning-making practices on the part of both interviewers and respondents. We contend that if interview data are unavoidably collaborative, attempts to strip interviews of their interactional ingredients will be futile” (p. 4). In the next sections Clara’s written words appear as flowing sentences, whereas her spoken words are separated by ellipses (...) to differentiate between communication that occurred via e-mail and in face-to-face interaction respectively.

Meaning Themes

As soon as I opened the door, and before I could state my intentions, the woman at the front desk had told me, “Clara is waiting for you—I’ll tell her you’re here,” and had walked away into a side office. As I waited for Clara to be notified I had arrived for our first interview, I looked around the reception area of the small family-owned printshop where she worked. Several desks, each with a computer and a phone, and stacked with folders and papers, were
I turned around and followed with a state-
tightly intertwined, each depending on the other.
Furthermore, reasons of clarity. However, in Clara’s experience they are
weeks that followed, we generated three main themes that
Clara’s style—direct, efficient, to the point.
This one too had a computer and was stacked with papers and folders. A laptop computer and a bowl of peanut
M&Ms marked this desk as different from the ones I had
seen in the other room. “Sit,” Clara said, pointing to a chair
next to the desk while she walked around to find her place.
The cadence of her walk seemed to mimic the uneven
rhythm of the presses in the background.
Clara handed me a signed copy of the interview con-
sent form I had sent her a few days earlier. “I … understand … all … it … says … I … can’t … remember … anyone … ever … asking … me … that … question … before … I … don’t … know … yet … how … to … answer.”
Without greetings or other social formalities our first
face-to-face interview had begun. Soon I recognized this as
Clara’s style—direct, efficient, to the point.
Throughout our meetings and e-mail exchanges in the
weeks that followed, we generated three main themes that
characterize Clara’s experience—nostalgia, abandonment, and hope. These themes are presented here separately for reasons of clarity. However, in Clara’s experience they are
tightly intertwined, each depending on the other.

Nostalgia
Clara’s experience in the present is frequently marked by
memories of her life before her accident and comparisons of
who she is now to who she was before, or who she might
have become had she not sustained a head injury. Her life is
divided into “before” and “after” chapters. Clara wrote:

I was exuberant, a complete extrovert. I loved feeling free, and
felt charged with an electric urge to get things done, to energize
others, to connect with each other. My life was full. I
guess I had the sense that I would always be surrounded by
friends and family, and that I would have lots of energy. I
never really thought about my life, I just tried to experience it
to the fullest. I loved to be spontaneous—after work, on my
way home, I would sometimes decide to drive to the mountains
for the night and just show up at a friend’s door. We would sit
up talking half the night, and then I would leave to go back to
town to be ready for work on time the next morning. I would
still be that way. I think, if life hadn’t changed. Now I don’t
do much spontaneously, and everything takes a lot of planning.

On a different occasion she wrote:
I like the work I do, but I would never have thought of doing
this before the accident. Before, I always worked with lots of
people—now, I spend most of my time quietly working on
written materials.
Before, I used to go out to eat a lot, and would drag people
around to try every new restaurant in town. Now, I like to
keep my routine pretty even—it takes too much out of me to
change it too much.

Clara frequently memorialized the past with sentences
that began with the phrase “I was,” followed with a state-
ment that depicted her image of the person she believed she
had been on the way to becoming. That past had a sense of
perfection and peacefulness, which was lacking in her pre-
sent:
I was always aware of others around me. I felt fulfilled. I
would have continued to work on my causes and made a dif-
ference to the world. Now, I am not sure of what difference I
make. I have tried to keep up with some of my projects from
back then, but because I can’t really be involved, I don’t think
I really contribute to them. Yes, I send some money now and
then, but I know what makes a difference to people who are
homeless and hungry, for example, is to have people be with
them, work with them, not just send them money.

Clara’s view of the past was created in the present by her
retrospective look upon it. She described a sense of simply
living the past, unaware of its meaning at the time. It was
her present life that gave her a sense of what she had now
irrevocably lost and made fond memories bittersweet:
I often reflect on how wonderful my life was before, I remem-
ber once a group of us had gone to the camp and early one
morning, before anyone else woke up, I saddled a horse and
grabbed some stuff, and went off by myself on a trail that led
to a lake. I spent the morning there, swimming, lying in the
sun, or walking in the alpine meadow enjoying the flowers. I
think back then I could enjoy being alone like that because I
knew there were lots of people waiting for me somewhere. I
didn’t realize that then—I took that for granted and had no
close. Without thinking, I lived as though life would always be
that way. But how wonderful that was. I often wish I could
return to that place, that day, that feeling.

Clara kept the past ever-present through several activi-
ties. For example, although she had not returned to the
camp she helped start and where she was headed the day of
her accident, she has continued to send money and write
letters to potential donors. She has also maintained an
extensive mailing list and sent Christmas and birthday cards
to “all the people I knew before my accident.” Furthermore,
she has kept scrapbooks about the camps and other causes
she was involved with 20 years ago. While interviewing
Clara at her home one day, we were interrupted by a phone
call. She let the answering machine pick up the message,
but she realized the call was from her college roommate and
sprang up to intercept the call. Clara did not speak much
on the phone, but when she returned, she told me she had
recently tracked this friend down after 15 years and sent her
a birthday card. I asked how she had tracked her friend, and she went to a desk and brought back a binder that she opened on the table in front of me. In it were newspaper clippings, letters from friends, and so on. The binder was titled with the name of that friend. Clara pointed to a shelf where about 15 similar binders stood in a neat row, each with its own name:

I … spend … a … lot … of … time … looking … for … special … friends … from … the … past … or … keeping … track … of … them … I … don’t … know … what … I … would … do … if … I … couldn’t … do … this. It … helps … me … feel … like … I … still … belong … to … them … and … to … the … life … we … shared … back … then …

Abandonment

Clara used the term “abandonment” several times before I asked her to say more about it. For example, in one message she stated, “I felt abandoned by everyone and everything I knew—I was engulfed by a huge void …” On another occasion she stated, “My … will … to … live … had … abandoned … me …” and later, “I have to abandon the past. It’s gone—that’s it.” Her response to my request for clarification of the meaning of the word “abandonment” exemplified both the preconscious nature of experience and the intuitive emergence of phenomenological understanding. Further, it exemplified a characteristic van Manen (1990) ascribed to this form of inquiry when he wrote that “the interviewee becomes the coinvestigator of the study” (p. 98). Clara stated:

Your request that I say more about “abandonment” startled me. I had not realized that I used that word, but looking back to our discussions, I see it has come up several times. Thinking about this stirred up something in me—I don’t know if it is fear of reliving the past or of opening up a wound I still have. I have the sense you will understand and help me better understand what it is I am thinking and feeling. I will try again to write as my thoughts come, as though we were having a conversation as you suggested. At first, the word “abandonment” made me feel very uncomfortable—as though I had somehow disclosed something I had no control over and something I really did not want to think about. I felt it throughout my body, as though I was having to get ready for a fight or something. Even now, as I write, my palms are sweaty.

Clara ascribed several dimensions of meaning to abandonment, all of which had to do with being separated from something or forsaking something. First, the term represented her relationship with her body and her struggle to maintain control over it. She described a sense that her body acted on its own impulses, that 20 years later she was still not used to her body:

I was trapped in the most desperate way. I could understand what people were saying to me and about me, and my mind planned and thought it executed the movements needed to speak, but nothing would come out. It still is something I sometimes feel desperate about. You would think that after 20 years my body wouldn’t keep playing tricks on me. There are times when without thinking I respond to something automatically—or at least, in a way I think I remember it was like to respond automatically, and my mind takes steps much more quickly than my body. It is as though my mind leaves my body behind, and my body takes a long time to catch up or, often, cannot catch up at all … But, it’s more like my body has abandoned me.

An equally poignant abandonment is the one Clara continued to experience in her relationship with others. In addition to the passivity of being abandoned by others, she recognized that she too had abandoned them. Her early experiences in rehabilitation continued to be a powerful filter for how she believed others thought of her:

I have a sense of total aloneness and isolation I started to feel during my rehabilitation and that has never left me … I couldn’t talk, I couldn’t move. I could understand perfectly what was going on around me, but I’d get frustrated because I couldn’t tell them how wrong they were when they’d tell my sister or father that I would only function at a “reflex level” the rest of my life—that I probably didn’t have much of a mind left. Inside of me I was screaming! I felt marooned, and it took several years before my sister finally figured out that when she put a pencil in my fingers I was trying to actually scribble something, I couldn’t bear the pity in my father’s eyes, the constant tearfulness of my sisters. I think everyone still just sees a twisted body and assumes I have a twisted mind to match. I don’t know if it is my family and friends who can’t get past my disability, or if it is me. I watch them talk to each other with such ease, and then turn to me and talk to me like a child. They can’t understand my horrible voice and turn away as though I had said all I needed. Why try anymore? I am used to being marooned, I don’t want to look at their faces when they cannot understand my voice.

After years of working on her own or with her sister, Clara mastered typing on a laptop computer with her right index finger. I found myself enthralled watching her hand fly over the keyboard, as fluid as the most experienced word processor. This skill became Clara’s demonstration to her family that she was still quite capable:

Although they were amazed at what I could do, and I have showed them that I can keep track of a lot of things, they still can’t get over the fact that I can’t do simple things like make my bed without falling, cooking without burning something …. It took years for my father to finally trust that I was doing my work at the shop OK—he finally stopped double-checking everything I did and pretending that he had never doubted I could do it …. But he still won’t just sit and talk to me, and I don’t really try to sit him down and talk to him either.
Hope

Although the abandonment Clara spoke of often painted a picture of her as passive or a victim unable to resolve her loneliness, another theme emerged in which she was a main actor. She began to use the term “abandonment” in a different way to describe her growing realization of the need to let go of her past. This letting go had to do with a change in her view of her future, and contained a sense of hopefulness and meaning, albeit vague and nondescript. In the following excerpt, Clara wrote about “the ravine,” a metaphor she used to describe many aspects of her life with a disability:

I remember my life before my head injury as full, active, fun. Noisy—I really miss the noisiness. I was going along doing what I thought was right, what God would want me to do (and I still think that is true) and then suddenly I woke up and the best way I can describe it is as though I woke up on one side of a ravine looking over at the other side where that full life of mine had taken place and where I saw everybody else’s life taking place. I didn’t know how I had ended up on this side, but I wanted to get back to the other side. At first, I thought therapy would help me cross back over to the “good side,” but it did not take me too long to realize that my body just was not up to the task of crawling down to the bottom of the ravine and then climbing back up to the other side.

Although this ravine symbolized different aspects of Clara’s life, through the reflective interview process Clara articulated a new or emerging meaning for the metaphor:

Over the years the ravine has become deeper and darker. It has meant a scary emptiness, a darkness I have been afraid would be necessary for me to crawl into if I ever am to crawl out of it again on the other side. I don’t know why I am thinking about this in this way now. Sometimes about writing to you has made me think a little differently. I am no longer trying to crawl back to my old life and pick up where I left off. I am just trying now to find who I really am and what my life is about…

Another sense in which I think of abandonment has to do with what I must do and redo every day in order to cross that ravine: I have to abandon my expectations of myself, the past, and others in order to live as fully as possible. I have to let go of everything I think holds me back so that I can actually wonder at what is… My body is always going to be like this, but doing this project has shown me that it is possible for others to understand me, to know I’m not just a jumble. I think that is something I have learned through this too.

The emergence of hopefulness, or anticipation that, at present, she was “becoming” a transformed person was linked to Clara’s sense of connection with others—to feeling understood by others and of learning to understand herself and her body. She explained:

But I insisted—actually, I just walked out. I kept telling myself in my head, “abandon yourself to this new day—abandon yourself to what might be new for you today—abandon yourself to what may come, and let go of what you wish were true. Keeping your hand clenched on the past doesn’t let you accept anything new—abandon yourself and open your hand to see what new might come.”

When I got to my office I had to call [my sister]. It dawned on me that all these years she has seen in me the potential to let go. I tried, I really tried hard all those years—I tried to do everything told me would be good for me, but didn’t realize that it wasn’t important what I did or even how I did it. What was important wasn’t “doing” at all. It was that through doing I could realize I could be myself, and be someone who, like others, continues to live and change and grow. So, I called her and we both cried on the phone.

This event seemed to trigger a qualitative shift in the way in which Clara thought of the people around her. She noted a reflective insight a few days later as she continued to think about why she had called her sister the day she walked to work:

All these years I have thought of myself as the person with the disability, that I was the different one, the one who had been dealt the merciless blow in life. I don’t know how this changed or where I got the idea, but I find myself thinking about what it must be like to be someone who lives with and cares for someone who has a disability. It dawned on me that in order to really describe what it’s like to live with a disability, that I should also think about what it has been like for my sister and my dad, and what it has been like for me to be with them. With sadness, I realize that part of me was disappointed in others because they had abandoned me—but I abandoned them just as much. Without realizing it, I thought of myself as someone without anything to give, but [my sister’s] tears made me realize that she too lives with my disability in a very personal way.

Clara concluded the message by saying:

Maybe it wasn’t all wasted time. Maybe I needed this time to go by so I could finally be ready to let go. Maybe this disability can give me the opportunity to relate to life more meaningfully. Maybe there is something I can share with others after all. It is time that I work on talking more.

Discussion

Writers who have disabilities have frequently been critical of the lack of understanding and persistent devaluing of their personal experience by health professionals. Oliver (1990) wrote that, “Throughout the twentieth century … disabled people continue to be portrayed by health professionals as more or less than human, rarely as ordinary people doing ordinary things” (p. 91). Others have claimed that to most
nondisabled people, those with disabilities symbolize everyone's imperfection and vulnerability to weakness, pain, and death (Overboe, 1999). Yet others have argued that in order to demonstrate their own success, health professionals often cast disabled people in a heroic light, thus contributing to a cultural emphasis on able-bodiedness (Oliver). Wendell (1996) stated that, "While disabled heroes can be inspiring and heartening to the disabled, they may give the able-bodied the false impression that anyone can 'overcome' a disability. Paradoxically, the image of the disabled hero validates the lived experience of a few disabled people and invalidates the lived experience of the majority of disabled people because they cannot meet such expectations" (p. 116).

I began this project conscious that what attracted me to Clara in the first place was a sense of her heroism—that I had, in fact, been confronted with my ableist attitude the night I met her and rushed to keep her upright and later feigned understanding of her words. I recognized that I had been surprised by her perceptivity that evening and her eloquence in her first e-mail message—that I too had a preconscious expectation that the appearance of her body was a representation of her mind. Yet, having recognized that, I still subconsciously set out on a "heroic" path of my own—to research Clara's experience and give her the voice I erroneously presumed she did not have because of her difficulty with speech. The phenomenological method was a natural choice as its object is "essentially a linguistic project: To make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible" (van Manen, 1990, pp. 125–126). To relate the lived experience of Clara, however, only tells half the tale of this phenomenological inquiry process. In the same way in which our intense conversations and subsequent reflection seem to have led Clara to new levels of self-awareness and awakened a liberatory transformation in her, the process had a transformative effect on me. As van Manen (1990) warned, "Indeed, phenomenological research is often itself a form of deep learning, leading to a transformation of consciousness, heightened perceptiveness, increased thoughtfulness and tact, and so on" (p. 163). Understanding Clara's experience of life with a disability has added not only to my own "becoming" as a researcher and occupational therapist, but also has given me insight in my own way of being in the world.

The phenomenological method calls for attention to be paid to "the way in which the appearances of an object are constituted in and by consciousness ... to the way of appearing of things, ideas, values and persons" (Spiegelberg, 1960, p. 87). It seemed necessary, therefore, that at the same time that I intently attempted to understand how disability was constituted in Clara's consciousness, I also remained very attentive to personal beliefs that might affect my examination. A frequent theme in my reflective notes was captured in my questions, "Does Clara really understand what she is saying? Does she have a hidden cognitive disability?" The persistence of my doubts, especially in the face of no evidence whatsoever, demonstrated how difficult it was to set aside or "bracket" my professional training in order to "undo the effect of the habitual patterns of thought and to return to the pristine innocence of first seeing" (Spiegelberg, 1960, pp. 656–657). Little by little a new phenomenological inquiry took place, parallel to that of understanding and describing Clara's experience. This new process was that of examining my own process of bringing my preunderstandings to consciousness. Of particular significance was my recognition of a qualitative shift in the way I referred to Clara in my reflective notes. Whereas at the beginning of the project I frequently noted the ways in which, by virtue of her disability, Clara was different from me, toward the end my reflection turned to the ways in which we were alike and each unique. For example, early on I recorded my reactions to the unclarity of her vocalizations, the high muscle tone in her left arm, and my continued concern that she might fall. After a few weeks of our interactions, my notes had shifted to descriptions of Clara's existential questioning, and I noted to myself:

Why did I think that [Clara's] questioning the meaning of her life was a natural consequence of her disability? Where did I get the idea that someone with a disability would be more likely to doubt the worth of their existence, when it seems that in some ways, she would be questioning this whether she had a disability or not, just like I wonder—and probably most of us do—from time to time whether what I do has meaning beyond my own gratification? Maybe she is ahead of most of us in this regard.

New questions replaced my initial focus on doubts about Clara's ability; my thoughts now focused on whether occupational therapy theory and philosophy carry inherent ableist prejudices and if our education sufficiently prepares us to truly enter our patients' worlds. Peloquin (1993) concluded that behind labels, medical jargon, and many "professional" behaviors lies the helper's desire to avoid being confronted with the patient's fear, pain, or anguish, and thus also to avoid being reminded of the helper's inability to cure and his or her own existential anguish. Recently Hasselkus (2002) noted the inherent assumption we make that people with disabilities "need" our services in order to be more "normal" or "functional," which often means "to overcome the difference, or at least to be less different [from the able bodied]" (p. 54). Hasselkus further noted that occupational therapy, like other health professions, faces a
contradiction between providing services aimed at decreasing differences between people on the one hand, and on the other hand relying on diagnostic labels that validate difference in order to guarantee access to our services. The validation of difference ultimately assures our livelihood as a profession. A phenomenological collaboration between patient and therapist may engender a more genuine connection in which personal meaning truly is the cornerstone of occupation-centered treatment.

Scholars describe “phenomenological intuiting” as an important operation in the inquiry process. This intuiting involves the researcher primarily opening his or her consciousness to the object of attention (Petitmengin-Pegot, 1999; Spiegelberg, 1960; Stewart & Mickunas, 1990; van Manen, 1990). Although the literature described this as a requirement for the researcher, Clara noted one afternoon: "As I composed a message to you describing how my body felt at work, I began asking myself, as if I were the researcher, "Is this what the experience is really like?" I read in your notes to yourself that you asked that question several times, and thought it curious that, without realizing it, I had started asking myself the same question about what I was trying to convey."

It was clear to me from that point onward that Clara had become a coinvestigator of her own experience, and that we were involved in a process in which “the interview turns indeed into an interpretive conversation in which both partners self-reflectively orient themselves to the interpersonal or collective ground that brings the significance of the phenomenological question into view” (van Manen, 1990, p. 99). Again, my personal reflection turned to the usual process in occupational therapy intervention, and I wondered whether the very act of “evaluating” a person's function problematizes that person’s life and detracts from a more personal reflection of the meaning of the phenomenon. From a traditional clinical perspective, our professional tendency would have been to measure Clara’s functional deficits, identify with her which of those were most important for her to address, and initiate a graded program designed to either restore or compensate any functional impairments. However, as Clara investigated the function of disability, a more important effect of reflecting and naming these themes was also unfolding—a change within Clara from passive victim who had internalized the world’s view of disability to an active constructor of her own identity. These themes will undoubtedly change over time as Clara herself changes and continues to develop her sensibilities.

The themes of nostalgia, abandonment, and hope contained within them the basic themes that existential phenomenologists emphasized in the description of lived experience or of “being-in-the-world” including the importance of the body, freedom of choice, and intersubjectivity (Stewart & Mickunas, 1990). Clara’s nostalgic reflection often departed from her bodily experience, from her consciousness of the effort she must make to control her movements and the bodily memory that reminded her of the contrast between the past and the present. In her struggle with abandonment, Clara recognized choices she had before her—to climb into the dark ravine or to avoid it altogether. And finally, in hope, she came to recognize both her own humanity and that of others, and to view herself as part of a community.

In one of my last entries in my reflective notes I wrote: "If I had been Clara’s occupational therapist rather than a researcher, would I have recognized that what Clara needed to do, more than anything, was to reflect on her life project? Would I have defined as a deficit what she now seems to recognize as an asset that is giving her insight into herself and others? Would I have insisted she find meaning in activities, and not thought of helping her find meaning through those activities? Would I have insisted she feel good about herself because she could more easily dress herself or make her bed, and ignored that not being able to do those things might actually be opening the door for her to discover herself and others more authentically?"

Perhaps application of the phenomenological method to the therapeutic process, particularly the therapist’s phenomenological reflection of his or her own experience of the
client’s lifeworld would yield very different, collaborative intervention plans and goals. Ultimately, if meaningfulness is to be a measure of intervention, the process must more accurately reflect the client’s lifeworld. This might only be possible when the therapist is committed to a process of identifying his or her preconceptions and engaging in the discovery of meaning together with the client. A question for future investigation remains: “What would happen if we worked with our clients as coinvestigators of the meaning of their life experience rather than recipients of our expert knowledge of able-bodied function?”

Clara’s final words as we formalized the ending of this project aptly serve to close this paper. Quoting Soren Kierkegaard from an unknown source, she reminded me, “Life is not a problem to be solved but a reality to be experienced.” This, I believe, is at the very heart of occupation-centered practice.

Acknowledgment
This paper is as much Clara’s as it is my own. She declined to appear as coauthor, even though she read all the drafts and provided valuable insights into the content of the final manuscript. The shortcomings are certainly my own, and reflect my learning process. I am indebted, however, for all Clara has taught me in the course of this project.

References


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