Disability Identity: Exploring Narrative Accounts of Disability

Dana S. Dunn and Shane Burcaw
Moravian College

Objective: To review a type of narrative identity, *disability identity*, which is a potentially important topic concerning the social psychology of disability. Disability identity entails a positive sense of self, feelings of connection to, or solidarity with, the disability community. A coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles. Attention to disability narratives will enable rehabilitation psychologists to develop detailed theories and plan empirical investigations aimed at exploring the psychosocial applications of disability identity. *Method:* We examined six narratives (e.g., articles, chapters, books, blogs) written by people with disabilities in order to identify excerpts illustrating disability identity. *Results:* Using themes drawn from disability-identity research (i.e., communal attachment, affirmation of disability, self-worth, pride, discrimination, personal meaning), we categorized excerpts from the narratives. *Conclusion:* By highlighting positive aspects of disability identity, the study of disability narratives can inform persons with and without disabilities about how individuals live with disabilities. We discuss reasons rehabilitation researchers and practitioners should consider disability identity and narratives in their respective efforts.

Keywords: identity, narrative identity, disability identity, social psychology of disability

Disability identity is a frequently used but imprecisely defined concept . . . [but] there is general agreement that people experiencing disability often feel affinity, or even solidarity, with others who also experience disability . . .

– Michelle Putnam (2005, p. 188).

Although it might be hypothesized that disability identity and feeling a part of a disability community are buffers against the stresses of being an oppressed minority, this has not been directly examined . . . Is disability identity a buffer against . . . disability-specific hassles?

–Rhoda Olkin & Constance Pledger (2003, p. 302).

Impact and Implications

• Disability identity is presumed to be an important and adaptive psychosocial construct in the lives of many people with disabilities, yet there is a paucity of scholarly research on the topic. The present review is a preliminary effort, one aimed at drawing rehabilitation researchers' and practitioners' attention to this neglected topic in order to encourage future theoretical and empirical efforts.

• Disability narratives that highlight issues of disability identity can provide people with disabilities and their families and friends, caregivers, rehabilitation researchers and therapists, and nondisabled persons with a resource for understanding and learning from the social psychological experience of disability. Such first-person accounts disclose and promote appreciation for the common and unique factors that shape the experience

of disability, a goal of the "Guidelines for Assessment of and Intervention with Persons with Disabilities" (APA, 2012).

Introduction

The term *narrative identity* refers to the personal evolving story of the self that an individual consciously and unconsciously creates to bind together many different aspects of the self (McAdams, 2006; McAdams, Josselson, & Lieblich, 2006; Singer, 2004). The purpose of this article is to explore a particular type of narrative identity, *disability identity*, a potentially important area of research concerning the social psychology of disability (Dunn, 2010; Olkin & Pledger, 2003). We propose to begin exploring disability identity by examining published narratives written by people with disabilities regarding their experiences. For people with disabilities, disability identity entails growing up with a positive sense of self, and a feeling of connection to and affinity or solidarity with other members of the disability community (Gill, 1997; Olkin & Pledger, 2003; Scotch, 1988). Following the available literature, we explore the idea that disability identity has beneficial and adaptive qualities based on connections between the self and other persons with disabilities.

In this article, we define disability identity according to the existing literature and explain its importance to understanding critical aspects of life with a disability. We then discuss some key identity themes found in prior empirical and theoretical work on disability identity. The third section of the article examines selected narratives illustrating these identity themes. We conclude the article by discussing why rehabilitation researchers and practitioners should consider disability identity and narratives in their respective efforts. We believe that a review of disability narratives and identity themes will enable rehabilitation psychologists to develop detailed theories and plan empirical investigations aimed at broadening understanding of disability identity.

Defining Disability Identity

Identity is by no means a new construct in the psychology of personal development; rather, it is a firmly established empirical part of the study of the self (Adams, 2012; Leary & Tangney, 2012). In psychology, the term *identity* is often used to refer to conceptions of the self, expressions of individuality, and accounts of group affiliation. Identities define us because they contain traits, personal characteristics, roles, and our ties to social groups, and they can be focused on our past (what was true once), the present (what still is true), and the future (our wishes, expectations, and fears) (Oyserman, Elmore, & Smith, 2012). Psychologists have been interested in the development of personal identity as being rooted in group membership and minority status; hence they have studied identity in the context of race, gender, and sexual orientation. Disability qualifies as another identity context, one that clearly marks individuals as part of a group and as members of a minority sometimes subject to prejudice or discrimination.

Identities help people make sense of different and distinct parts of their self-concepts (Oyserman, Elmore, & Smith, 2012). Thus, for people with disabilities, an identity should contain relevant content and goals linked to disability. In effect, disability identity should guide people with disabilities toward what to do, what to value, and how to act in various circumstances in which their disability is a salient quality. Within this context, Olkin (1999) raises an important issue that should shape any inquiry into the nature of disability identity: When do people consider themselves to be persons with disabilities? Olkin's analysis suggests that disability identities need to be considered on a continuum, a point that has some heuristic as well as descriptive value. At least two groups on this continuum can be presumed to have no disability identity: Those individuals who are not disabled and those persons who possess a disability objectively but do not identify themselves as someone with a disability. That is, although members of these respective groups might possess a positive sense of self, for example, they do not do so with any social or emotional connection to the disability community.

In Olkin's (1999) view, three disability-identity groups do stand out, however. Individuals with some functional limitation who identify themselves as persons with disabilities or as having some handicap represent one group. Olkin includes here those who can "pass" as nondisabled because their disability is neither severe nor salient, which means some may identify more with nondisabled people than with a disabled minority. A second group is comprised of people whose disability is linked to their overall self-concept and its valence can be positive, negative, or ambivalent. Generally, however, these people feel they are a part of the disability community. The third and final group is comprised of disability rights activists who characterize disability as a social construct and a civil rights issue. Members of this group routinely associate with other people with disabilities and advocate for the rights of people with disabilities.

Does disability identity supersede other identities a person may possess (e.g., parent, friend, spouse, employer, employee)? Not at all, as research on self-concept indicates, identities develop from past experiences, personality traits, abilities, physical appearance, values, goals, and social roles (e.g., Campbell, Assanand, & Di-Paula, 2000). At any given moment, only a small portion of the large collection of beliefs about the self are apt to be accessible and engaged in a person's focal awareness (e.g., Baumeister, 2011; Markus & Wurf, 1987), presumably as a reaction to distinct situations, people, or social interactions. Disability presumably operates like other particular aspects of people's self-concepts (e.g., race, gender) that stand out when or because they are unusual or uncommon within a given social context (e.g., McGuire, McGuire, Child, & Fujioka, 1978). Thus, an individual's disability identity might be activated when he or she is confronted with an inaccessible public building but not when drafting a legal brief with a colleague at the office.

As defined, disability identity appears to be a viable aspect of some individuals' self-concepts. We now explore its role as a vital quality in the development and maintenance of these self-concepts. To do so, we turn to available research on disability identity and some key themes therein.

Research on Disability Identity: Some Key Themes

Much of the available scholarship on disability identity has its origins in the study of disability activism and disability policy studies rather than rehabilitation psychology (see, e.g., Davis, 2001; Olkin, 1999). A recurring theme in the formation of disability identity is the importance of community, where people with disabilities are actively engaged with their peers due to common experience.

Communal Attachment and Affirmation of Disability

When they were analyzing the survey responses of some disability activists, a factor analysis performed by Hahn and Belt (2004) found that many possessed a self-identity linked to a positive affirmation of disability. A noteworthy aspect of the study is that many of the individuals involved were adamantly opposed to receiving any treatments that might cure them of their disabilities. In effect, living with a disability was perceived to be a valuable experience, one that provided "a positive source of personal and political identity instead of viewing their disability as a negative defect or deficiency that results in a loss or decline of bodily functions" (p. 453). The authors suggested that disability identity entails favorable feelings toward and a desire to affiliate with a broad community of people with disabilities. Gill (1997) referred to this sense of community-based identity integration as "coming home" (p. 42). Hahn and Belt referred to respondents with these characteristics of *communal attachment* as "disability integrators" in contrast to "disability isolaters," who lacked this sense of connection and felt of little use to other people with disabilities (recall Olkin, 1999).

A second personal identity factor emerged in the data, indicating that many respondents were disposed toward an *affirmation of disability*. Hahn and Belt (2004) suggest that this factor was a result of private beliefs and experiences rather than as reactions connected to the aforementioned disability community. This personal affirmation is arguably a means toward feeling included in the greater society, having the same rights and responsibilities as other citizens (Gill, 1997). This facet of disability identity emphasizes a desire to be recognized and treated like everyone else within a group or society more generally. Yet Hahn and Belt's results indicate that the experience of disability is complex and ultimately an individual one (cf., APA, 2012), as not all respon-

dents affirmed a positive identity (see also, Olkin, 1999). Some respondents reported less favorable views on personal identity that led to a component reflecting a "denial of disability."

The combination of communal attachment and affirmation of disability suggests that disability identity can develop as a way to cope with social discrimination, outsider status, and the recognition of being different in everyday life (Gill, 1997; Hahn & Belt, 2004). These positive qualities are also likely to help people with disabilities constructively cope with physical barriers (i.e., absence of ramps or elevators, narrow doorways) so that the problems with daily living with disability are seen as social and environmental rather than as physical impairments or functional limitations. Interestingly, Hahn and Belt also found that personal identity and affirmation of disability were linked to age of onset of disability. Individuals who acquired a disability prior to adulthood are likely to have a stronger personal sense of identity with disability (as both a personal quality and as an affiliation factor binding their experience with others), echoing Erikson's (1963, 1968) claims about beneficial adolescent identity formation. As already noted, however, these authors were primarily interested in explaining respondents' rejection of a cure for disability, whereas our point is to note that a positive disability identity is apt to appear prior to adulthood.

Yet how should rehabilitation psychologists reconcile the factors of disability-community connection and affirmation of disability with the desire of many people with disabilities to be seen by nondisabled people as individuals with many qualities *besides* disability? Are these motivations contradictory? We do not believe so because, as noted earlier, the salience of a person's particular identity is likely to shift in response to a given context; different aspects of disability identity are likely to come to mind, depending upon particular circumstances. Thus, connection and affirmation are likely to be triggered when an individual socializes with other people with disabilities or when engaging in disability activism, for example, but perhaps to a lesser degree or not at all when socializing with family and friends.

Themes Drawn From Disability Identity Politics and Activism

In research developing a framework for understanding political disability identity, Putnam (2005) affirms the view that disability identity entails a sense of affinity or solidarity with other people with disabilities. Putnam identified six primary domains or as we will refer to them—themes—as being relevant to political disability identity and its link to disability activism, and three seem relevant to disability identity as understood within psychological contexts: self-worth, pride, and awareness of discrimination. Putnam's other three domains—common cause, policy alternatives, and political action—are more aligned with public policy and social action concerns, not psychology or identity per se.

Self-worth, the idea that one values oneself, is dependent on an individual's ability to perform activities or tasks viewed as important to the self, others, and society more generally (e.g., performing activities of daily living; Crocker, 1999; Crocker & Wolfe, 2001). A sense of self-worth enables people with disabilities to see themselves as possessing the same worth as individuals who have not experienced a disability. At the same time disabled people believe they contribute to their communities, they also realize that,

in general, people with disabilities are undervalued by society at large. According to Putnam (2005), self-worth allows people with disabilities to resist being influenced by prevailing negative attitudes and beliefs. In effect, a strong sense of self-worth can help people with disabilities combat and overcome the social stigma of having a disability (Linton, 1998).

Distinct from self-worth, *pride* refers to being proud of one's identity and, in the process, acknowledging possession of a socially devalued quality, such as a mental or a physical disability (Putnam, 2005; Swain & French, 2000). Pride encourages people with disabilities to "claim" rather than deny, mask, or hide disability, and to adopt the perspective that physical or mental impairments are normative within humanity (Hahn, 1997). Accompanying these beliefs is recognition that, although disability is not inherently negative, some social, cultural, or physical settings can make it seem to be (Putnam, 2005), reinforcing the well-established view that disability results from Lewin's (1936, 1939; see also, Dunn, 2011) person–environment interaction (e.g., Dunn, 2010; U.S. National Institute on Disability and Rehabilitation Research, 2000; NIDRR; Wright, 1983). Finally, pride is also a quality of disability identity that promotes a sense of belonging within the disability community.

The third theme, *discrimination*, entails awareness and recognition of and often direct experience with the fact that people with disabilities are often the targets of biased, prejudiced, and unfair treatment within daily life (e.g., Chan, Livneh, Pruett, Wang, & Zheng, 2009; Lam, Tsang, Chan, & Corrigan, 2006; Phemister & Crewe, 2004; Smart, 2001; Thornicroft, Rose, Kassam, & Sartorius, 2007). Generally, attitudes toward people with disabilities are negative (e.g., Brodwin & Orange, 2002; Frank & Elliott, 2002; Yuker, 1988) and even professionals are not immune from harboring biased feelings (Chubon, 1982; Tervo & Palmer, 2004; but see, Satchidanand et al., 2012). In the short run, such negative attitudes are "invisible barriers" during rehabilitation, whereas in the long run, such prejudicial attitudes and discriminatory behaviors serve as ongoing disruptions to daily living.

A primary reason for attitudinal and behavioral antipathy is that many nondisabled people lack meaningful personal relationships with people with disabilities or have not had sensitization training (Yuker, 1994). According to Putnam (2005), recognition of discrimination among persons with disabilities entails believing that the minority group is negatively stereotyped and treated differently (again, often negatively or at least negligently) compared with nondisabled people. As an element of disability identity, discrimination makes persons with disabilities aware of inequality where social opportunities and economic resources are concerned. In some cases, this awareness can galvanize resolve and foster social activism on behalf of themselves or other persons with disabilities.

Some sociopolitical qualities of daily life clearly contribute to the development of disability identity. But how do individual, private psychological experiences influence disability identity? Within research in rehabilitation psychology, identity is often found in the search for meaning in disability.

Personal Meaning and Disability

Finding *personal meaning*—searching for significance, engaging in sense-making, and finding benefits associated with disability—is arguably an important aspect of disability identity because

it represents a form of personal acceptance. Wright (1983), for example, proposed that when disability is accepted by an individual as a nondevalued quality, it becomes incorporated in the person's self-concept. Wright's "coping versus succumbing" framework indicates that individuals who are coping with disability emphasize their existing or potential assets while broadening their scope of values beyond those compromised or never realized abilities precluded by disability (see also, Keany & Gluekauf, 1993). Assets can be tangible (e.g., income, skills), achieved or attainable (e.g., education, goals for the future), social (e.g., family, friends, coworkers), or psychological (e.g., sense of humor, resilience). In contrast, a succumbing orientation is marked by denying or trying to mask a disability, by idolizing "normality" (i.e., no disability) or seeking an impossible standard of performance or behavioral perfection, or simply emphasizing deficits linked to disability (Smedema, Bakken-Gillen, & Dalton, 2009). Constructive acceptance of what is, then, can solidify the meaning of disability while promoting a favorable disability identity.

Other research reveals that people often find positive meaning associated with their acquired physical disabilities (Bulman & Wortman, 1977; Dunn, 1994; Heinemann, Bulka, & Smetak, 1988; Taylor, 1983; Taylor, Lichtman, & Wood, 1984; Shontz, 1982). In effect, the search for meaning following adversity, such as the onset of disability, often results in the discovery of a "silver lining." As previously noted, accommodating to the existing circumstance is a means of accepting the situation (Thompson, 1993) and disability (Wright, 1983). Among a group of men and women who had undergone limb amputations, for example, Dunn (1996) found that positive meaning linked with acquired disability was associated with lower levels of depressive symptoms.

In the next section, we illustrate the six identity themes—communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning—within selected excerpts drawn from disability narratives.

Exploring Disability Identity Through Disability Narratives: A Preliminary Venture

Our review of narratives is not an exhaustive one; rather, we identified six published narratives that illustrate the aforementioned themes associated with disability identity. In the discussion that follows, we elected to briefly highlight sample narrative comments linked to one theme within each of the exemplar works. As shown in Table 1, however, each of the works we selected illustrates more than one of the disability-identity themes. Readers are encouraged to explore other themes associated with each work

on their own. One caveat regarding identity themes: More than one theme will often appear to be operating in a narrative excerpt. For example, instances of communal attachment are likely to suggest elements of disability affirmation, just as situations illustrating recognition of self-worth might seem similar to pride, and so on.

We also want to highlight an important point regarding the stories people tell about themselves, their lives, and their experiences with disability. Although these stories are rooted in biography, they evolved based on the needs of their respective authors' identities. As McAdams (2001) explains:

> [Identity] stories are based on biographical facts, but go considerably beyond the facts as people selectively appropriate aspects of their experiences and imaginatively construe both past and future to construct stories that make sense to them and to their audiences, that vivify and integrate life and make it more or less meaningful (p. 101).

To McAdams (1993) and other psychologists who examine identity and narrative, the issue of valid or verifiable truth is less important than the beliefs storytellers develop and rely on to understand, navigate, and share their life experiences with others. We now turn to the narrative exemplars.

From Counterculture to Disability Community

Disability researcher, psychologist, and activist, Simi Linton (2007), came of age in the late 60s. Now an expert on disability and the arts, when she was in her early 20s, a car accident on the way to a Viet Nam War protest organized in Washington, DC left her with spine injuries resulting in paraplegia. In this autobiography, Linton writes about her personal and professional development following the onset of her disability. A prominent and often revisited theme in the book is how she develops communal attachment to other people with disabilities as she tries to define her role in the disability community. When she reenrolled in college and navigated campus with a wheelchair, Linton encountered few people with disabilities, recalling that:

> I was reluctant to approach any of the disabled people I saw on campus. I would often see a woman walking with a cane and could see that she had difficulty getting up the stairs . . . but I talked myself out of speaking to her. There was an unwritten code I had grown up with that said you don't acknowledge a person's disability (Linton, 2007, p. 61).

Across time, she acknowledged disability, her own and that of others, often in response to the lack of accessible facilities or those that were barely adequate. She also befriended many people with

Table 1

Disability Identity Themes Found Within Selected Disability Narratives

Narrative source	Communal attachment	Affirmation of disability	Self-worth	Pride	Discrimination	Personal meaning
Linton (2007)	✓	X			X	X
Johnson (2005)	X	✓	X	X	X	X
Cole (2004)		X	✓		X	
Drolsbaugh (1996)	X	X		✓	X	
Saperstein (2010)	X	X	X		✓	
Tollifson (1997)	X	X	X	X	X	✓

Note. ✓ = Highlighted disability identity theme in narrative; X = Other identity themes prominent within a narrative.

disabilities, including individuals who engaged in activism promoting civil rights linked to disability issues. Describing her growing connections to the disability community, she wrote:

> I have become a disabled woman over time. I certainly would have rejected such a title in the beginning . . . My advancement was due to other disabled people and, significantly, to the times we were living in . . . For me and other disabled people, the process of claiming disability as an identity and the disability community as our own is complex (Linton, 2007, pp. 108–109).

Linton's communal attachment is complex precisely because she effectively led two "lives" with different perspectives: An early life without disability and the majority of her life with one, and much of it prior to ratification of the 1990 Americans with Disabilities Act (ADA, 1991). Her initial approach/avoidance reactions to becoming part of the disability community and later embrace of it illustrate her need to negotiate the tension between holding an outsider perspective that subsequently becomes informed by insider experience (e.g., Dembo, 1969; Dunn, Fisher, & Beard, 2012; Wright, 1983).

Reflecting on what her experience and development of disability identity taught her, Linton noted that:

> I saw . . . how big disability is, not the Condition I or others have, but the elaborately constructed network of ideas and practices that keep disabled people in place . . . I have gotten to this place not by denying my disability or, implausibly, "overcoming" it, but by sailing headlong into it. Making sense of it had become the most meaningful thing I could do (p. 120).

Affirmation Through Activism

Born with a progressive neuromuscular disease, Harriet McBryde Johnson (2005) realized at an early age that her life would likely be cut short. When she wrote this memoir (Johnson died in 2008), she had already surpassed the 40-year mark by several years, a feat she never thought possible. Throughout her narrative, Johnson explores life as a disability activist, author, and civil rights lawyer from the seat of her motorized wheelchair.

A prevalent theme throughout Johnson's (2005) narrative is a strong affirmation of her disability. As a teenager, Johnson accepted the fact that her disability made her different, which only increased the positive view she held of herself, a result consonant with Hahn and Belt's (2004) observations. When scoliosis caused her spine to twist and bend in her early teens, she briefly experimented with a back brace that delayed scoliosis. However, she reveals that:

> At age 15, I threw away the back brace and let my spine reshape itself into a deep twisty S-curve . . . Since my backbone found its own natural shape, I've been entirely comfortable in my own skin (pp. 1–2).

Johnson further epitomizes the idea that her disability does not make her "less than" a nondisabled person, particularly when she recounts protesting the annual muscular dystrophy association (MDA) telethon. Although it might seem ludicrous to some people that a person with muscular dystrophy would oppose a telethon raising money for a cure, Johnson adamantly voiced her reason for opposition:

> I don't like the way the telethon depicts people with disabilities . . . It's all about stirring up pity, when we don't want pity . . . Jerry Lewis ought to be fired. He actually called people in wheelchairs "half persons" (Johnson, 2005, p. 48).

Johnson's (2005) narrative reveals that her disability identity was formed early in her life and that it informed her subsequent career and activism wherein she made conscious choices to affirm her disability. Although she was clearly dedicated to the disability community (and was communally attached to it), Johnson viewed herself as individual with responsibilities to the society in which she lived (see also, Johnson, 2003 and 2006), echoing Gill's (1997) perspective.

Spinal Cord Injury and Self-Worth

In his book documenting narrative stories of several people living with spinal cord injuries, Jonathan Cole (2004) writes about a man named Graham who epitomizes the theme of self-worth. As a 22-year-old college student at Reading University in London, Engla during the 1960s, Graham was involved in a drunk driving accident that left him paralyzed from the waist down. With a diagnosis of a complete spinal cord injury of the cervical vertebrae at the C6/C7 level, he also lost considerable movement of his hands and arms.

Recollecting the initial days in a rehabilitation hospital, Graham demonstrates that self-worth was important to him almost immediately after the injury when he tells Cole (2004) that:

> I realized I would not walk and I was not going to get my hands back either, so I worked very hard to maximize what I could do. I needed to get out, go to university, and get a job (p. 27).

Instead of lamenting about all the activities he could no longer perform, Graham focused his attention on the values and qualities he still possessed. Becoming paralyzed did not stop him from being a contributing member of society. He returned to college and eventually earned a degree in quantity surveying, which led to a 24-year career with a local city council.

Beyond proving his self-worth to himself and to others by earning a degree and finding employment, Graham maintained his perception of self-worth as an individual by forming friendships with nurses from the rehabilitation hospital. He recounts to Cole (2004) that, "There was drinking, sometimes too much, and even, for the first time in a long time, there was fun" (p. 28). Graham's ability to continue normal activities, such as working and socializing with friends, undoubtedly contributed to his positive feelings of self-worth, but he also found value in engaging in activities unknown to him before the injury. Graham tells of an arm-powered tricycle that he bought after his injury. It gave him the ability to travel far distances on his own, which greatly increased his sense of self-worth:

> . . . I must admit that I have had more pleasure out of it than from any thing else since I have been disabled. I am cycling, going from one place to another under my own control . . . It almost feels as though I am not disabled (Cole, 2004, p. 32).

Pride in Disability

Throughout childhood, Mark Drolsbaugh (1996) experienced progressive hearing loss that eventually led to his deafness. He

enrolled at Gallaudet University in 1989, the only "Deaf" university at that time, and went on to earn degrees in psychology and school counseling. Since then he has been a columnist for numerous Deaf magazines and published two books relating his experience of being deaf.

In a short piece written for a learning disabilities website (www.ldpride.net), Drolsbaugh (1996) shared his pride in being deaf. He begins by admitting that for a large portion of his life he was embarrassed by his disability and tried to be a "hearing person." However, after discovering and choosing to get involved in Deaf culture, his attitude changed completely. Drolsbaugh attributes this change to:

> Meeting other deaf people like myself, sharing similar stories of oppression and ridicule, swapping humorous anecdotes, learning ASL [American Sign Language], and seeing other deaf people succeed . . . (Drolsbaugh, 1996).

Joining the Deaf community taught Drolsbaugh to embrace his disability. His experience is also an example of communal attachment, illustrating how one aspect of disability identity can influence or lead to another. Reflecting on how joining the Deaf community influenced his pride, Drolsbaugh concluded that, "I am no longer ashamed of my deafness, I am proud of it. I am proud of who I am, proud of what I've overcome, and proud of my culture" (Drolsbaugh, 1996).

Discrimination and Life With Asperger's Syndrome

Jesse Saperstein (2010) writes that he was diagnosed with Asperger's syndrome when he was in high school. He and his parents knew he was "different," perhaps disabled, much earlier in his childhood, but Asperger's was not a widely recognized disorder in 1982, when Jesse was born. For this reason, even after his diagnosis, Jesse's social quirks and awkward behavior were not well received or understood by the community around him. Saperstein's memoir about growing up with Asperger's highlights apparent discrimination as a large part of his identity.

Regrettably, the discrimination he experienced started at home. Saperstein (2010) learned early on that mental and social disorders such as Asperger's were a stigma. Unfortunately and perhaps unintentionally, his mother was the person that led him to this understanding. Remembering her attitude, he wrote that:

> When another child psychologist claimed she saw some "autistic-like tendencies," my mother had to restrain herself from slapping the woman who dared insinuate I had something as devastating as autism (Saperstein, 2010, p. x).

Having a child with Asperger's just wasn't acceptable to his mother, and he witnessed her negative reaction. Fortunately, as Saperstein saw more specialists, his parents learned to understand and eventually embrace their son's differences.

Still, social life did not get any easier when Saperstein reached high school. He notes that because of his social awkwardness and unusual behavior, he was constantly bullied. Saperstein (2010) recalled that the torment took on various forms:

> On a good day, the bullying was tolerable and even humorous . . . Most of the time, however, lessons of mitosis were combined with sharp kicks to my ass cheeks while I deftly ducked spitballs flung in my direction (Saperstein, 2010 p. xii).

Saperstein realized that the bullying he encountered was a direct result of his Asperger's, but nonetheless chose the negative attention over no attention at all. He described himself as, ". . . someone who's usually invisible to other people (or, worse, avoided like a plague;" p. 115).

Social discrimination followed Saperstein (2010) for the rest of his life, eventually leading to more serious forms of discrimination. For reasons related to his disorder, for example, he struggled through college and had difficulty securing and maintaining a job. To Saperstein, a frustrating aspect of being discriminated against is knowing that he and other people with Asperger's are not social deviants. In fact, he urges readers to understand that, ". . . most of us do have the potential to make outstanding contributions to society when presented with the right opportunities" (p. xiv).

Imperfection and Personal Meaning

Joan Tollifson was born with a birth defect that caused her to lose her right hand and half of her right arm. In a reflection on her experiences with meditation, she reveals her journey toward finding personal meaning in her disability in an edited volume on the experience (Fries, 1997). Finding meaning in a disability can be a daunting, often lifelong, task for most people. Such was the case for Joan. She admits that she spent a large portion of her childhood and teenage years hating, denying, and ignoring her disability:

> Growing up, I wanted to dis-identify myself with the image or label of being a cripple. I wanted to be normal . . . I held a great deal of pain and rage inside (Tollifson, 1997, p. 106).

For Tollifson, this inner rage led to alcohol and substance abuse. Eventually, after surviving a near-death experience related to her substance abuse, she "woke up" and found herself the help of a therapist (Tollifson, 1997, p. 106). Based on advice from her therapist, she hesitantly joined a group for women with disabilities. After realizing that she shared many interests, beliefs, and experiences with these women, Tollifson slowly began to accept her disability.

Tollifson (1997) eventually took up Zen meditation, admitting that, ". . . the process of awakening took yet another turn," (p. 108). After learning the art of Zen—the practice of listening to one's body and its surroundings, accepting the world as is, and living in the moment—Tollifson saw her life and disability in an entirely new context. Practicing Zen led Tollifson to develop personal meaning for her disability, one connected to the idea of imperfection:

> Imperfection is the essence of being organic and alive. Organic life is vulnerable; it inevitably ends in disintegration. This is part of its beauty (Tollifson, 1997, p. 106).

Accepting this idea allowed Tollifson to live freely and in the present. She closes her narrative with a powerful statement about the meaning she discovered living with one arm, saying:

> It [life with one arm] teaches me to appreciate the miracle of what is, to feel affection for my actual life. Cardboard ideals of perfection are flat and pale by comparison (Tollifson, 1997, p. 112).

Recommendations for Future Research on Disability Identity

We consider the present review and investigation to be a first foray into the narrative study of disability identity. The themes identified in the examined narratives—communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning—represent a blending of concepts from disability studies and rehabilitation psychology. This is an important consideration for at least three reasons. First, some researchers suggest that these scholarly areas of inquiry could benefit from working more closely together where advancing understanding of the experience of disability is concerned (Olkin & Pledger, 2003). We concur. Second, there is currently a paucity of research on disability identity in rehabilitation psychology and the available scholarship is more speculative than either theoretical or empirical. Our project is admittedly preliminary but nonetheless suggestive and promising. Third, rehabilitation psychologists should avail themselves of any tool—including the qualitative approach advanced here—to explore and explicate the experience of disability. To be sure, a blending of qualitative and quantitative methods is apt to be useful for expanding our knowledge of disability identity and the role it plays in lives of people with disabilities. To that end, we believe the present work suggests that the study of disability identity can inform future efforts aimed at exploring the psychosocial influence of disability narratives in both rehabilitation research and practice.

Narrative Research and Rehabilitation Psychology

As illustrated by the narrative approach used in this article, qualitative research relies on verbal reports, recollections, descriptions of events, and how people reflect on and interpret their experiences. Generally, the goal of qualitative research is to disclose the richness and variety of human experience (e.g., Frost, 2011; Lincoln & Guba, 1985). To do so, qualitative research relies on an open-systems view where the data are gathered (again, chiefly verbal reports and reflections) with few fixed categories or preconceptions.

In the present work, we elected to examine published narratives through the lens provided by existing identity themes based in earlier research on disability identity. Our choice here was strategic: To demonstrate that disability narratives are available to rehabilitation psychologists and can be readily categorized using existing resources. We are not suggesting that there are no other themes to be found within the sample narratives we selected; to the contrary, we suspect that there are quite a few that could (will) inform our understanding of the development, benefits, and role they play within disability identity. Our purposes here were to provide a preliminary model and suggest a direction for future research efforts grounded in a narrative approach.

Our particular approach to narrative analysis aimed to make meaning out of people's disability stories by using the thematic model (e.g., Riessman, 2008), one of several systematic approaches used in narrative research. The thematic model focuses on the content of narrative material rather than its structure or how it is presented. A chief advantage of this approach is that it allows researchers to identify and make sense out of thematic similarities and differences found among a number of narratives (here, six).

How might thematic approaches be used in any future, inductively oriented research? For example, perhaps people with amyotrophic lateral sclerosis or ALS share a common feeling of societal detachment experienced by some people who are blind? Many public places are not well-suited for people who use wheel chairs. The same is true for people who are blind. The ways in which people with either disability cope with such environmental obstacles might offer practical advice for people with other disabilities who are dealing with similar or related issues. Beyond such practical concerns, a narrative analysis approach to this question could be used to explore aspects of disability identity among individuals who have either disability in order to develop greater understanding of their ongoing psychosocial experiences.

Thus, we hope the present research inspires other investigators to examine disability narratives—either published examples or those that might be collected from client/consumers in future research efforts. Indeed, we believe research options abound. Some researchers might be motivated to launch their own studies of disability identity by having persons with disabilities write or recite their own narrative experiences. These stories can then be archived and their contents analyzed and categorized using established or novel identity themes. To broaden understanding of disability identity, participants could also be asked to complete a variety of measures assessing various psychosocial constructs (e.g., resilience, well-being, depression), personality factors (e.g., the OCEAN traits; McCrae & Costa, 2008), and self-reported behaviors. Subsequent observations could be used to develop and expand theory regarding disability narratives and the social psychology of disability.

Critical examination of disability narratives using an inductive approach (as compared to the deductive method we employed here) will allow the content of people's disability stories to suggest additional categories and themes related to disability identity. These yet-to-be discerned themes can supplement the preexisting ones described in this article and in previously published scholarship on disability identity. Such additional identity themes can help to expand empirical work on disability narratives and our understanding of the importance and impact of disability identity (either potential or realized) in the lives of many people with disabilities.

Listening for Disability Identity

How can the study of disability identity inform therapeutic practice? Minimally, becoming familiar with disability narratives and their identity components is likely to be a convenient and compelling way to combat the aforementioned antipathy (often unknowingly) harbored by professionals who counsel people with disabilities. Attending to the content of disability narratives and subsequently recognizing the presence and psychosocial influence of identity themes in discourse with clients may help therapists and their professional staffs provide better services.

Practitioners who counsel people with disabilities can define and describe the potential importance of disability identity to their clients. Depending on the circumstance, a therapist might encourage a client to read a published narrative (for examples, see Fries, 1997) in order to highlight a particular disability identity theme potentially connected to the client's own disability experience. Alternatively, some practitioners may want to use narratives in their therapeutic work with clients who experienced a relatively

recent onset of disability. For example, particular narratives can be used to promote the "coping versus succumbing" framework (e.g., Cole, 2004; Drolsbaugh, 1996; Johnson, 2005) advocated by Wright (1983).

Rehabilitation practitioners could encourage their clients to write their own narratives concerning disability identity as a way to reflect on the experience of disability; some may already do so for personal or professional reasons (for instance, the second author of this article, who has spinal muscular atrophy, writes a regular blog on living with his disability: http://laughingatmynightmare.1000notes.com/). Social psychological research clearly demonstrates that constructing a self-narrative can help individuals cope with negative life events (Pennebaker, 1997, 2004) and develop positive outlooks and behaviors in response to them (Wilson, 2011). Naturally, use of any narratives in a professional context should be done in a careful manner, one that makes an effort to demonstrate their effectiveness and any benefits, which means empirical assessment is essential.

For their part, therapists and practitioners will want to listen closely to the narratives their clients share. Recognizing the presence of a particular theme, such as self-worth, could help a practitioner recognize therapeutic progress as when, for example, a client emphasizes an interest in using once familiar abilities or acquiring some new ones. Conversely, when a search for personal meaning is not evident in what a client reports or writes, pushing that client to find significance or benefits too soon could lead to a negative outcome. Thus, actively listening for the presence and influence of disability identities during the therapeutic process may well help practitioners better match their techniques to client needs at appropriate points in time.

Identity and Disability

As a starting point for subsequent empirical investigations of disability identity—to provide direction and develop theory—we suggest rehabilitation psychologists should familiarize themselves with disability narratives. The study of disability narratives can capture significant psychological events (e.g., onset of disability, awareness of difference) while also covering the more quotidian aspects of life (e.g., friendships, socializing, hobbies). We believe these narratives can inform both persons with and without disabilities about how individuals live with and learn from life with a disability. Following other investigators and people with disabilities themselves, we suggest that a coherent disability identity can help an individual adapt to disability (Smedema, Bakken-Gillen, & Dalton, 2009) or navigate the social stresses of being a member of an often ignored minority group (e.g., Gibson, 2006, 2009; Johnson, 2005, 2006).

As the narratives excerpted in this article illustrate, powerful stories do leave lasting impressions. Perhaps reading and reflecting on disability narratives can encourage some individuals with disabilities to reflect on their own disability identities. Some may elect to form closer ties with the disability community while others may consider whether their own personal stories contain elements of pride, affirmation, self-worth, or some other aspect of disability identity. Individuals who develop a chronic disability later in life could find the identities portrayed within some disability narratives to be a helpful resource for navigating the initial phases of disability or the experience of rehabilitation. Family members and caregivers of people with disabilities, too, will likely benefit from

learning about disability identity and the themes represented within disability narratives. By reading, listening to, and reflecting on the content of disability narratives, rehabilitation researchers and practitioners can learn to recognize disability identity as an authentic and important aspect of the social psychology of disability.

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