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Disability as Difference - A Fictional Representation

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Abstract

This study presents three perspectives about how the life experience of individuals with disabilities is profoundly affected by the attitudes of others. A first perspective is presented by three individuals who had sustained significant, traumatic injuries. They each shared with me their experiences with acceptance and the attitudes of others. A second perspective comes from me, as the author of this article. As a person with a virtually lifelong disability, I have interpreted those experiences through a lens mediated by my own relationship to disability. These interpretations have informed a third perspective, that of a fictional representation of the role that the attitudes of others play in the lives of individuals with disabilities. That representation of attitude is presented as a one-act play. Within an oral history framework of narrative inquiry, the play offers a synthesis and restorying of the meanings inherent in each of these individual stories. Its purpose is to provide the reader/audience with a more intimate understanding of disability, demonstrating the relationship between others' perceptions of disability and its apparently significant and categorical difference from the mainstream. Finally, the implications of this perception of disability as difference are made specific within the context of the ongoing employment challenges that continue to confront individuals living with disabilities.

Keywords

Disability, Creative Non-Fiction, Narrative Inquiry, Oral History, Employment, Difference

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Disability as Difference – A Fictional Representation

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This study presents three perspectives about how the life experience of individuals with disabilities is profoundly affected by the attitudes of others. A first perspective is presented by three individuals who had sustained significant, traumatic injuries. They each shared with me their experiences with acceptance and the attitudes of others. A second perspective comes from me, as the author of this article. As a person with a virtually lifelong disability, I have interpreted those experiences through a lens mediated by my own relationship to disability. These interpretations have informed a third perspective, that of a fictional representation of the role that the attitudes of others play in the lives of individuals with disabilities. That representation of attitude is presented as a one-act play. Within an oral history framework of narrative inquiry, the play offers a synthesis and restorying of the meanings inherent in each of these individual stories. Its purpose is to provide the reader/audience with a more intimate understanding of disability, demonstrating the relationship between others' perceptions of disability and its apparently significant and categorical difference from the mainstream. Finally, the implications of this perception of disability as difference are made specific within the context of the ongoing employment challenges that continue to confront individuals living with disabilities. Keywords: Disability, Creative Non-Fiction, Narrative Inquiry, Oral History, Employment, Difference

Introduction

Current rates of disability in Canada are significant and likely to increase as the population continues to age. In 2012, 10.5 percent of working age Canadians, aged 15-64 years, were estimated to have disabilities. Of these, approximately 85 percent were acquired throughout the lifespan, with only 15 percent being congenital (Statistics Canada, 2012). This cohort of Canadians demonstrates a significantly lower rate of employment than does the general adult population (Breen, 2015; Turcotte, 2014). These employment rates have remained virtually unchanged, at approximately double the rate of the general population, in Canada (Rioux & Patton, 2014) and in other industrialized countries (Copeland, Chan, Bezyak, & Fraser, 2010) for the past 30 years.

Current research indicates that negative attitudes within the workplace toward people with disabilities are a principal contributor to these low rates of employment (Vornholt, Uitdewilligen, & Nijhuis, 2013). These same negative attitudes also contribute to an overall lack of social inclusion for those with disabilities (Miller & Dishon, 2006; Reinders & Schalock, 2014). However, these negative attitudes, often based on misperceptions regarding the nature and consequences of disability, may be susceptible to change through emotionally engaging representations of the social experience of disability.

This study represents disability as a fluid social construct (Shildrick, 2012; Thomas, 2010), various iterations of which are manifested under the rubric of *disability* only when a particular characteristic is perceived as attaining a critical degree of difference within a particular social environment (Nagi, 1976). For example, disability as difference currently includes challenges with written text in academically-focused environments but not in past,

agrarian based societies (Oliver, 1990). Similarly, even minor congenital physical atypicalities have, at various times, been attributed to individual or familial moral failings, resulting in shunning or other penalties. However, as noted by Edwards (1997), in classical Greek times, the ability to participate in community activities, regardless of various acquired physical limitations, determined the acceptance of individuals. Even military service was carried out by individuals with significant impairments. However, those born with disabilities were often killed at birth (Braddock & Parish, 2001). It is clear that *disability* has been categorized and treated differently across cultures and societies (Shakespeare & Watson, 2001).

I have termed the point at which a perception of *difference* becomes sufficiently significant to be considered a *disability* as the point at which it rises above the *horizon of social notice*. In addition, as a fluid social construct, it is equally capable of sinking back below that horizon, when as a particular bodily category, it is no longer perceived as significantly different.

The process involved in the transition from being able-bodied to living with a disability is often compared to entering a new culture, without intent or preparation. In this study, I make use of a creative non-fiction approach within a narrative framework (Clough, 2002), to serve as a conduit between the affective nature of experience and the sense making or meaning required by our cognitive selves. By “transforming ‘factual’ data into fictional form” (Wyatt, 2007, p. 319), literary and dramatic techniques may be employed to “draw readers closer into the emotional worlds of the research subject(s)” (ibid.). It is a representation, a socially framed application, of the meanings inherent in lives touched by disability that I offer in this fictional account. However, it is for the reader/audience to determine what these meanings may be. As the author, my role is to present an image of lived experience; it is the reader/audience who may choose to interpret and incorporate that experience into their own understanding of disability as difference.

Narrative inquiry can be understood as a collection of techniques and processes intended to allow for a range of coherent representations of experience. On the one hand, this *applied coherence* can be seen to create a conduit from the particular to the more general and theoretical. On the other hand, the goal of narrative inquiry may be to interpret and present stories, including those contained within interviews, in a manner that more readily exposes their meaning (Reisman, 2008). This study is intended to accomplish both of these tasks; to *existentialize* original experience in a way that will allow readers/audience to gain a more comprehensive understanding of the nature of disability and to apply this understanding beyond the examples that I have portrayed.

Each of the three men upon whom this study is based had acquired a significant and permanent disability through traumatic means. Each had agreed to engage in a discussion regarding the circumstances surrounding their trauma and what effects that trauma had had on their lives. These men were between 27 and 53 years old; their traumas had occurred from as recently as four years prior to these interviews to almost 35 years ago. I interviewed each of the three participants separately, transcribed the taped interviews, reviewed these materials, and extracted each of the statements and comments associated with the transition from being able-bodied to disabled and each that considered the impact of that transition on their lives. (*All names and identifying circumstances have been changed to ensure confidentiality.*)

My intent is to bring these original data together into a performance that would maintain the integrity of the original material and offer a more generalized account of the understandings put forward by the study participants. Following Clough (2002), I have attempted to offer “a deeper view of life in familiar contexts; (to) make the familiar strange and the strange familiar” (p. 8). To accomplish this, I aligned these data with a fictional representation that is intended to present the reader/audience with opportunities to participate in this research by reflecting on

changes to your own understanding of the relationship between disability and difference as the story unfolds.

The purpose of fiction is to create an image suggestive of a meaning greater than its literal representation (Ricoeur, 1988). With this notion in mind, the following performance, presented as a play involving two central characters, one with an acquired disability and one with a lifelong disability, attempts to actualize that universal meaning in a manner that illustrates not only the cognitively-based, restoried “summing up” of the original data but also the emotional process that leads to that result (Hogan, 2011). Through the use of a fictional possibility, I have attempted to create a circumstance that allows for a more ready appreciation of reality (Bruner, 2002) and to provide a means to experience this seemingly foreign culture first-hand. At the same time, I need to acknowledge my own multiple roles as narrator, interlocutor, and character (Bruner, 2002) within the performance.

What relevance or value might be associated with this fictional experience? To me, as a person with a virtually lifelong mobility disability, this question needs to be considered in several ways. First, the larger, non-disabled population will benefit from a deeper understanding of the life experiences and meanings associated with this increasingly visible group.

Second, by representing disability through different relationships to blindness, I have attempted to demonstrate a more nuanced insight into the heterogeneity of disability than many readers/audiences may be expected to bring to this performance. Limited and/or rigid categorizations of disability, with arbitrary and overgeneralized stereotypical characteristics, create unwarranted perceptions of *difference*.

Third, the staged environment within which the story unfolds provides a means to display disability within a more readily accepted, fictional world. The story is represented as existing within a real environment, rather than as a stand-alone textual report that may be more challenging to understand, and feel, as part of a common experience. Although the environment is fictional, narrative inquiry benefits by being able to blur the distinction between fact and fiction (Clandinin & Connelly, 2000). In this study, that distinction is purposefully made hazy to assist with a suspension of disbelief (Gamer & Porter, 2008) on the part of the readers/audience. I have attempted, through this fictionalization, to provide support, clarification, and an enhanced degree of familiarity with the original data provided by the study participants.

Presented as a fictional one-act play, this study is intended to both recreate the fracturing experience of trauma-based disabilities and to demonstrate the continuity of life that surrounds these events. The typical and the unexpected blend together in a manner that demonstrates how deceptive the appearance of disability can be, both for the audience and for the players. The format of the fictional text evokes both the fracturing nature of the experience described in the original data and the coherence inherent in unfolding lives. The relationship between the three participants and this fictional representation is that of their informing this retelling of the original data as a composite story (Clough, 2002) that is intended to engage the reader/audience through a more broadly developed dramatic representation of whole lives which contain disability.

Finally, one further comment on my roles in this study. I am the researcher, the data analyst, as well as the author of and, although somewhat obscured, a character in the fictional representation. However, I bring no answers to the question of how others living with disabilities understand their own realities. What I believe that I have been able to bring to this study is a level of comfort with the original participants created by being on the “same team” (Goffman, 1956, p. 50), including a long term disability, a history of competitive sports, and a belated return to academia. I believe this has provided me with an opportunity to explore the experiences lived by the three participants of this study from a perspective that would otherwise

be considerably more difficult, if not impossible. As noted by Lieblich, Tuval-Mashiach, and Zilber (1998), the relationship created between the interviewer and the interviewee plays a part in determining what is shared. My relationship with the three participants was influenced by these several common factors and generated a unique set of dialogues that were informed by that circumstance.

In addition, my relationship to this inquiry has been influenced by both my personal and professional experience. I have lived for virtually all of my life with significant mobility limitations. However, it was only during my early career as a designer and manufacturer of healthcare products that I began to come into contact with others living with disabilities. During that period, in the 1980s, I determined that I would only hire people with disabilities in my business. Soon, my small workforce was populated almost entirely by individuals with various disabilities. At the same time, I became interested in wheelchair sports and found myself in my first wheelchair playing racquetball. Until that time I had used crutches exclusively. I also found that I was quite athletically competitive and ended up playing for the Canadian National Wheelchair Racquetball Team. These experiences resulted in my being contracted to provide various *disability awareness* training programs for a number of organizations that were struggling with new Canadian initiatives to employ, accommodate, and manage those with disabilities. I continued to pursue issues associated with disability and employment, sold my business, and, over the next several years, managed two agencies involved in employment services for people with disabilities, served as chair of a Canadian Territorial Human Rights Commission and, in 2004, became the manager of disability employment services for the Yukon government. All during this time, I also maintained a consultancy working within the context of employment and disability.

Over the past several years, my interests have become more focused on the causes of the very low employment rates for people with disabilities. To more thoroughly explore this phenomenon, I returned to academia in 2013 and am currently a PhD candidate in Social Work. My research interests include the development of a model of disability as difference; I am also developing a self-report questionnaire to measure co-workers' acceptance of disabled employees. These interests have been based to a large extent on a consideration of the several current models of disability and their apparent failure to bring about desired economic and social benefits to those with disabilities, particularly within the field of employment.

Literature Review

Historically, societies have imposed divisions between those with disabilities and others (Davis, 2000). Considered variously as necessary for identity formation (Stainton & Swift, 1996), as a means of classification of the human condition (Fujiura & Rutkowski-Kmitta, 2001) and as a way to maintain a coherent worldview (Guidano, 1995), various models have been created as both explanations for disability and as strategic underpinnings for social development (Oliver, 1990). Current models of disability fall within one of three broad categories (Haegele & Hodge, 2016). Each of these, the medical model, the social model, and the embodiment model, have been put forward to explain the many challenges facing people with disabilities. Emerging in the late 19th century, the medical model of disability was framed within a humanist, scientific analysis of disability. It was, at the time, understood to be a progressive way to understand and treat illness (Oliver, 1990). The medical model associated disability with personal tragedy (Barnes, Mercer, & Shakespeare, 1999) and a responsibility on the part of the individual with a disability to accept their "sick" role as submissive, to submit to professional opinion, and to make efforts to be "cured" (Parsons, 1952). The medical model, according to Bickenbach et al. (1999) defines disability as a deviation from structural or functional norms, caused by trauma, disease or other health challenges.

The social model was first developed in the United Kingdom in an effort to shift the responsibility for disability from the individual to society (Oliver, 1990; Shakespeare, 2006). This model distinguished individual impairments from socially constructed disabilities, the latter of which were seen as the inability or unwillingness of the larger society to properly accommodate individuals with impairments (Oliver & Barnes, 2012). The social model has been further parsed into the strong, or UK, model and the weak social model. According to Shakespeare and Watson (2001), the former incorporates the concept of disability as social oppression. The latter, containing both the American model and the Nordic model (Gustavsson, 2004), does not include the necessity of oppression as a central tenet. The American model, framed within a civil rights structure, argues that disability challenges align closely with other minorities (Titchkosky, 2001). The Nordic model suggests that disability is brought about by a combination of social challenges and individual impairments (Bhaskar & Danermark, 2006).

Lave and March (1975) state that models should be evaluated, not by investigating the truth of their assumptions, but rather by examining the effectiveness of their derivatives. This perspective is supported by Schatzman (1991), who notes that care must be taken not to allow predetermined political, sociological or ideological positions to unduly influence the development of models.

The Difference Model of disability is an attempt to reconsider the relationship of disability to the mainstream without a prior analysis of responsibility, whether personal, social or political. Instead, based on a recognition that the strategic application of any of the current models of disability has not been successful in meeting the employment goals of those with disabilities, the Difference Model has been extracted directly from the perceptions of people with disabilities. Within the context of injured workers and their return-to-work progress, several studies have examined a number of factors, including age, gender, and employer characteristics associated with the varying degrees of success (Blackwell, Leierer, Haupt, & Kampitsis, 2002; Cheadle et al., 1994). However, none have considered the importance of the meanings derived from their experiences which adults with acquired disabilities may connect to their successful rehabilitation. That is the goal of this study.

Methods

This study was conducted within a phenomenological framework, in an effort to appreciate the shared experiences of the respondents and the meanings that each of them attached to this experience (Creswell, 2007). The principal method of data collection was individual, semi-structured interviews with the participants. In an effort to most realistically understand the lives revealed through this research (Creswell, 2007; Hanley-Maxwell, Al Hano, & Skivington, 2007), I approached this process from a perspective of developing a “thick description” (Geertz, 1973) of the experiences shared by the informants.

The overarching question for consideration was “What stories of loss, support and transition are told by employed adults with acquired disabilities?” I had selected “employment” as a focus for this study to acknowledge the difficulties of individuals with disabilities in obtaining work (Strauser, 1995) and to gain a greater understanding of the meanings attached to the acquisition of a disability by adults who had sought to enter or return to employment following a traumatic injury. To this end, I advised each participant that I was interested in hearing their stories as a way to make use of their experiences to benefit others who had not yet been able to move back into employment.

The study included a purposive sample of three adults with acquired disabilities. All participants were males. Although I sought equitable gender representation for the study, given the small number of subjects and the greater number of males of working age with acquired disabilities (Pyper, 2006), gender parity was not attained. Following a review of the proposed

study by the University of British Columbia Behavioural Research Ethics Board, I contacted and provided background information and recruiting posters to eleven disability-related service and support agencies within greater Vancouver, British Columbia.

Within three weeks, three people had volunteered to participate in the study. Each had been employed prior to their injury. All had post-secondary degrees. Participants were advised that interviews would take up to 90 minutes and that these could take place at a location of their choice, including their home. This latter option was intended to address the potential mobility and transportation restrictions that may have required accommodations. Ultimately, two interviews took place at participants' employment locations and one in a local coffee shop. The interviews took place over a period of two weeks. Each interview was digitally recorded and transcribed verbatim. Interviews ranged in length from 40 minutes to 70 minutes. I conducted all of the interviews.

Each of the interviews began with the completion of an informed consent document. I had previously provided the participants with background information to the study through a letter of introduction. That letter included an acknowledgment that this study would be dealing with a sensitive topic and that it could potentially be emotionally distressing. In the letter of introduction, I committed to terminate the interview if the subject advised or appeared to be in distress. In addition, I checked with each subject at the end of his interview to ensure a satisfactory comfort level.

Each subject was given the opportunity to review the transcript of his interview and provide comments or to recommend any clarifications, additions or deletions. One participant chose to review his transcript and advised me that it was satisfactory as written.

I reviewed the transcripts for meaningful phrases and concepts that represented the experiences of the participants that corresponded to the pre-existing codes that I had earlier anticipated and which also began to create additional codes that were emerging (Creswell, 2007). From these codes, I re-organized the data into meaning groups and then into eight overarching themes. The three most frequently referenced were the experience of a shattered reality, comfort with others with disabilities, and support by others. These three, viewed as the effects of others, both disabled and non-disabled, on the ongoing personal experience of disability, were the subject of "The Disability Blues".

<p style="text-align: center;">THE DISABILITY BLUES</p>	<p style="text-align: center;">Quotes from interview transcripts</p>
<p style="text-align: center;"><<<<< <i>Introduction to Disability</i></p> <p>The Players</p> <p>DIANE - a blind woman, approaching 30 years old, blinded during a family camping trip as a child of twelve, is a "coffee house" musician, has recorded one blues album, wears a fedora pulled down low over her eyes.</p> <p>JACK - a blind man in his early 30's, born with no eyes, counsels blind people on how to "fit in and get on with your life", played on national goal-ball team several years ago. Always wears wrap-around sunglasses.</p> <p>BOB – Diane’s guide dog. Portrayed by a black silhouette of a medium sized dog with a guide dog harness painted on.</p>	<p style="text-align: center;">>>>>></p> <p>I remember being nauseous with the pain, the pain was so extreme. ... My last recollection is the paramedics arriving at the gym.</p> <p>The space just dropped off to the side. It was as simple as that. Dropped ten feet and that was it. Nothing dramatic. Well, I wish I had some dramatic story to tell, but not at all.</p> <p>I have some recollections of my time in intensive care. I spent four days in intensive care and another ten days in neuro-intensive care. I remember a lot of screaming. I remember a lot of</p>

<p>MARIA – owner of local café. Moves about serving customers.</p> <p>OTHERS - in background (on street, in café, represented by silhouettes only.)</p> <p><i>Goal-ball is a game played by blind people. Two 15 foot wide "hockey goals" are placed 50 feet apart in a gymnasium. Each team consists of three players who stand in front of their net facing the opposing players. The ball looks like a basketball but is heavier and has a bell in it so the players can hear it. The teams take turns bowling the ball at the other team's net. A point is scored if the ball goes in the net. The team defending its net can stop the ball with a foot, a hand or any other part of the body. Players may remain on their feet or dive into the ball's path. In competitive play, no padding is allowed.</i></p> <p>FX – All scenes are tightly lit to focus on Jack and Diane. Everything beyond their “<i>personal space</i>” is in shadow.</p>	<p>people in pain. I don't think that I was screaming but perhaps I was, I don't remember.</p> <p>Okay, basically what it was, was an off-road motorcycle accident. So, I was going really, really slow and just didn't know it was there.</p> <p>I went down to Lake (<i>deleted</i>) and dove into some shallow water and broke my neck.</p> <p>I remember the final moments of that, uh, of the brain hemorrhage, in extreme pain and passing out in the reception room of the, of the gym.</p> <p>Guy said you've broken your neck. I didn't understand what that meant, no concept of it. Thought, oh well, I'll get better. You know, didn't know, it was a really weird feeling the way my legs were all twisted backwards.</p>
<p><<<<<Into the Unknown</p>	<p>>>>>></p>
<p>ACT 1</p> <p>Diane, her guide dog "Bob" and Jack are walking down a trendy, downtown street. It is night - streetlights are dim, few passersby, spotlight on Jack and Diane. Diane walks with Bob on her right side (Street Side) and Jack holds her left elbow with his right hand. She carries her guitar case in her left hand. Jack taps a long, white cane in his left hand.</p> <p>JACK: (<i>to Diane</i>) I know - Bob knows what he's doing. I'll just be his back-up.</p> <p>DIANE: Is this too awkward? We could get a cab if you like.</p> <p>JACK: No, I'm fine. I've just never been able to completely trust a dog since my friend Steve was killed. That does go back a long time – to the early '90s. His dog Fang walked him out in front of a cattle truck in Winnipeg. The dog walked away. But Steve got turned into hamburger.</p> <p>DIANE: (<i>stopping</i>) Is that true? A truck full of COWS? (<i>starts walking again</i>)</p>	<p>I was going into this total unknown. It would be like you, you were transported to a different country with, not knowing what to do, where to go, what the language was, being lost. I'm going like, jeez, how am I going to figure this out? What do I do? Where do I go? I just didn't have any roadmap, no plan. That was really, really scary.</p> <p>Powerless times. But then, because I was a troublemaker it was empowering, also. Because I had an effect. We all want to be able to have an effect, negative or positive. We always think it's positive, but as long as we can make a difference, whether it be a troublemaker or an asset we always want to be able to make a difference... and that's negative or positive, right? That's a value.</p> <p>Exactly, yeah, there's some connection between him, and I'll use “him” because the vast majority of people that get hurt are guys, than say him and a lot of the staff members because it's basically, you</p>

JACK: It's true. Everybody thought that the dog got confused by the scent of the cows. But that's not really what happened. Steve was doing a lot of drugs. So was Fang. Fang was so stoned that he wouldn't have known a cow if it fell on him. After it was all over, they were going to put him down. Bad for the guide-dog image, I guess. Anyway, I took him. He was pretty messed up, but at least he was trustworthy after that. You couldn't force him to cross a street. Mostly, he wouldn't even leave my yard. But Fang's long gone now.

<<<<<Mostly Normalizing >>>>>

DIANE: *(starting up again)* I'm having a little trouble with your story. And it sounds like I should be more concerned about being around blind guys than guide dogs. But you'll be happy to hear that Bob's straight as an arrow. No vices. *(pause)* You know, my place is still a few blocks away but my favourite café is just down the street here. Want to stop for a coffee?

JACK: Sure. And if you'd rather, you can just point me to the nearest bus stop after that. But I am supposed to be walking you home.

DIANE: I'm still working on that.... Here, it's just on your left.

(They enter the café with minimal difficulty. The spotlight stays tightly on them. The rest of the room is in semi-darkness.)

MARIA: (from across the room) Hi Diane. Your table's empty.

DIANE: Thanks Maria. Hi. *(turns to Jack)* It's over to your right, Jack. *(Says to guide dog)* Bob! Table! *(They maneuver to a table in the corner. Bob lies down against the wall. Diane places her guitar on the floor beside Bob. Jack folds his cane. They sit.)*

MARIA: *(Bringing bowl of water for Bob)* Hi Bob. How's it going, Diane? *(Without waiting for answer she turns and speaks to Jack)* How are you? *(Jack does not realize that Maria is speaking to him)* Hello? *(Jack turns toward Maria.)*

JACK: Oh, sorry. I didn't realize you were talking to me. I'm blind, too.

know, quite often they'll say "yeah" but they don't know what it's like, really. At the end of the game, at the end of the day, they don't. And in some ways it's true. It doesn't matter how much they can try and empathize, try and understand, they still haven't gone through the experience.

All these programs gear, geared towards you being out in the community and living your life. So instead of focusing so much on the four or five months you're here, it's more like the rest of your life out in the community which is obviously where everybody's going to end up anyways.

Is there a normal? I don't know, I think it's a highly ambiguous term...

I know that there's staff here who are able-bodied that quite understand the issues.

And then, I'm trying to manage how that affects my work life, the expectations of other people. The most significant thing about my injury is that it's not visible to the naked eye. If I was in a wheelchair, I would have an easier life in some way. I know that sounds callous, but it's not. It's true.

If I was in a wheelchair, nobody would ask if I was better. They would say, you have this, poor guy. We won't expect too much from you. Because they don't see that they expect more of me than they do of people who have obvious disabilities...

<p>MARIA: Oh, I'm...oh damn. I'm...</p> <p style="text-align: center;"><<<<<Accepting Difference >>>>></p> <p>DIANE: It was a surprise to me, too. He asked me if I'd like him to walk me home from The Blue Room. He forgot to mention the blind part until later. (<i>Everyone chuckles - tension breaks</i>)</p> <p>JACK: No problem. Nice to meet you, I'm Jack.</p> <p>MARIA: Hi, I'm Maria. Forgot to mention the blind part, huh? That's pretty good. Coffee?</p> <p>JACK: Please.</p> <p>MARIA: Diane? Coffee?</p> <p>DIANE: Yes. Thank you. (<i>To Jack</i>). Well, now that we're here, what should we talk about?</p> <p>(<i>Maria drifts in and out of scene, bringing coffee, refills, etc.</i>)</p> <p>JACK: So.... would you mind talking about your work?</p> <p>DIANE: No, I guess not. Why?</p>	<p>I started to see some value in what I was able to do rather than focus on what I couldn't do.</p> <p>When people are kind of afraid of me, it's probably not me that they are avoiding, it's the presentation. So I have to, it's incumbent upon me to reach out, to engage so you can get by the disability and get on your relationship.</p> <p>The initial part was difficult to deal with, the physical part like the more difficult part to deal with, down the road, is the psychological part...I mean the mind part. You know, they say, if I'd known what I know now, I would have spent more time working on my psyche. You know, what was it I was thinking about? How was I feeling? My emotions, my psychological state, because that's important in terms of how you're going to cope, long term.>>>>></p> <p>People asked him (Edmund Hillary) why he went up there to die, because people knew it would be very hard to breathe, so they asked him why did you up there to die. He said I didn't go up there to die, I went up there to live.</p> <p>My therapist says that part of my problem is that I don't talk about, um, is that I'm masking my problems, that I'm, I'm, because I don't want to admit them to myself, right, I don't tell other people about what I'm going through, because I don't want to admit it to myself, right. I don't want to say, oh, this is me now.</p>
<p style="text-align: center;"><<<<<Doubt and Disability >>>>></p> <p>JACK: Well, I was just wondering. So many of your songs are so, well, I don't know, redemptive, happy... there's no wallowing. Where does that come from? Wait! That was incredibly presumptuous. I don't think I meant to say that. I...</p> <p>DIANE: Let's see, I've known you for, oh,... (<i>presses her watch face, it says, "Hi, Diane, it's 10:30 p.m."</i>)... let's</p>	<p>>>>>></p> <p>After the fifth doctor, I started insisting that they shake my hand. I'm like, I'm a person, because you can't just, hello Dan (<i>name has been changed</i>), please tell me if you can see this, my, or sometimes they don't even say hello, they just, just come up and go, okay, let me know if you can see, um, I would just put my</p>

say two hours and so far you've tricked me into walking me home and now you're going to psychoanalyze me. Not bad. What's next? A deep and meaningful relationship by midnight?

JACK: This isn't going too well, is it? I didn't plan on saying that. I never say things like that. But, you can't be upset about the walking home part. That was pretty funny.

DIANE: Okay. It was. But let's talk about you instead. Such as, other than hanging around coffee houses and trying to pick up the singers, what do you do?

JACK: I wasn't just hanging around trying to pick up the singer. I was trying to, well, trying to pick up a particular singer - in a polite sort of way. Do you know that I had to tell the guy at the front that I was your blind cousin so he'd put me at your table? I sort of let him think that we're part of a blind family. Can you believe it? "Hi, we're the blind family. We all play the blues." I can't believe I said that either. Not the blind family part, the part about picking you up. That's not what I was really thinking. It was more because of your music. I felt like I knew you already.

<<<<<The Dancing Bear >>>>>

DIANE: You can't know me. We just met. I'm just a blind blues singer with a dog named Bob and...

JACK: I didn't know you were blind until you mentioned that your guide dog's name was "Bob" in your first set. I had just come in and was standing at the back until I heard you say that.

DIANE: Oh, I, um, you may be contagious...I don't usually say things like this either but thanks for that. Sometimes I think that people come to see me just because I'm blind.

JACK: I know what you mean. It's not how well the bear dances. It's just that he can dance at all. Is that what worries you? Well, take it from me, the bear's dancing pretty well. You have a way of making your songs feel like absolution. Do they work for you, too?

DIANE: Enough of me. Who might you be? Do you work? Hobbies? Anything I should know?

hand out and say hello, hi, how are you, it's nice to be here...

I just walk out of the neurologist's office and people look at me like "you look so normal, what the hell".

And so when people come and see me they automatically understand that I understand. And, you know, I don't sort of have to say any fake words. Automatically, I can understand because they know I've gone through it. And they understand in the sense that, you know, most people ask me what happened to you and I really tell them, right?

Even though it's been 30 years I can still see myself as the "pre" Bob, the able-bodied Bob and the post-injury Bob, this disabled person and, too, I've never completely integrated those two pieces and it's not in the negative it's just the reality. The reality is that one day I was able-bodied and the next day I'm disabled and I still long, in some ways, to think about that.

When I first went to (*deleted*) you were in bed by 7:00 because why would anybody, because why would anybody want to be up past that time? Well, Dr. (*deleted*), have you ever been up past 7:00? I was known as a real troublemaker. I mean, I'd bring beer in and... they threatened to send me to (*deleted*).

The physical part, initially, was the terrible part. The second hard part was more the psychological, emotional part that was not taken care of. The main, the mind stuff.

JACK: Well, mostly I dispense free advice. But I'm also thinking of starting up a part-time business advising how to pick up blind blues singers.

<<<<<Then and Now >>>>>

DIANE: I'll have to introduce you to Old Blind Joe. He's the best slide player I've ever heard. But I don't know if you're his type.

JACK: Thanks. I appreciate the offer. I've actually been to one of his shows. He's pretty amazing... but what a name. It's like calling yourself Joe the Cripple.

DIANE: He's been around a long time. People weren't exactly politically correct when he started off. And that's just the way he deals with it. "I'm old, I'm blind and my name is Joe. If you don't like it, you can take a hike." That's pretty well the way he is.

JACK: It sounds like you know him pretty well. How he deals with what?

DIANE: We're friends, sort of. I studied with him for a while. He comes in here sometimes, too.

JACK: How he deals with what?

DIANE: Oh, you know. I call it "the edge". His attitude keeps it away. He says that the blues lets you dabble with it. Like a safety valve on a steam engine. But we were talking about you.

<<<<<Disability and Identity >>>>>

JACK: Okay....Back to me, I really do work. I dispense free advice to recently disabled folks. How to pick up the pieces and keep going. Employment, residential problems, family stuff, sex, addictions, how to deal with other people. You know, how to stay "one up" - if you have "one" left. It's always about transitions. How to make the leap from then 'til now....However, that's not my only talent. I also offer free advice in any number of other situations. Would you like some?

I see people who sometimes wrap their whole identification around being a person with a disability and they tend to not end up getting on with their life, and sort of wallow in the rehab world and I see that and it's kind of sad because when you keep on doing that for how long, long time that's all you know ... and less and less able to kind of break away and start making your own path in life.

It's fear. It's a huge comfort when you're with your own peers as opposed to breaking away. So, it's ...like...I would go to a different country and I would find the nearest Canadian, the nearest group of Canadians, as opposed to being out and engaging the larger community. So it would be like me going to Germany or France where I would find the Canadian club and hang around with a bunch of Canadians.

I was actually regressing. I was getting depressed. I didn't want to be here. I was (uh) probably doing things I shouldn't have been doing. I needed to leave. I was happy to go. But I was also scared to go. The more you think about it, the more depressed you get, the more scared you get.

I was really, without admitting it, scared to death.

After two months... I could feed myself and I could... I was very anxious about the incident, I was very anxious, I didn't know if it was going to happen again. Right? I was, um, I had a number of panic attacks the first two months and was readmitted to (deleted) with a series of panic attacks.

DIANE: Just a bit, if that's okay. But you're not going to pretend it's not there, are you?

JACK: But I don't...

DIANE: How long?

JACK: Since birth.

DIANE: You see what I mean. It's just a matter of acknowledgement. I was twelve. I got shot on a family camping trip, hunting pheasants You know something.... Jack... I almost forgot your name... I don't usually have this discussion the first time I meet somebody. And I don't press people, but...

JACK: No, it isn't exactly my first choice either, but "the edge" certainly sums it up. It's always so easy to advise someone else. (*Takes on a serious voice*) "Just consider your options, you'll feel differently later on...". You know, sometimes I feel that all I'm really doing is... oh, I don't know... it's like that Monty Python sketch about how to learn to play the flute. "You just blow in one end and wiggle your fingers at the other end." A good idea but a little weak on particulars.

DIANE: It's the place I avoid. It's as if my whole life was splashed onto a giant landscape – right in the middle is a black hole - sucking in everything that gets too close. That's what I'm trying to avoid. But sometimes I can't see where it is. It gets a little unnerving, in case you fall in. But what about you?

JACK: My imagery is different. I've always been blind. I think I "see" with an accent. To me it's chaos. Too little predictability. That's "the edge", isn't it? That's what you're talking about. Whatever gets to you in the middle of the night.

DIANE: Whatever you call it - what do you do to manage? I just write songs.

JACK: The same as everybody else.

DIANE: And what's that?

JACK: I hesitate to use the phrase here but it's really just 'blind faith'.

So, that's very hard to live with. It creates a lot of anxiety. I don't know when I'm going to go again so I do what I can to avoid that. I take (inaudible), I take medication and I regulate my diet, exercise and so forth in ways that, hopefully, prevent it.... After the hemorrhage, I kept waiting for another hemorrhage. And after the seizures, I keep waiting for another seizure.

I say to people, you know, I truly feel, kind of, in some ways blessed to do what I do, because there's a lot of freedom, a lot of influence to make some profound changes in people and you never know how profound you're going to make it. You know, sometimes you do things and you don't hear until much, much later from clients saying, you know, you've really made a big difference in their life.

I think, inherently, we all have a great desire to contribute, not to be takers. And, although we think at times that that's our pursuit, I think inherently we have a desire to give... to the people we love, to our community, to society. We want to be contributors. I think that's, when you feel that that's lost, that you've lost one of the basics of life.

At first it's odd but when you start getting to know other people (*with disabilities*), it's cathartic. It's like, oh, thank God, someone else deals with this as well. Uh, please, it's... it's empowering, because you're surrounded, you have people you share your problems with, and they have attitude. Each step you take, you see a little further ... Each step you take, you see a little further. But it's people who assisted me to take that step, a scary step but it opens the skies in a scary way, at first. Then you see more as you're able to do it.

In the early years, a friend who is going to (deleted) said, well, can you see one of my classmates? She's just having lots of difficulties. And I said well sure I'd like to meet her. And that process just kind of kept going

DIANE: I don't think I understand.

JACK: It's my unsubstantiated belief that with a little bit of luck I can actually know someone. And I'm not talking about knowing like in some kind of introductory philosophy course. Can I really know anyone well enough to trust them absolutely? Or at least to be willing to accept whatever consequences came from that trust? Unfortunately, this question has several possible....

DIANE: Wait! Let me try. First, you can start from a position of absolute trust and see what happens. Second, you could start off trusting no one and stay there. Third, you can just blunder ahead and not think about it. Did I miss anything?

JACK: How did you do that? I've spent years thinking about this and you just, bang, zip off the answer. But maybe the real issue is that I don't trust myself. And yet here I am, talking to a stranger about...about very personal stuff. It's because I trust you...maybe it's your music.

DIANE: So what would happen to that trust if I stole your wallet or excused myself and didn't come back?

JACK: Well, I guess I'd feel like a bit of a jerk. But I'd probably do the same thing again. Remember, I said "blind faith"? It's only real use is to help you take otherwise ridiculous risks. You're a risk... but it feels right. And it feels good.

DIANE: I could say I'm flattered. But I can suggest other reasons to explain your behaviour, I could even say *unseen reasons!*

JACK: Ouch. I guess it's my turn to squirm. Go ahead, tell me.

DIANE: Maybe this is all just a pickup line. Some blind twist. Or you just like my music. Or you're just playing some part that doesn't really have much to do with me. Where does that leave me? I would be sort of up a stump, with the short end of the stick, and I wouldn't know it. And there's no way for me to tell, either.

where people would bring people just to chat and they felt that it was helpful... All of a sudden I could see some value.

I have, oh, I can't do that. No, I have to wait, this is going to take me another year, this is going to take me another two years, um, this is going to take more time. I don't admit that so I am, so I'm more vulnerable to these things, and I don't admit that and I don't tell other people, so consequently they treat me differently. They treat me as though there's nothing wrong.

And sometimes it hits you in a very, very odd way. It's like, a few weeks ago I was looking, watching someone go upstairs, and I thought "I wonder what it's like to go upstairs?" Just a random thought. Wasn't sad, it wasn't negative, it was just this kind of odd curiosity. I was thinking, do I really remember what it's like to feel that and I couldn't really, right? Because it's been so long.

And there is the lack of boldness, a real sense of fear of taking that next step in getting into the real world. The real world being the everyday world.

<<<<<New Horizons

>>>>>

JACK: Well, how about this. You could always fall back on the "no options" argument. It goes like this. There is no way to know anything that isn't logically demonstrable. States of mind are not logically demonstrable. Therefore, states of mind can never be known to be true. There, that allows you to duck pretty well everything. But you miss out...

DIANE: I'm starting to feel a little battered. Sort of like being in the middle of Punch and Judy debating with Jean-Paul Sartre.

JACK: I don't really get that imagery. But ask yourself, right now, how do you feel? No, wait! I'll answer first. I feel happy. I'm interested in your thoughts... in your perceptions of the world. I would like to understand your point of view. I like you a lot. I trust you.

DIANE: You need to know this is absolutely against my better judgment. I know it's going to hurt. I do much better when I stay in my own track.

JACK: Can I touch you?

DIANE: My left hand is on the table.

JACK: (Covers her hand with his) You have a very gentle hand. (He turns it palm up, touches her palm with his index finger) Let's see...you're 5'6" tall. You have dark curly hair, weigh 130 pounds and...and you're wearing a hat.

DIANE: That's impossible. How could you know all that from my hand? (Pause) You couldn't know I'm wearing a hat. Wait, you're not really blind. You bastard, that's really low, you..

JACK: No...no... wait. After I heard one of your tunes in the record store, I asked the sales guy to describe you. He mentioned that you always wore a fedora on stage. I guess he must have thought that, since I'm blind, I knew you were, too. He didn't say. I just guessed about the fedora since you were performing tonight.

DIANE: Oh, no. (Putting her hands over her face) This is very embarrassing. I'm so sorry.

My equation of value was how hard I worked, how many widgets I could put out, how many goals I could score, how popular I was. That was my value. Now, of course, I'd lost my identity. You're all about your body and your looks. I was fit. I was applauded for what I could do on the (deleted). Now I'd lost that.

After my surgery, my parents say I've changed, but I'm a different person that, uh, I guess I have a different view of life, right? I know how short life is. I've watched at least 40, no, at least 20 to 30 people die in intensive care...Like when I have a seizure I wake up in, like, the emergency room so I'm watching people die all the time. I saw a guy next to me dying and his wife puts her arms round him and, bang, he's gone. I've got old ladies moved into intensive care for the last hours of her life... I don't waste my time. I think one of the consequences of my disability is that my experience, I don't maintain, I rarely maintain, I have difficulty maintaining personal relationships.

I don't want to sit here and have this conversation with you. I'm sorry, but I do... and I wish I'd never met you. It's, like, I didn't want this...and... yeah.... In geological time they talk about the KT event that wiped out the dinosaurs, alright, so no one knows exactly what that was, most of us assume it was a meteor....this was my meteor, this is.... Bang. Life, your life begins again, um, you go over here, there is no way back.

The biggest rehab was probably the peers, their attitude, you know, with life. It wasn't about their disability. They'd been in there for long times. There was one guy who just lived life, he was a good model.

Guy said you've broken your neck. I didn't understand what that meant, no concept of it. Thought, oh well, I'll get better. You know, didn't know, it was a really weird feeling the way my legs were all twisted backwards.

<p style="text-align: center;"><<<<<Perceptions of Value >>>>></p> <p>JACK: That's all right, (<i>feels for her hand and then reaches out for it</i>). You know what else I see? I see that you are very beautiful. It says so...right here. (He taps a spot on her hand)</p> <p>DIANE: Stop teasing me.</p> <p>JACK: I didn't mean to embarrass you. I didn't mean to say you're beautiful. Well, no, not that I didn't think that, I just didn't mean to...actually, I guess I did. We're different you know. I've never seen anything. You have visual memories. I don't, I don't even have anything to compare you to. Can I try to describe what I mean when I say you are beautiful? Even if you're a little embarrassed?</p> <p>DIANE: How can I say "no" to that?</p> <p>JACK: It's that same feeling - trust - believability - a sense of intensity, I don't have any external images. Your hand feels beautiful because feeling it makes me feel good. Your voice is beautiful because it feels so true, Who said "Truth is Beauty" - Plato? - He was right.</p> <p>You feel nice, you sound nice, you even smell nice. But there's something else about you. You demand truth – and I think you get it. How do you do that?</p> <p>DIANE: I don't know what you mean. I don't demand anything....</p> <p>JACK: It's not about what you want. It's like you were a mirror...but you only reflect what's true. And nobody wants to screw up when they're staring into their own face. You don't have to try...there's no option. Does this make any sense?</p> <p>DIANE: This is really embarrassing. (Takes her hands away and puts them off of the table) You're picking on me. I can't be responsible for you. That's not fair...I should be getting going anyway. It's getting late. (Presses watch face. It says, "Hi, Diane. It's 11:14 p.m."). I have an early appointment. I should go...damn...I don't like</p>	<p>After a few weeks I realized this was a hell of a lot more serious than I'd initially thought, 'cause I wasn't moving.</p> <p>I'm still adjusting to my new skin.</p>
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this. You're the first guy in a very long time to...to say things like this to me.

JACK: To say what? You're a mirror? Oh...you're beautiful? Is that it? Hey, no nodding.

DIANE: Yes. I don't know how to deal with this. It's not fair. I know it's supposed to mean something. But it doesn't to me. I don't know what I look like...except for when I was twelve years old. Do you know what that does to me? To have you describe me like that? I don't even know what it means?

Do you know that people do things for me before I even ask? If I even look like I need something - someone is suddenly there to help. It makes me crazy.

- The End -

Closing score: Tom Traubert's Blues (Tom Waits)

Discussion

Narrative inquiry contains a variety of ways of organizing experience that allow for the creation of a coherent relationship between our past, present, and future selves. This fictional representation of the understandings shared by the three participants in my original interviews has been framed within a “*three-dimensional narrative inquiry space*” and the “directions” this framework allows our inquiries to travel – *inward, outward, backward, forward, and situated within place*” (Clandinin & Connelly, 2000, p. 49, italics in original). This approach allows for a more holistic consideration of the experiences of the storyteller and their interaction with those in the story. This three-dimensionality is represented in the subtitles of the play itself. “An Introduction to Disability”, is a description of interests, activities and lifestyles which, for some, will have an almost exotic feeling to them. “Into the Unknown” is an image of transition, an event rather than a static image of disability. Finally, “The Dancing Bear” illustrates somewhat matter-of-fact perceptions from a perspective foreign to most.

As represented within the fictionalized representation, developing an understanding of disability is a process, both for those directly involved and for those who observe through a series of intimacies. This process is not intended to be perceived as being particularly linear, or even as categorically predictable. However, even those whose lives have been lived entirely within this framework are seen to experience developing degrees of awareness pertaining not only to the outside world but also to their individual identities.

The themes extracted from the original interviews, and which were represented in the play, support current research which indicates that the attitudes of others are of significance in the lived experience of individuals with disabilities (Burke et al., 2013), most noticeably within the area of employment (Vornholt, Uitewilligen, & Nijhuis, 2013).

The participants' descriptions of their experiences all began with graphic and detailed, but somewhat detached, illustrations of the events leading up to their acquiring a disability. There was very much a sense of these events being described as though by third parties who witnessed a tragic accident. However, as this opening part of our conversations moved to a description of their cognitive and emotional states following the precipitating event, the tone

of the discussions changed dramatically. It was as if each of the participants had been able to come to terms with the event of the disability much more readily than with its aftermath. Although the reasons for this difference are speculative, it may be that the acceptance of the event itself was within the control of the individuals themselves; however, the ongoing challenges associated with each of the ongoing life experiences were substantially influenced by the attitudes and behaviours of others.

I believe that the results of this study, and the imagery through which it is fictionally represented, may be generalized to a much more broadly based population of adults living with disabilities. The experiences of a “shattered reality” related by the original participants are similar to those put forward within theories of psychosocial adaptation to disability (Livneh & Antonak, 2005). In addition, participants’ recognition of the impact of external attitudes is supported by a broad range of research, including an American study of 3,797 employers who most often indicated that their perceptions of individuals with disabilities were more negative within an employment context than within other social environments (Domzal, Houtenville, & Sharma, 2008).

This study also presents several possible limitations. These include the age and gender of the participants. Younger respondents, and women, may have quite different perspectives on the relationship between the attitudes of others and their own life trajectory. In addition, all of the participants in this study had been employed for a period prior to their acquiring a disability and each had a post-secondary degree. Given the ongoing high unemployment rates for individuals with disabilities, these respondents could be considered somewhat atypical.

This study has examined the social relationship of disability and its effects on those living with and participating in those lives. Although this restoried fictional account, similar to the original data, has no definitive resolution, it has made visible a possible and witnessed trajectory. Intended as participatory research, each reader/audience member is challenged to reflect on how or whether their *horizon of social notice* has been influenced by the characters in this representation. This research demonstrates how disability is a process, rather than an event, and that this process is influenced by others’ perceptions. Further explorations of these perceptions, including their causes and the means necessary to bring about positive changes, would add to these understandings of disability.

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