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The author used phenomenological (interpretive) ethnography to uncover how living with physical disability shapes self-understanding (identity) in adolescents born with spina bifida. She conducted multiple in-depth interviews with 11 late-stage adolescents (ages 18 to 24 years). Analysis of their narrative accounts illustrated differences with respect to how study participants understand and experience physical disability and its attached meanings in relation to self-understanding. Study participants took up (claimed) disability in three primary ways: identity as overcoming disability, identity as objectifying disability, and identity as integrating disability. These informal explanatory models of self-understanding were fluid, not static, mirroring identity development in youth. Findings suggest that individuals born with physical disability confer explanatory meaning to their disability that occurs within a background of deeply held, taken-for-granted assumptions, meanings, and practices from local and larger sociopolitical contexts. These informal explanatory models offer insight into positive disability identity.

Keywords: *disability; explanatory models; identity; phenomenology; spina bifida*

Individuals assign explanatory meaning to their disability. Explanatory models are notions or beliefs held by an individual about their particular medical condition (Kleinman, 1988; Toombs, 1993). Grounded in experience and strong emotion, they tend to be more practical than theoretical with seemingly changeable and contradictory properties (Kleinman, 1988). Explanatory models serve to order individual experience within a sociopolitical framework and give it meaning (Kleinman, 1988). In addition to serving an explanatory function, they are constitutive in how individuals experience their disability over time (Schrag, 1997).

REVIEW OF THE LITERATURE

Spina bifida describes a group of multiple complex congenital anomalies and abnormalities involving imperfect development of the neural tube and related structures (Forrester & Merz, 2000; Kaufman, 2004). Although the primary lesions involve the spinal portion of the central nervous system, there are an array of

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manifestations and sequelae affecting seemingly disparate structures and functions, including the brain, bony spine, extremities, bowel, and bladder (Kaufman, 2004). In addition to the physical effects, there are psychosocial challenges associated with spina bifida, including body image concerns, low self-esteem, social isolation, and stigma (Blum, Resnick, Nelson, & St. Germaine, 1991; Rauen & Aubbert, 1992; Simeonsson, McMillen, & Huntington, 2002; Spina Bifida Association of America, 2005; Wolman & Basco, 1994; Yeo & Sawyer, 2003).

Adolescents born and living with spina bifida demonstrate differences with respect to how they understand and experience physical disability and its attached meanings in relation to self, world, and other. Such understandings and experiences are not static but fluid, changing and evolving over time in repeated interactions with family, friends, school personnel, health care professionals, and society at large. The manner in which disability and chronic illness are apprehended might relate to how closely the condition is connected to one's sense of self (Estroff, 1993).

Integration and Self-Development

Integration is a recurrent theme in classic theories of personality development and refers to the process of incorporating or combining into a whole. In developmental psychology, integration refers to an essential struggle of polarity in the developing self. Specifically, the individual struggles to resolve opposing forces of separation and unity and achieve integration, internally within themselves and externally in relationship to society (Gill, 1997). In psychoanalytic theory, for example, the healthy psyche harmonizes three potentially competing parts of itself: the parental and moral conscience (superego), the instinctual pleasure circuitry (id), and the realistic self (ego) (Blos, 1962). Within the social environment, the focus is on harmonization between our internal self-image and our ideal self (how we wish society to view us). Integration is linked to positive emotional health, maturation, and cohesion (Gill, 1997).

Identity Development

Identity development is a classic example of our human pursuit for integration. The path leading from childhood to adulthood is predicated on developing a sense of personal identity honed through recognition of one's abilities and achievements by self and others (Erikson, 1968). Although qualitative differences in a person's identity might be culturally derived, the quest or need to define oneself in relation to one's environment has universal properties (Muuss, 1996). Identity concerns are particularly heightened during adolescence. Social interaction and feedback from others, particularly peers, assist the adolescent in solving the identity question of "Who am I?" by promoting a sense of self through mirroring, modeling, and recognition practices (Erikson, 1959; Taylor, 1995). Successful resolution of the identity crisis is demonstrated by the ability to establish a meaningful self-concept blended out of past, present, and future and manifested in the development of a new signature identity and personal value system (Erikson, 1963, 1968; Muuss, 1996). A realistic appraisal of self (ego identity) at the close of adolescence signifies integration of an individual's inner and outer experiences (Blos, 1962; Erikson, 1968). Failure to forge a distinct or separate identity might interfere with internal cohesiveness and the ability to form genuinely intimate relationships with others (Erikson, 1968; Marcia, Waterman, Matteson, Archer, & Orlofsky, 1993; Muuss, 1996).

Discourse on Disability and Self

Despite advances in the quest for civil rights for persons with disabilities during the past 30 years, including recognition as a social minority, physical disability continues to be highly stigmatized within our culture (Nussbaum, 2004; Wendell, 1996). Extant negative images of people with physical disability linger within the cultural consciousness as a consequence of ignorance, fear, and past exclusion from greater society. Integration and identity formation as individuals and as a minority group continue to be hampered by hostility within the physical and social environment (Gill, 1997; Olkin, 1999; Toombs, 1993). Signs of oppression toward persons with disabilities can still be located in inaccessible structures, higher rates of poverty and unemployment, continued biomedical categorization of difference as deviance, and social rejection of “disabled others” by persons both within and outside the disability community. The phenomenon of stigmatized difference is particularly salient for disabled youth with regard to identity development, as the self is formed dynamically and dialectically out of everyday interactions with others and within a social and cultural framework (Geertz, 1973; Goffman, 1959, 1963; Strauss, 1959). The risk is that individuals born with physical disability might internalize the stigmatized reflection that society holds up for them and begin to see themselves and “disabled others” through the stigmatized lens (Coleman, 1997).

PURPOSE

The aim of this study was to investigate how intersubjective experiences, including cultural narratives of disability, constitute self-understandings in late-stage adolescents born with spina bifida.

METHOD

Ethnography in the phenomenological (interpretive hermeneutic) tradition as informed by Benner (1994), Dreyfus (1997), Geertz (1973, 1988), Heidegger (1962), Jackson (1996), Kleinman (1988), Merleau-Ponty (1962/1994), and Taylor (1988) was the method used in this study. The phenomenological turn in anthropology is reflected in its refusal to invoke cultural privilege as the ground for evaluating lifeworlds. It respects individual voice and experience while acknowledging the intersubjective, interexperiential, and cultural origins of self.

Sample

Purposive sampling was used to seek the perspectives of late-stage adolescents living with spina bifida. Individuals were included if they were between 18 and 24 years of age (mean age 21 years), had a neural tube defect in the form of spina bifida, and did not have a history of mental retardation. This age group was targeted because most late-stage adolescents have the cognitive ability to be self-reflective. Late-stage adolescence (18 years to mid-20s) occurs for those individuals thought to be delayed in their acquisition of adult roles as a consequence of educational goals or other social factors, including chronic illness and physical disability (Elliott & Feldman, 1990; Hallum, 1995; White, 1997). The sample included 7 female and 4 male participants. Five study participants were White, 5 were Hispanic/Latino, and 1 was of White-Latino mixed ethnicity. Seven study participants lived at home with their parents, 3 participants lived off campus with other college students, and 1 lived with her boyfriend. Two were seniors in high school, 7 were in college, 1 was enrolled in a vocational training program, and 1 was employed full-time.

With respect to medical history, 8 study participants had a neural tube defect in the form of myelomeningocele, 2 had a lipomyelomeningocele, and 1 had a lipoma with a sacral agenesis. Seven of 11 participants had required cerebrospinal fluid diversion (ventricular shunting) during infancy for hydrocephalus. Ten out of 11 study participants catheterized their bladder a minimum of four times a day, with only 1 participant being able to void independently; 5 out of 11 wore disposable underwear (diapers). Six out of 11 study participants had ambulatory capability (2 using a combination of crutches and leg braces, and 3 using leg braces only); 5 of the study participants were full-time manual wheelchair users; 2 other participants used a manual wheelchair for traversing longer distances.

Study participants were recruited from two large medical centers in Northern California with spina bifida specialty clinics from March to October 2001. Approval for human subject research was obtained from both institutions. The purpose of the study was reviewed in depth during initial telephone contact with the adolescents. Once they agreed to participate, times were established for the first interview. Written informed consent was obtained during the first face-to-face interview, and demographic data were collected at that time.

Procedure

I conducted 43 one-hour interviews with 11 study participants during a 7-month period (mean number of interviews per participant = 4; mean time to complete interview series per participant = 8 weeks). Follow-up interviews were scheduled in a manner that allowed time for participants to digest questions from the previous interview as well as give me enough time to listen to the interview on tape, consider its meanings, and formulate follow-up questions for further understanding, clarification, and corroboration. The total number of 1-hour sessions needed to complete the interview guide varied among study participants. The majority of study participants ($n = 5$) required five sessions each, 3 study participants required four, and 3 required two. The interview guide was completed on all 11 study participants. Interviews were conducted at the individual's home, place of employment, school campus, and/or community clinic. Assuring privacy, confidentiality, comfort, and convenience for all study participants was a determining factor in establishing interview locations.

I developed the interview guide based on pilot study interviews with adults living with spina bifida as well as issues raised in the literature and in clinical

TABLE 1: Interview Guide—Major Themes With Sample Questions

Life narrative	Tell me a little bit about yourself—when and where you were born, what growing up was like, how things were with your parents, if you have brothers or sisters.
Recent and current experience	Describe those people closest to you. How, if at all, does living with spina bifida impact on those relationships?
Belief systems	How, if at all, has the experience of having spina bifida affected you? Have your viewpoints changed over time?
Friendships/ intimate relationships	Please describe your closest friend(s). How did you meet this individual? What kind of relationship do you have with this person? What kind of things do you do with this person now?
Disability/illness experience	When you were very young, did you have any spina bifida–related problems, such as controlling your bowels and bladder? Walking? Participation in group activities/games/sports? Tell me about that and how you think those experiences affected you later in life.
Life history	What are some of the things you liked best about your adolescence? Can you tell me more about that? What were some of the hardest things about your adolescence? Can you tell me more about that?
Family history	How does your father/mother respond to your having a physical disability? Has that changed over the years? His/her most positive qualities? His/her most negative qualities?
School and peer relations	I am interested in hearing about your experiences as a teenager living with spina bifida. Are there particular memories or stories that stand out in your mind that you can share? As an individual living with spina bifida, what do you think is one of the biggest assumptions/misconceptions that your peers have about you? Tell me about that.
Body and sexual experience	What were your earliest sexual experiences, if any? How did you feel about your body and your sexuality at the time?
Self-help and empowerment	Have you participated in any disability-related support groups/recreational activities/camps? When? For how long? How (if at all) did this group/activity help you deal with spina bifida / physical disability?
Career/vocation/ future planning	Can you describe your dreams and goals for your life?

practice. Interview questions were open ended and designed to elicit narratives about the experience of physical disability in the form of spina bifida and its attached meanings in relation to self, world, and other. The interview guide was divided into 11 main categories with several questions under each. See Table 1 for a listing of the interview categories and sample questions. Complete interview guides are available from the author on request. All interviews were tape-recorded and transcribed verbatim. I checked each written transcript against the audiotape to ensure the accuracy of transcription. Field notes were taken during the interviews in as unobtrusive manner as possible and expanded on immediately after the interviews were concluded.

Naturalistic field observations were undertaken in the community to ascertain how the structural (built) environment affects accessibility, mobility, and sociability for physically disabled individuals. Field observations with study participants included traversing college campuses and attending classes, riding county transit buses and university shuttle buses, visiting faculty offices and bookstores, and being a passenger in cars with hand controls, furthering understanding of the day-to-day world.

Data Analysis

Narrative accounts and field notes of the intersubjective experience of late-stage adolescents living with spina bifida were interpreted and reported here. I conducted data analysis in consultation with an expert panel of qualitative researchers about developing interpretations. Analysis of narratives from each adolescent and analysis of narratives between adolescents were conducted over the course of the study. Extensive interpretive notes and memos were written on each case. I then proceeded with cross-case analysis. New data sometimes led to new findings, corroborated and amplified initial findings, or led to reinterpretation of initial findings. Details of narrative accounts and field notes were analyzed with the aim of making sense of the whole of the data as well as the parts. Themes, paradigm cases, and exemplars of narrative illustrating similarities, differences, tensions, and contradictions in relationship to self-understanding in disabled adolescents were identified and are put forth as the findings that substantiate interpretive conclusions (Benner, 1994). Based on preliminary analysis, sufficient depth of data as evidenced by repetition of thematic content was obtained after the completion of 43 1-hour interviews with 11 enrolled study participants. Ethnograph v5.0 software program was used for data storage, retrieval, analysis, memo writing, categorization, and theme building.

FINDINGS

Study participants were noted to take up (claim) disability in relation to self-understanding in one of three primary ways: (a) Identity as Overcoming Disability; (b) Identity as Objectifying Disability; and (c) Identity as Integrating Disability. A paradigm case is presented to explicate each informal explanatory model or stance and is described in relationship to distinguishing qualities, particular concerns, and prevalence within the entire study sample. Paradigm cases are rich, powerful, and illuminating instances of a particular phenomenon, designed to promote recognition and advance understanding of experience (Benner, 1994). In discussing the findings, fictitious initials will be used for all study participants.

Identity as Overcoming Disability Stance

The hallmark of this stance is an identity, or self-understanding, as one who overcomes; specifically, overcoming the culture's understanding of them as weak, fragile, needy, and incompetent. These study participants downplay physical challenges and hide vulnerabilities while serving as figures of inspiration to family, friends, and coworkers. Having unconsciously internalized the culture's negative stance toward disability, these individuals stratify or compare their level of ability in relation to disabled "others." Three out of 11 study participants used the Identity as Overcoming Disability stance as their informal explanatory model of self- understanding (see Table 2). All 3 of these study participants (2 females and 1 male) were community ambulators; 2 of the 3 used leg braces alone or a combination of leg braces and crutches when ambulating.

TABLE 2: Informal Explanatory Models/Stances of Self-Understanding in Adolescents With Disability

Informal Explanatory Model/Stance	*Number of Adolescents*	*Gender of Adolescents*
Identity as overcoming disability	3	2 F / 1 M
Identity as objectifying disability	3	0 F / 3 M
Identity as integrating disability	5	5 F / 0 M
Total	11	11

NOTE: F = female participant; M = male participant.

Paradigm Case "E"

The study participant best exemplifying this informal explanatory model of self-understanding is "E" and will serve as the paradigm case of the Identity as Overcoming Disability stance. E is a 20-year-old woman who is currently struggling with deteriorating physical health; specifically her body's ability to withstand the constant pounding of her hips, dislocated from birth, against a deformed and thinning pelvic wall. She experiences constant pain in her back and hips that is aggravated with ambulation. E walks with an exaggerated Trendelenburg gait, wears ankle-foot orthoses (AFOs), and uses one crutch.

Recently, she has been advised by the spina bifida clinic's multidisciplinary team to limit ambulation to very short distances and to begin using a manual wheelchair for most activities to diminish the pain and preserve joint function. This medical prescriptive is counterintuitive to her self-understanding as one who overcomes adversity. Her ability to walk, despite having spina bifida, has been central to her self-concept, a personal triumph of sorts, reflecting inner strength, determination, and fortitude. It has also provided E with an important line of demarcation between herself and those physically disabled "others" needing a wheelchair for mobility. E experiences the wheelchair negatively, as a symbol of fragility and weakness.

> The wheelchair represents, as whoever is in there is, is weak . . . is an outcast . . . an alternative for someone because they weren't capable of doing, the regular things in life.

She attempts to mitigate any impression of physical weakness with a veneer of mental toughness.

> I don't like to always say that I'm hurting or anything. 'Cause then I feel like even more looked down upon.

To compensate for what she understands to be a personal failing (her disability), E attempts to avoid any further demonstration of weakness.

> I think, for me my number one weakness is my disability . . . and I think, since I feel that I'm weak in that way, that I do, I try to like, you know, I'll put my guard up. That way it doesn't show that I'm weak.

Leg braces, bladder catheterizations, crutches, a self-described "penguin-like" gait, and, now, the possibility of a wheelchair make her feel unattractive and undesirable. Having unconsciously internalized the negative images propagated in the culture about persons with disabilities, E experiences herself as a liability and projects these negative feelings on anyone willing to partner with her.

> If I have a relationship with a guy . . . it's happening, but it's really not because in the back of my mind, I'll still be questioning, like, "Well, why the heck do you want to, like . . . be with me? What's the catch . . . like, what, what's your motive?"

This negative self-image is reinforced whenever E finds herself in close proximity to other persons with disability. The widespread cultural notion that a person is his or her disability and that being disabled is negative contributes to her feelings of discomfort.

> There is fear, I guess. Fear and an insecurity . . . Growing up, I wasn't around other people who had disabilities . . . and, so, going into a room full of them, believe it or not, is like shocking to me, is like "whoa!" Then I start to see myself. And then I don't like it.

If the culture is unable to see beyond a person's disability, how can she be expected to, perhaps even in the presence of a formalized educational program on the politics of stigmatized difference? E has not had the benefit of diversity training, either formally or informally. Consequently, she attributes discomfort around disabled others to lack of exposure rather than to unconscious internalization of the culture's fear, ignorance, and misunderstanding. Viewing the disabled wearing the blinders of the culture, E sees painful, distorted images. She describes being introduced to a young man with a disability similar to her own, who asks her out on a date. E declines the invitation.

> It hit me when I saw him walk. And so it was almost like looking into a mirror and watching me walk. And so that's what freaked me out. And that's what's scaring me. And that's what made me feel insecure . . . and it's not like every day I think of how I'm walking. . . . It scared me. It made me feel uncomfortable, you know. . . . It made me more aware of who I was, and so in a way, like, I was running from that.

Identity as Objectifying Disability Stance

The hallmark of this stance is an identity, or self-understanding, as one who objectifies or externalizes his or her disability. Individuals experience their physical disability apart from their internal, or core, self. They engage in strategies of defense designed to limit or contain the psychosocial impact of disability for survival's sake. Three out of 11 study participants used the Identity as Objectifying Disability stance as their primary informal explanatory model of self-understanding (see Table 2). All 3 of these individuals were male, full-time wheelchair users, and had experienced significant emotional trauma in relationship to their disability.

Paradigm Case "L"

The study participant best exemplifying this paradigm is "L." L is a 19-year-old man who has spent a good portion of his life thus far attempting to manage the physical and psychosocial sequelae of physical disability/spina bifida. His life has been punctuated by a series of physical and emotional ordeals directly and indirectly linked to having a disability. These traumas precipitated a suicide attempt at 14 years, while L was attending middle school. Since then, L's focus and attention have been directed toward doing what he has to do each day to "survive" and maintain his spirits. For L, that often equates with consciously or unconsciously attempting to avoid, limit, and/or block out stressful, painful, or depressing thoughts, as well as reframing disability and its relationship to his core or internal sense of self.

L's desire to limit the scope and effect of his disability has its roots in early childhood socialization experiences.

> I was always dealing with the fact that I was different and that would cause certain problems in social life, with kids being as brutal as they can be . . . just trying to deal with the fact that kids weren't always comfortable being around me or making friends with me, or even talking.

Because L was born with a high lumbar spina bifida lesion, it became necessary for him to use a wheelchair for mobility at home and at school. Rather than affording him greater accessibility to persons and places as intended, it had the opposite effect, isolating him from his peers.

> Kids were always a little nervous. Some of that nervousness, you know, turns into, I don't know, I don't want to say it turns into hatred. They just don't understand and don't know how to deal with people being in a chair.

Transition to middle school only exacerbates L's feelings of not belonging, particularly in relation to his peers. Although challenging for most early adolescents, middle school is particularly difficult for those individuals perceived as different. L experiences a growing sense of isolation and alienation.

> I don't know. It's just situations that arise out of adolescence. Finding a place to be, finding where you belong. And trying to fit in with the, the social order, or whatever you want to call it.

To complicate matters, there were no other individuals with a physical disability within the entire school. L was essentially without a peer group at a time developmentally when fitting in and being liked by others is highly valued and associated with individual worth. L becomes depressed.

> It was pretty awkward. 'Cause I was the only one that had a physical disability. . . . I was dealing with depression and I was just really quiet, isolated loner, and being stuck in a situation where you can't exactly socialize with the other kids in your class, it just made it all worse.

By the time L reached the 8th grade, he was overwhelmed with the increased demands of middle school, emerging adolescence, and the added burden of numerous acute illnesses, multiple hospitalizations, subsequent failing grades, and burgeoning social isolation. As the stressors mount, so did the depth of his depression and hopelessness. L attempted to end his life by taking an overdose of prescribed medication.

> I was having difficulty at school. My grades were falling, and I was failing, like, most of my classes. I was in and out of the hospital constantly, dealing with medical issues and I didn't really get a clear idea of what was happening to me—whether it was something serious or whether it was just growing up or I was aging, going through puberty. But I just had a lot of emotions that eventually got too intense, and I just couldn't take any more.

He began to see a psychiatrist and was started on antidepressant therapy. He remained a loner for the duration of middle school and high school.

Currently, L is in his 1st year of community college. Like many at this developmental age and stage, L's focus is on obtaining a degree in medieval history, moving out of his parents' home into a place of his own, and keeping his depression in check. During our interview sessions, self-descriptions are essentially void of any reference to having a physical disability. His body language demonstrates visible discomfort whenever I refer to his disability during the interviews.

> Well, dealing with my disability . . . I don't think about it much, right now . . . I try to keep it, you know, pretty much out of my life or out of relations with other people.

Because L uses a wheelchair for mobility, catheterizes his bladder several times a day, engages in a nightly regimen for bowel evacuation, and relies on paratransit services and public transportation to get around as a consequence of a visual-perceptual condition that prevents him from driving, the thought of his trying to keep his disability "out of his life and/or out of relations with others" seems a Herculean task. Understanding disability strictly as a difference provides him that opportunity.

> It's difficult. It's actually near impossible, 'cause I know I am disabled and it's clearly evident (long pause) . . . I just try not to view it as being different as being disabled . . . just being different as everyone is different . . . treating it more as, you know, a difference like a person is male or female, Black or White.

Reframing disability as difference and placing it within a sociopolitical framework serves to mitigate disability's stigmatizing effects. Kleinman (1988) referred to this practice as remoralization, whereby individuals devise strategies to maintain hope and move forward amid enormous challenges and suffering.

Another strategy involves focusing almost exclusively on his depression. L monitors his depression carefully, working hard to keep from being overwhelmed by it. He does not perceive a connection between his depression and his physical disability, nor does he acknowledge a connection between his physical disability and his inner, or core, self. Claiming depression as part of his core self is the locus of his attention and concern rather than the physical hardships he faces daily.

> As far as the counseling, I've been with psychiatrist, we really focus . . . more on the depression rather than disability. . . . My depression is how I feel inside . . . how I feel about myself. As far as my disability, I just do not think about it.

Identity as Integrating Disability Stance

The hallmark of this stance is an identity, or self-understanding, as one who integrates his or her disability, its personal and social meanings, into his or her sense of self. These individuals articulate a shift in self-understanding over time that proves world altering, culminating in a desire to claim disability as part of their core self. These study participants consciously acknowledge the stigma surrounding disability while actively working toward self-acceptance. They allow themselves to be vulnerable and express need. Their friendships include relationships with both disabled and nondisabled persons. Five out of 11 study participants (all female) used the Identity as Integrating Disability stance as their primary informal explanatory model of self-understanding (see Table 2). Two are community ambulators, and 3 are wheelchair users.

Paradigm Case "C "

The study participant best exemplifying this stance is "C." C is a 21-year-old woman who, in the past 2 years, has come to know and understand her physical disability and its personal and social meanings in new, more integrated ways. Since moving across state to attend a large public university in California, C has had to confront her disability, its opportunities, and its challenges more directly, sparking a myriad of new feelings and experiences, both exhilarating and distressing, liberating and constraining.

In addition to all of the usual challenges and upheavals that 1st-year college freshmen experience, C has the added demands and responsibilities that accompany physical disability. Her first personal crisis involves her ability to traverse the large, hilly university campus and surrounding neighborhoods with her usual assistive devices, long leg braces, and forearm crutches. She finds it physically exhausting and enormously inefficient. Consequently, C is forced to consider using a wheelchair almost exclusively, both on and off campus. Despite the efficiency, energy savings, and practicality of using a wheelchair, C struggles with her decision and its ramifications. She is cognizant of the ingrained cultural misconceptions associated with the wheelchair and the inherent irony in such misunderstanding.

> People are more prone to help me, and it's kind of ironic because I can get around faster and a little bit better, and more efficiently, and I can certainly carry things, when I'm in my wheelchair, and I can't when I'm using my braces and crutches, but I think, because see people see me walking, they assume I can do more.

What she gains in self-sufficiency and efficiency, she loses in social stature and acceptability. A social differential is created in the simple act of sitting down.

> There's something about, being able to stand that puts people at ease, in social situations. And there's something in the way that standing enables you to look at someone eye to eye on the same level that changes the dynamic of any interaction.

The wheelchair serves as metaphor for her disability, becoming overdetermining and overdefining, concealing other aspects of C's character and appeal while undermining social relationships. Feelings of loneliness and alienation fester and mount over time. By her 3rd year of college, C acknowledges being lonely and depressed. In a move that proves world altering, C enrolls in a disability studies class. The instructor, course readings, and discussions, as well as supportive classmates, provide her with new opportunities for self-discovery.

> It pretty much coincided with taking Disability Studies classes and meeting disabled people and having disabled friends . . . just having that kind of forum to talk about anything and to finally get everything out, that I'd been holding back, for years.

She finds signification and validation for feelings previously experienced but neither acknowledged nor fully understood.

> I was hearing all these things, from outside sources, that I've been feeling my entire life, and didn't really have a name for, and thought that a lot of it was just the way I felt, and didn't know, it was just this like overarching theme in disabled people's lives. . . . It was sad and it was frustrating, and it was scary, because it wasn't really something that I could separate myself from. Say, "This is academics, it's not me." Because it was, or it could be. And that was really really hard.

One such overarching theme involves unconsciously stratifying one's own ability in relation to "disabled others" and assigning value or worth depending on placement or rank.

> There's a very weird kind of almost self-wounding thing that I've noticed in the disabled community. . . . It has to do with levels of ability. Because we're taught that the more able you are, the better you are. Which translates into you being a better person, a superior person, to other people, who have less range of movement.

C's exposure to disability theory provides her with a sociopolitical framework for understanding past feelings of discomfort toward herself and others with disabilities, precipitating advancement to a new level of self-understanding and acceptance.

> And I kind of just have a better idea of how things go and my placement in the world. . . . I'm just so much more at ease with myself. . . . I'm not so constricted into trying to be this person that I think people want me to be.

Despite C's newly emergent optimism and ease with herself, she is realistic about the physical and psychosocial complexities associated with her disability, particularly with regard to romance and sexuality. In addition to braces, crutches, and a wheelchair, C currently wears disposable underwear (diapers) for incontinence despite catheterizing her bladder several times a day. She is highly sensitive to the degree of risk in disclosing this type of personal information. Consequently, sexual experimentation, including casual sex, not uncommon at this developmental stage, seems a distant possibility for now.

> My friends treat sex a lot differently than I do. . . . It's on a much more freer, casual basis. . . . I have to build a certain level of trust with someone, before I can even think about that. Just because it does take a certain level of maturity, to deal with, like, you know, "Hey, so I have a bladder disability." . . . I don't think I'm going to be able to find that casually.

Although C is willing to confront these challenges openly and honestly, they are no less poignant.

> Being in a family or being close to someone with a disability can introduce you to disability culture and things like that, but there's nothing like being disappointed for yourself rather than for someone else. Like, feeling empathy is totally different from, like, having it be you.

DISCUSSION

There is not one particular way to take up disability but several. In this study, I have identified three informal explanatory models of self-understanding, but there might be others within a larger sample population. Although a primary informal model was identified for each individual, study participants exhibited self-understandings incorporating characteristics of all three informal models. Each stance carries risks and rewards, opportunities and loss.

In the first paradigm case, E's quest to overcome adversity has been world defining, providing her with an identity other than disabled, an alternative, more socially acceptable mirror. This identity has been central to past and present relationships. From an admiring public, she has received numerous accolades for her positive attitude, work ethic, and tremendous inner strength, providing her with a sense of purpose, pride, and self-worth while contributing to her successes. Lately, however, changes in her physical health have begun to undermine her overcoming stance. Whereas in the past, her ability to ambulate, hence her identity as an overcomer served a therapeutic purpose, now, if she continues to ignore medical advice to "sit down," she risks permanently undermining her overall health as well as her ability to walk.

Self-understandings aimed at "overcoming" disability are often encouraged by unwitting family members, medical professionals, and socially significant others and might be directly attributed to extant negative images of disability still prevalent within society. The desire to "overcome" disability is often rooted in the desire to overcome the demeaning images of "other," including notions of incompetence, mental retardation, laziness, and neediness. In an attempt to disprove the cultural stereotype, individuals risk exhaustion in an effort to overcome their "defects." Persistent overcoming requires persistent denial of a central aspect of one's self: the disabled self. As long as these individuals continue to disown the parts that are disabled, there will continue to be gaps in their identity and barriers to achieving a fully integrated sense of self (Erikson, 1968; Gill, 1997; Muuss, 1996).

In the second paradigm case, L's desire to objectify his disability, keeping it separate from his core, or inner, self, serves protective and motivational functions. Traumatized by disability-related medical problems and rejection from his peers, L seeks ways to avoid disability's disheartening effects, initially by attempting to end his life and later by reframing disability's "place" in his life. By focusing on the depression rather than the disability, L might be attempting to put his energies into a less stigmatizing condition and one that holds the possibility of regeneration.

Objectification at the hands of others might cause youth with disability to reflect on their bodies as damaged and undesirable objects, undermining their sense of bodily integrity and resulting in corporeal alienation. If I am my body, and my body is considered "damaged" by others, physical disability might be experienced as a threat to one's body (self). Under these circumstances, an individual might consciously or unconsciously objectify his or her physical body as a means of separating it from his or her personhood to avoid further identification with something demeaned and stigmatized within the culture (Toombs, 1993). Rejecting the part of themselves that is disabled places individuals at risk for disintegration. Trying to form a stable identity with central parts of the self excluded undermines personal integrity and psychic cohesiveness, interfering with all aspects of integration (Gill, 1997).

In the third and final paradigm case, C's desire to integrate her disability into her self-understanding has been world altering, opening up some possibilities and closing down others. C's decision to explore her disability, its attached meanings, and its relationship to self, world, and other has had a positive influence on her sense of self and place. Acknowledging her previous fear and discomfort with other persons living with disability, C now understands its sociopolitical roots. Adolescents who have disabilities frequently exhibit stigma contagion, that is, rejecting socialization opportunities with other physically disabled peers out of worry that their affiliation will further brand them as undesirable, incompetent, and weak (Gill, 1997).

Accepting her disability as part of her core identity provides C with the opportunity to reclaim her life, directing her efforts and activities in areas that reflect her personal beliefs, interests, and abilities. In this way, C has the potential to create a more integrated, authentic, and cohesive self with prospects for agency, mastery, and a sense of belonging within both mainstream culture and the disability community. It is not without risk, however. Contained within a sociopolitical understanding of disability comes recognition of the stigma associated with it and the continuing potential for marginalization, discrimination, and prejudice.

Overall, adolescents take up disability in relation to self-understanding in different ways. Paying attention to the manner in which clients claim their disability can provide clinicians with important insights into specific concerns and personal meanings of disability, including positive disability identity, as well as what these clients might perceive as possible, challenging, and/or threatening (Folkman, Schaefer, & Lazarus, 1979). Such information is crucial in establishing effective patterns of communication and mutual goals, and developing appropriate and meaningful treatment strategies, as well as clarifying expectations (Benner, 2000; Kleinman, 1988). Understanding the adolescent's explanatory model of disability might be of particular importance to rehabilitation professionals when organizing and integrating strategies for clinical care designed to enhance functional capacity, conserve energy expenditure, and promote positive disability identity development. Failing to work collaboratively with these adolescents will likely threaten cooperation, undermine relationship, and result in treatment failure, ultimately placing individuals living with disability at further risk (Carson, 1986; Kools, Gillis, & Tong, 1999; Toombs, 1993).

Limitations of the study include a small sample size ($N = 11$). To obtain a richer, more textured accounting of the lived experience of these late-stage adolescents, I chose to conduct multiple in-depth interviews with a smaller number of study participants in an effort to understand their world more fully. There might also be some concern of an "elite bias," as study participants were recruited from my place of employment as well as from another large university medical center. However, all clients who met the inclusion criteria from both institutions were invited to participate in the study. All those who volunteered or agreed to participate were enrolled. Finally, there were no real differences with respect to the tone, flow, quality, and content yield of the study participants between the two institutions.

IMPLICATIONS

The social environment can enhance, delay, and/or interfere with ego development, hence identity formation, in youth. Identities and possibilities about the future occur within a background of deeply held, taken-for-granted assumptions, meanings, and practices from local and larger cultural contexts. Even supposed self-chosen futures are not freely made but constructed on a bed of social and political circumstances and opportunities. Individuals born and living with physical disability in the form of spina bifida might experience challenges with respect to achieving a fully integrated, cohesive, and coherent sense of self by virtue of the medical diagnosis, specific physical constraints, treatment regimens requiring daily dependence on parents or significant others for assistance, accessibility constraints, social isolation, and stigma.

Successful transition from adolescence to adulthood entails individuation, a psychological process whereby an individual feels connected to but separate from others, more self-defined than defined by others; essentially, more of oneself. Individuation is a particularly challenging process for members of socially oppressed minority groups. Assisting disabled youth toward psychological wholeness needs to become a priority in future transition planning. Specifically, this should involve devising and implementing developmentally age-appropriate, socialization-intensive programs that celebrate individual biography, particularity, and difference while fostering a positive sense of self. Programs designed to promote integration between what these youth know about themselves personally and what they wish the outside world to see are necessary to enhance emotional well being, inner wholeness, the capacity for intimacy with others, and positive disability identity.

Future research might explore how social structural factors, developmental phases, or gender can contribute to an individual's explanatory model of self-understanding in relation to disability; how client explanatory models might be utilized to promote positive clinical outcomes, and/or what strategies are most effective for promoting positive disability identity in youth.

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