Disability, Identity, and Cultural Diversity
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Abstract: Eighteen disabled individuals, nine with disabilities present at birth and nine with acquired disabilities participated in tape recorded interviews lasting between 60 and 90 minutes. For this study, disabilities present at birth were defined as those disabilities identified or diagnosed by the age 5 years; acquired disabilities were those disabilities that occur after an individual's 5th birthday. Life stages were identified as: Middle Childhood/Adolescence (ages 8 years through 17 years); Beginning Adulthood/Young Adulthood (age 18 years through 34 years); and, Middle Adulthood/Later Adulthood (age 35 years and older). The mixed method design relying on semi-structured interview and inductive analysis was used to answer the following research questions: (a) what are the nature and scope of disability cultural identity articulated by informants; (b) and what differences in disability cultural identity are related to informant age, condition and onset? Five themes emerged from the transcripts: fitting in; disability wisdom; it's just what you do; I can do it despite what you say; and disability talk as shared interest versus talk as boring. None of these themes revealed cross disability identity. Despite being unable to answer the initial research questions in the manner anticipated, the data analysis provided important and challenging knowledge and implications for further inquiry and practice.

Key words: culture, identity, qualitative inquiry, disability theory

Introduction:

Until the disability movement was initiated in the early 1970s, individuals with disabilities were seen as medically or functionally disadvantaged. And for the most part, health and human service professionals were educated to understand disability as a long term to permanent result of pathology or injury. Consistent with the view of disability as pathology or anomaly, services for disabled adults typically focused on individual rehabilitation or adaptation of the environment to accommodate the disabling intrinsic condition. Since the 1970s however, alternative conceptualizations of disability have been advanced in the scholarly literature with legislation, policy, and habilitative and rehabilitative practices rhetorically reflecting these theoretical changes. The shift from disability as internal condition to human condition in which the disabling factor is a hostile social context has evolved and currently dominates much of the academic discourse within disability studies. Central to the social view of disability are the notions of disability culture and cultural identity, both which position disability within the political and discursive agendas of cultural diversity. Given the multiple definitions and perspectives on the meaning of disability, how disability is explained by those who are disabled, by providers, and by policy makers is critical in determining the nature of community supports, services, policy, legislation, and overall quality of life for individuals with disabilities. This study was initiated to examine the primacy and nature of disability cultural identity in a set of diverse informants with disabilities. The study

was intended to position the discussion of disability within health and social service professional practice, education, and research not only as a medical condition or explanation but, as a social and cultural phenomenon positioned within diversity, civil rights, and marginalization discourses.

Literature Review

Historically, disability has been conceptualized, explained, and treated in numerous ways. There is no agreement in the literature regarding a clear definition or even taxonomic organization of disability theories. However, a synthesis of the literature on disability definition reveals commonalities that fall into four categories: disability as medical, social, political, and cultural. While these categories are not mutually exclusive, they each have an important focus which influences how disabled individuals are perceived and responded to in their social contexts (Gilson & DePoy, 2002).

Disability as Medical

A medical approach to disability defines disability as a long term to permanent impediment and positions individuals with disabilities as less able than those who can recover from illness or who are non-disabled (Gilson &DePoy, 2002). As a form of biological determinism, the focus of disability in this definition is on physical, behavioral, psychological, cognitive, and sensory inadequacy and thus the problem to be addressed by disability services is situated within the disabled individual (Shakespeare, 1996). Interventions are designed to be curative, restorative, or adaptive. That is to say, services are aimed at curing the condition if possible, and if not, restoring function to the extent possible, and then adapting the environment to diminish the limitations imposed by the individual condition (Finkelstein, 1991; Gilson & DePoy; Quinn, 1998).

Disability as Social

In this broad perspective disability is viewed as a hostile environment in which social barriers limit community participation and civil rights of individuals with selected impairments (Hahn, 1993; Ravaud & Stiker, 2001; Swain, Finkelstein, French, & Oliver, 1993). Negative attitudes, limited physical access, limited access to communication and/or economic, political, or social resources and to the rights and privileges of a social group are considered as just some of the barriers that interfere with the impaired individual's potential to actualize his/her desired roles (Barnes & Mercer as cited in Barnes & Mercer, 1997). Thus impairment is seen as diversity of the human condition and disability is the imposition of purposive restrictions on those with impairments (Swain *et al.*). The focus of intervention from the social perspective shifts from the individual to the social systems that create disabling circumstances.

Political Model of Disability

Closely aligned with the social model of disability but moving the focal emphasis into the domain of power and resources is the political model (Stone, 1986; 2002). In this

view, the disabling factor is curtailment or withholding of the opportunity to earn or possess economic resources in part or in total from impaired individuals. The disability from the political vantage point therefore refers to the absence or limitation of resources to be exchanged for privilege in a global economic environment (Gilson & DePoy, 2002; Oliver, 1992; Scotch & Schriner, 1997).

Cultural Definition of Disability

Defining disability as culture transcends internal determinants of disability, subsumes social and political definitions, and creates a cultural discourse that characterizes the collective of disabled persons. Cultural views of disability suggest that all individuals who define themselves as disabled belong to a unique group that shares experiences, tacit rules, language, and discourse. In this view, the notion of disability is one of group belongingness and distinction from other groups who do not share the disability identity (Hahn, 1993). Within this definition, issues of race, class, gender, and power differential are important determinants of the shared experiences that bind disabled people together in a single, identifiable community of concern (Charlton, 1998; Linton, 1998). Furthermore, positioning disability within current multicultural discourse provides the disabled individual with a precedent and social action model enacted by other minority groups to counter discrimination. It is therefore not surprising that disabled activists are asserting disability identity as a construct that is or should be central to the lived experience of disabled individuals. While disability identity has been examined, characterized, and described (Gill, 1997; Linton, 1998), the complexity of age, condition, and circumstances of onset have not been studied. Research building on current knowledge, and further informing theory, policy, professional education and practice is therefore needed to elucidate disability identity as it occurs in diverse individuals.

Method

A mixed method design relying on semi-structured interview and inductive analysis was used to answer the following research questions:

1. What are the nature and scope of disability cultural identity articulated by informants?

2. What differences in disability cultural identity are related to informant age, condition and onset?

Eighteen informants, ranging in age from 5 through 65, with diverse birth-based and acquired disabilities at corresponding life stages participated. Disabilities present at birth, for this study, were defined as those disabilities that are identified or diagnosed by the age 5. Acquired disabilities are those disabilities that occur after an individual's 5th birthday. Life stages were categorized as Middle Childhood/Adolescence (ages 8 years through 17 years); Beginning Adulthood/Young Adulthood (age 18 years through 34 years); and, Middle Adulthood/Later Adulthood (age 35 years and older). Table 1 presents the demographic and personal characteristics of the informants.

(Insert Table 1 about here)

Announcements in multiple, accessible formats were distributed to community agencies serving children and adults with diverse disabilities. Informants and/or their families were asked to contact the interviewer to discuss the study. Informants were selected purposively to represent a range of ages and conditions, as well as gender and ethnic diversity. Following informed consent from adults and assent from children, interviews were scheduled and conducted. Each interview lasted between one and two hours. Broad, open-ended questions were posed at the beginning of the interview and followed by semi-structured probe questions if the necessary data were not offered in open-ended responses. All interviews were audio-taped and transcribed verbatim with each line of text numbered. Thematic analysis was conducted with the intended purpose of providing categories for content analysis to examine differences in identity related to age and disability. However, content analysis was not performed because the data analysis did not yield clear categories relevant to these queries. To assure rigor, authenticity and trustworthiness, the analysis was completed independently by two investigators and then negotiated for meaning.

Findings

Five themes emerged from the transcripts. However, none revealed cross disability identity as discussed in the literature and thus we were unable to answer the initial research questions. Despite the lack of answers to the initial questions, the data analysis provided important and challenging knowledge and implications for further inquiry and practice. We present each of the themes below with exemplars from the transcripts.

Theme #1- Fitting In

Contrary to the construct of disability as separate from mainstream culture, informants discussed their desire for acceptance in non-disabled groups to a greater or lesser degree. Youth were particularly vocal about wanting to be "just like everyone else." For example, one informant stated, "I mean most people even like my self are just like normal, so everybody that are my friends are like just normal people because, I mean, I usually have friends that are normal people that don't have any disability at all."

Only two of the youth articulated their differences from non-disabled peers, and their affinity to others with disabilities. As one youth lamented, "My girlfriend told me that she thinks like when girls see me they don't really think of me as like a regular guy."

Another youth stated, "My disabled friends have more of an idea of where I am coming from when I talk about..."

In both adulthood groups, informants saw their disabilities as personal characteristics among many others. Three were active in disability organizations. Yet, none, regardless of their involvement with disability efforts and organizations articulated belongingness to a separate and distinct disability culture. To the contrary, one informant who used a wheelchair stated, "I mean people; people don't look at me like I have a disability."

Of particular note within this theme was the interaction between limitation and disability identity. Although not initially or necessarily desired, the strongest expression

of disability identification among the informants emerged from unwanted negative experiences of isolation, discrimination, and exclusion.

The informant who stated, "So I have been just thumping along kind of glued, imprisoned in this room" strongly identified as a disabled man.

It is curious to note that with one exception, even those who perceived disability as primary to their lives and personal identities did not discuss disability identity as cultural pride. The exception was the informant who at the time of the interview was a professional studies graduate student who was reading scholarly works in disability studies, advocacy, and social justice.

"I think that I'm at a different place in identifying, I mean I've had more years in having identified, and very proudly so. But it certainly took me a long time to get to that point."

Common to all informants, regardless of age or disability pride, was the experience that acceptance of disabled individuals within non-disabled groups is a function of time and exposure necessary for comfort of all involved.

Theme #2-Disability Wisdom

The second theme that was commonly expressed by informants was the unique knowledge that comes from living with a disabling condition. While informants did not see disability as a distinct culture, many spoke about how living with non-typical conditions provoked unique learning. They believed that this learning would not have occurred without the disability. Not all saw this wisdom as desirable but many did. For example, one informant stated, "I am happy that this happened to me because it has made me a better person, and has made me a different person than I was. I don't know how long it would have taken me to get where I am today, and I don't consider myself financially successful. I haven't really achieved anything of great momentum to the public or to anybody but I feel that I have gained a lot inside and have become a better person and a greater person because of it. And I don't know if that ever would have happened if I hadn't been faced with the challenges that I have been faced with."

Theme #3-It's Just What You Do

This theme refers to the continuum of approaches that respondents discussed regarding the primacy of disability in their lives. On one extreme, the disability shaped the daily life and personal identity of the respondent. "Having friends is pretty much non-existent because I'm pretty much off the beaten path, all the friends I had were all back in [name of town], pre-injury. When we moved out here, my brother and his wife developed friends, but I didn't because there are no people around here like me so it is pretty difficult. These problems keep me around and confined to the house."

On the other extreme, tasks related to the disabling condition were simply seen as part of living and something that regardless of the nature of the challenge, all people face. For example, one informant stated, "What ever is gonna happen is gonna happen, I can't change that." Another said, "I deal with my disability when it is shoved in my face like when I have to do something in a practical way or I have to fill out some papers and then I get on with being just a human being."

No pattern related to age or nature of disability was found.

Theme #4-I Can Do It Despite What You Say

A strong theme, particularly in individuals who were not embittered by disability, was the notion that the disabling condition posed a challenge for "normalcy" of activity. Some informants were even motivated to perform highly competitive sports, work and so forth as a means to debunk the myth that disability is equivalent to inability. As one informant commented, "I have been determined for a long time to become a nurse and it is going to be a sight to be seen when I walk across the stage and get my diploma because I had to go through so much and I was determined to graduate."

In large part as a response to "a psychologist who said he was going to suggest to my parents that they put me into a nursing home or institution or something, which I would never do anything," one informant has set a career goal of public speaking and counseling disabled people.

Theme #5-Disability Talk As Shared Interest Versus Talk As Boring

This theme refers to how informants perceived the topic of disability when it arose in conversation. Respondents described a continuum of responses to conversations about their conditions and disability in general. Some experienced discussions of conditions and resources as an opportunity to share feelings and information with other disabled individuals or those concerned with disability issues while others felt that any reference to disability in conversation was a burdensome and boring topic. One informant expressed both perspectives. "But I don't talk to them [non-disabled individuals] as much about disability issues as I do with my disabled friends. Because I also don't want to make it the focus of my life and at times it has been the focus of my life, more so than I would care for it to be."

Illustrating the burden of disability conversations, one informant asserted, "you didn't want to hurt them, but what you really wanted to do was to kick their butt out the door."

Others described their conversation as non-disability focused, "we talk about girls and what the other guys are doing."

One informant noted that, "When I am around students with other disabilities, its student related, problems, questions, support. As a matter of fact I don't really know that any of us get that personal when we get together, at least not that I've seen. We may know basic things that we are married or not, age, what the disabilities are, but most of the time its student related issues."

On the other end of the continuum, is the phenomenon of disability conversation as special sharing as exemplified by the following quote, "You know I feel like I have more of a bond with people with disabilities or people with spinal cord injuries, there are just some things that are a part of me that I don't even share with [my husband], he wasn't there he doesn't even know what I went through. It's just like my own private little pocket of all kinds of stuff."

Sharing resources was also a component of disability conversation, as noted by one informant.

"With the disabled friends I can discuss things about my disability. Say, because the disabled friends and I have the exact same disability, we exchange things like how you deal with this thing and how you handle that problem and that kind of thing. It is back and forth information."

In summary, the five themes that emerged from the data set depicted disability identity as a personal, individual characteristic that varied in its primacy, importance, and meaning to each informant. With the exception of one informant who was studying disability and social justice scholarship, none of the informants expressed an awareness of disability culture as described in the literature.

Conclusions

The initial questions that framed this study were founded on theory advanced in the disability studies literature regarding the existence and desirability of a culture of disability that included membership from individuals with diverse conditions and experiences. Theoretically, members of the disability culture are posited to be bound by the experience of oppression and marginalization and to share a common language, values, and political powerlessness. Moreover, membership, while restrictive in some sense, is asserted by some disability studies and health and social service professional scholars to be an important prerequisite for personal esteem, sense of community, and assertion of civil rights on the part of all individuals who identify as disabled regardless of medical condition. Therefore, we believed that it was important to uncover the interaction between personal characteristics, onset and nature of disability, and disability cultural identity as a means to promote what the disability literature deemed as positive and essential group belongingness. However, this data set revealed that disability identity is distinct from cultural identity. Informants illustrated significant diversity in their responses to their disabling conditions. Some saw the disability as an important personal characteristic that defined their lives, social interactions, daily activities, and future dreams while others did not. Some saw disability as creating wisdom, while others saw it as a negative, restrictive, and limiting learning experience. This study did not support the construct of a distinct culture of disability and thus questions regarding how disability identity is related to developmental phase, onset, and nature of disability could not be answered. The findings, while unexpected, raise important questions about the fit of the construct of culture with disability identity. The notion of disability as culture emerged from academic discourse and is discussed primarily among academics and students. It is interesting to note that the only informant who was conversant in the cultural discourse was a graduate student who was exposed to this body of literature. Thus, the cultural perspective of disability seems to be a public yet elite discussion among scholars, and carries with it the political aim of joining disability with other social movements in which power has been garnered through cultural distinction and positioning. Thus, the application of the construct of culture to disability identity may be a useful and purposive academic aim to replicate and exploit the success of ethnic cultures in obtaining civil rights and political recognition. The question of disability culture as transductive thinking is also raised by this set of transcripts. Transduction is the attribution of a label or category to a phenomenon based on only one or a few of many characteristics. For example, using transductive thinking, we might assert that people are dogs because both

people and dogs have noses, eyes and ears and so forth. In transductive thinking, the commonalities are used to make comparisons but differences are not included in the reasoning. Applied to the disability literature, transductive thinking would suggest that the experiences of disabled individuals who as a result of their condition experience discrimination and exclusion are the characteristics that have been held in common with other minority groups. Therefore, the cultural paradigm which has been successfully applied to these ethnic and other marginalized minorities is assumed to fit disabled individuals based on this one essential characteristic. However, the findings of this study challenge that assumption. Because only one of the informants talked about a common identity with other disabled individuals, the degree to which the presence of a disabling condition is the criterion for membership in a cultural group is open for challenge and future inquiry. Further, the diversity of conditions and contexts in which these conditions are experienced seemed to obfuscate a group identity or even a unique language among the informants in this study.

Implications

The findings of this study have important implications for disability theory, as well as professional practice, research, and education as well as for disability studies in general. Regarding disability theory, the findings of this study raise questions regarding the distinction between cultural and individual disability identity. Individual comfort with one's disabling condition and thus one's disability identity seem to be idiosyncratic, personal, and individual in nature in this informant group. One's level of acceptance of a disabling condition and the degree to which the condition is experienced as positive further seemed to provide a lens through which the fit between the disabled individual and other disabled as well as non-disabled groups was perceived. The cultural paradigm, while critical to policy, academic theorizing, and social justice concerns seemed not to be useful or even relevant to the identity of individuals in this study who have disabling conditions. Positioning disability identity as a part of human diversity may be a more accurate context in which to begin to understand how a disabling condition affects the individual in his/her view of self, life goals, and daily activity. Aligning disability with other oppressed cultures seems to provide a purposive and powerful model for the assertion of previously denied civil rights, but not to explain individual disability identity. A second and important implication of this study for research and practice is the recognition that the debate about defining disability as culture, social, political, or medical circumstance merges from the lack of distinction in the literature between description and explanation. Informants described their disabilities in terms of their activity and their limitations and some offered explanations for what they were able to do or not do. Analysis of the data suggests that disability can be best understood at several levels and those descriptors of disability seem to lie in human activity. Medical, social, political, and cultural definitions lie in the domain of explanation and therefore are not necessarily competing. Rather, explanatory analysis provides analytic depth to descriptions of human activity. The need to advance theory and further investigation are therefore suggested by this study. For professional practice, research, and education, two important confounding positions that have characterized these domains provide the backdrop for the implications of the study. Many health and social service professions

have a history of viewing individuals as unique while simultaneously legitimizing categories or groupings of specific disenfranchised and marginalized communities. How then do health and social service professionals make a determination of how to respond to disability? The study seems to support recent movement by some professions to replace identity politics with broad categories of diversity that apply to all individuals (Council on Social Work Education, 2001). Descriptive understandings of disability as another element of the diversity of human activity fit well with the contemporary views of some progressive professional thinking. Adding the explanatory dimension guides the direction for thinking and action about health and social service interventions. For example, disability as medical phenomena may provide the basis for clinical intervention with disabled individuals, while viewing disability through a cultural lens forms the foundation rationale for policy and environmental change strategies. This study, while unsuccessful in answering initial questions about disability identity and culture has advanced important knowledge that has the potential to advance conceptual clarity and inform professional practice and disability studies discourse. Further inquiry and theory building regarding the nature of disability as human activity are warranted in order for much of professional practice to approach disability from an informed, clear, and purposive perspective.

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Table 1

Informants

Acquired (Post Age 5)

Birth Based (Diagnosed Before Age 5)

8 - 17 Years Old

1. Male - 15 Attention Deficit Hyperactivity Disorder

2. Male - (11) - Visual Impairment (Blindness)

3. Male - 14 - Bilateral Hearing Loss; (unclear if birth based)

1.   Female - 17 - Lupus Ararthamatosis (SLE)

2.   Female - 11 - Congenital Health (Heart - pace maker inserted age 1; "6 major operations and lot's of other little ones like half's")

3.   Female - 17 - Spina Bifida

4.   Male - 12 - Spina Bifida

18 -34 Years Old

1. Female - 31 - Blind

2. Female - 26 - Spinal Cord Injury (C-6-7 Incomplete)

3. Female - 33 - Multiple Sclerosis

1. Male - 19 - Muscular Dystrophy

2. Male - 28 - Cerebral Palsy

3. Female - 20 - Learning Disability (acquired) & Cerebral Palsy (birth based)

35 and Older

1. Male - 43 - Spinal Cord Injury (Cervical Six Level Quadriplegia)

2. Female - 36 - Rheumatoid Arthritis

1. Female - 36 - Significant, Progressive Hard of Hearing (HOH)

2. Female - Late 60s early 70s (would not be more precise) - STILLS Disease (form of Rheumatoid Arthritis)

3. Female - 55 - Spina Bifida

Males Equal = 7

Females Equal = 11