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Disability and Health: Exploring the Disablement Experience of Young Adult African Americans

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Abstract

Purpose—The objective of this study was to examine disablement as experienced by young adult African American men and women with permanent mobility impairment.

Methods—This study included a sample of 5 male and 5 female participants ranging in age from 22 to 39. An exploratory descriptive design and qualitative methods, including interviews and fieldnotes, were used. Interview data was analyzed using the process of inductive qualitative content analysis.

Results—Basic desires for independence, shared intimacy, and psychological and physical health were not diminished by physical limitations. The disablement experience of this group is reflected in the themes of “Cumulative Losses” and “Sustained Desires.” The findings of this study describe the high level of motivation that young adult African American men and women with disabilities have to improve levels of health and well-being within the context of their impairments.

Conclusion—This study provides a better understanding of the contextual factors and experiences that may contribute to the development of further disability and subsequent health-related problems over time. Increased knowledge of the disablement experience of these young men and women may assist health care entities and social service providers in improving health care and rehabilitation efforts targeting this group.

Keywords

Minority Health; Young Adults; African Americans

Introduction

The progression towards disablement [1] is shaped by a number of social and personal factors that can hasten or slow the speed at which an individual moves from impairment to disability. While existing literature reveals valuable insight into the social, personal, and contextual factors surrounding the disablement experience of older African American men and women [2-5], little is known about the disablement experience of young adult African Americans in particular.

Functional limitations and subsequent disability are challenging the health and prosperity of our nation's young adults. Indeed, there are over 15 million young adults with disabilities between the ages of 18 and 44 in the U.S. [6]. This indicates that a growing number of our working society is aging with early onset disabilities. Although all ethnic groups experience some level of disability, the authors suggest that the African American population may experience some of the greatest challenges while aging with disabilities. African American adults experience one of the highest rates of disability in the country, second only to American Indian adults [7] and having a disability is a risk factor for poor health and social outcomes, both related and unrelated to an original impairment [8-10]. This makes the prevention of social inequalities and co-morbid conditions throughout life a priority initiative for those providing care to young African American adults with early onset disability.

It has been documented that people aging with an early onset disability are at risk for poor health outcomes over time [8-10] such as increasing levels of fatigue or chronic pain [11]. Among older African Americans aging with disability, previous research reveals an excess risk for developing disability [3] and a high level of progression towards more severe functional limitations [5] when compared to Whites. However, there is a paucity of literature exploring the underlying factors, values, and experiences of young adult African Americans with disabilities at early stages in the life course that may shape the disability experience and subsequent health outcomes over time. Young adult African American men and women with disabilities have the potential to live long healthy lives, as people with early onset disabilities are living longer than ever before in history [12-13]. In order to assist this group in improving health related outcomes, health care providers need foundational knowledge of the African American experience with disability and how this might be unique to their ethnicity. It is possible that the African American experience with disability is no different than any other group; however, this is yet to be explored. The purpose of this qualitative, descriptive study was to explore the intersection of ethnicity, young adulthood, and disability by examining the disablement experience of young adult African American men and women with permanent mobility impairment. The following research question was addressed: How do young adult African American men and women describe disablement?

Methodology

According to Nagi [14] and Verbrugge and Jette [1], the disablement process is an avoidable path from an injury or pathology in the body to the experience of being disabled. Verbrugge and Jette define disability as the inability to perform a socially constructed role such as employee or socialite, secondary to a functional limitation. Although persons with disabilities are able to interact with their environment and influence the trajectory towards disability, the disablement model is limited in its ability to capture the experiences, emotions, and perceptions that influence individual responses throughout the disablement process. The added use of a life course perspective allows researchers to appreciate those cultural, social, biological, and psychological factors that help shape the disablement experience [15].

The theoretical perspective used to guide this study integrates a life course description of young adulthood within a disablement perspective as described by Priestley [16]. In this perspective adulthood is defined as a residual category made possible by independence; it is formed by the exclusion of other generational groups that depend on adults for survival. In this sense, adults with disability are viewed as occupying a liminal state. They are exempt from a social status of adulthood where reproductive and work roles are fulfilled unless they transition back into a non-disabled status or into a socially sanctioned status [17]. Youth are being trained to assume adult roles and judged for their degree of discipline and success by their bodies' level of fitness. Adults are judged primarily by their independent role

performance. The transition from youth physicality to adult independence is a key developmental task for the young adult with a functional limitation. He or she is tasked with overcoming and redefining the aforementioned cultural stereotypes of the youthful fit and the independently mature body.

African American young adults are categorized within this study of life course disablement as a group of people sharing an ethnic identity. Here, ethnic identity refers to “expressions of loyalty, commitment and belongingness towards an ethnic group” [18, p.32]. An ethnic group is a social construct formed from a common cultural and historical background. It is limited, however, in that it only partly captures any identity of its members [18]. For the purposes of this research, ethnicity and ethnic identity will assist in focusing attention on the symbolic elements of disability for a collective of young adult African Americans within our society.

Methods

Data Collection and Management

The purpose of this study was to describe the disablement experience of African American young adults. For this purpose, we used an exploratory descriptive design and qualitative methods. Data consisted of interviews, fieldnotes and demographic questions. The researchers conducted individual, one-to-one interviews using open-ended questions such as “What was a typical day like for you before your impairment?” and “What kinds of things do you do on a daily basis to take care of your body?” followed by probes to clarify and solicit additional information. All the interviews except one were conducted by the first author; the final interview was conducted by the second author. Each interview was audio-recorded, professionally transcribed verbatim, and checked for accuracy after transcription by comparing the audio to the transcripts. Interviews lasted approximately 30 to 60 minutes and took place in either the participants’ homes, the researcher’s office or in a private section of a doctor’s office. Each participant was provided a \$50.00 incentive for participation. During the interviews, participants were advised that observations regarding dress, body language, assistive devices, initial impressions, and environmental details were being noted for future recording in the field notes. All identifying information, such as names and addresses, was removed prior to data analysis. Each participant was given a pseudonym to protect their identity.

Data Analysis

Interview data was analyzed using the process of inductive qualitative content analysis as described by Graneheim and Lundman [20]. Content analysis is the systematic process of discerning and describing a phenomenon [21]. Using the following procedures, the first author used content analysis to identify themes related to the disablement experience. First, each interview was read several times in its entirety. Next, meaning units were identified and labeled by writing notes in the margins of each interview. Graneheim and Lundman [20] describe meaning units as “words, sentences or paragraphs containing aspects related to each other through their content and context” (p. 106). The meaning units were then manually grouped into like categories based on shared meaning. In inductive content analysis, instead of being predetermined as in deductive content analysis, categories are generated by the data during preliminary and ongoing data analysis [19, 22]. The first author (T. R.) reflected on the relationship between categories until themes were inductively created to represent the common experiences seen within the data. Detailed fieldnotes regarding the interview experience were gathered to provide context to the interview data [23].

This study's trustworthiness, or validity, was accomplished by steps taken to achieve (a) credibility, (b) dependability, (c) confirmability, and (d) transferability [24]. According to Lincoln and Guba [24], credibility is an assessment of the interpretation of research findings and how well those findings reflect the data, while confirmability is an assessment of how well those findings are supported by the data. Dependability refers to the integrity of all phases of the study's processes, specifically data collection and analysis. Transferability refers to the extent to which the findings of a study can be applied to another context. To ensure credibility and confirmability throughout the data collection and analysis process, the researchers reviewed interview transcripts several times as well as reviewed the coding procedures before and during data analysis. To ensure dependability and confirmability, the research expertise and input of the second author (T. H.) was sought throughout the analysis process. Fieldnote and demographic descriptive data added to the potential transferability of the findings by providing a detailed description of the context and sample description from which to base an understanding.

Sample

After approval from the local institutional review board, participants were recruited using fliers and word of mouth targeting list-serves, healthcare providers, disability activists and community agencies. Participants were recruited based on having self-identified mobility impairment, being between 18 and 40 years of age, being African American, and being willing to discuss their experiences. Interested people were asked to call or email the researchers. Upon receipt of their contact information, potential participants were immediately called and screened for eligibility.

To be eligible for this study, participants had to report a permanent mobility limitation related to any specified impairment as evidenced by reporting 2 of 4 functional limitations identified in the National Health Interview Survey [19]: the inability to walk 10 steps without resting, to walk a quarter of a mile, to stand for 20 minutes, or to bend down from a standing position. In addition, only participants residing in the community were included. If a person was eligible, a meeting was scheduled at a mutually agreeable time and place.

At the time of the meetings, written, informed consent was obtained from all participants. The purposive sample consisted of 10 participants; five young adult African American men and five young adult African American women with permanent mobility impairment. Participants were between the ages of 22 and 39 (mean age 31.5 years) and included persons with spinal cord injury, scoliosis, arthritis, systemic lupus erythematosus, low back injury, and osteogenesis imperfecta. The age of onset of impairment ranged from birth to 39 years with a mean of 19.3 years. See Table 1 for descriptive characteristics of the sample.

Results

The overall finding of this study stresses the young adult potential for health and life fulfillment. This is based on the synthesis of two overarching themes. The themes can be condensed into two main concepts: loss and desire. Participants maintained basic desires for independence, intimacy, and autonomy in the context of losses that they perceived were directly related to their impairment(s). The two themes represent the commonalities in disablement experiences discussed by the young men and women in the study: "Cumulative Losses" and "Sustained desires." "Cumulative losses" included four categories labeled the "loss of independence/autonomy," the "loss of identity," the "loss of intimacy with others," and the "loss of opportunities." "Sustained desires" included three categories: the "desire for autonomy/independence," the "desire to connect with others," and the "desire to care for self." These two themes, along with their associated categories, are listed in Tables 2 and 3.

Cumulative Losses

The theme “cumulative losses” refers to the personal losses that participants said had occurred throughout the course of their disablement experience. Losses are defined as any change in physical, social or mental status that is perceived as having a negative impact on the prior state of the individual. The impairment related losses were described as profound, cumulative events because the losses sprung from an initial impairment. In essence, the losses seemed to build upon each other as time progressed. For example, the loss of some degree of physical mobility commonly preceded loss of independence. Loss of independence would precede the loss of relationships, the loss of perceived opportunities, and the loss of feelings of accomplishment or life progression.

Loss of Independence/Autonomy—Every participant involved in this study shared significant losses of autonomy and independence during their experience of disablement. Autonomy is defined as the freedom of an individual to make and control the personal decisions that affect one's quality of life, while independence is the ability to live and function without having to depend on someone else. The loss of independence described by the participants usually began with the loss of physical control. For instance, Chris stated his body had “shut down” and was no longer able to respond with the desired level of mobility and functioning. They felt they had lost full control of their bodies. One female participant, Tina, stated, “I know I'm not used to this, but sometimes it makes me feel handicapped. And because I can't do what I used to do before, it's just like I can't drive and I want to get out there and drive. I don't have my freedom. I don't have my freedom and independence like I used to.”

Loss of autonomy resulted in a change in lifestyle that was difficult to adjust to for most participants. Kevin expressed that the change in lifestyle resulted in being “frustrated with my whole existence. I couldn't do nothing that I wanted to do.” This difficulty may reflect an unhappiness with the “looking glass self” mirrored to the young African American men and women as they tried to maintain a sense of ethnic and individual identity [25]. According to Hall [25], the “looking glass self” is a metaphor for how society reflects its view of the individual back to each person. At the life stage of these young adults, they had most likely emerged into a comfort with their ethnic identity and related lifestyles. The young men and women encountered social resistance due to their impairments, which amplified a sense of disability.

The loss of autonomy resulted in significant loss of independence that left control over their bodies to that of another person. Male participants in particular, disliked the idea of physical limitations and having to give someone else control over their body. Colby spoke of the difficulty in doing so,

That's the hardest thing. Just knowing that somebody else has to do it for you. Knowing that you're not able to move yourself around, put your own clothes on, just get up, and pick what you want to wear. You have to have them go in there, tell you what's in there, and tell them okay, I want this or that, or these shoes, or something like that. You know, then they have to dress you, roll you around to get your clothes on and, you know that's just a constant battle every day. You just don't want nobody to have to do that for you.

This quote reflects the notion that giving up control of their body and losing the ability to function independently was further compounded by the necessity of having to relinquish control to another person resulting in a loss of autonomy, independence, and freedom.

Loss of Intimacy with Others—The loss of intimacy or a decreased sense of a connection with others was commonly shared by participants. Participants frequently cited a lack of support from family, friends and health care providers. Participants expressed shock at the negative attitudes they perceived from health care providers and people within their circle. Several participants felt discouraged from looking beyond their impairment and entertaining the possibility of careers, family, and good health in the context of disability. The lack of perceived support and discouragement led many participants to develop a strong distrust of others.

Due to their distrust of others, many participants withdrew from others and frequently engaged with people on a superficial level, if at all. Several participants shared that they had grown tired of talking about their impairment. They were tired of people asking questions. Trent said he felt that sharing his history and experiences with people tended to lead to more inaccurate assumptions and labeling instead of an enhanced understanding and appreciation of his capabilities: “So if it was going to be held against me, then I didn’t want to have to talk about it. I didn’t want to have to deal with it.”

Loss of Opportunities—The loss of opportunities primarily pertained to financial opportunities that participants said were lost because of their impairment. Participants felt limited in their employment and educational endeavors because of their physical limitations. David and Gerald were both fired after their injuries due to their subsequent inability to fulfill their job duties. Tina had two children and was on leave without pay from her job due to her inability to work after her injury. Fathers, in particular, expressed disappointment and shame in not being able to provide financially for their families and children. In addition, several participants spoke of the burden placed on their spouses to be the sole providers for their family.

Being unemployed is a significant problem for people with disabilities. In 2010, the poverty rate among non-institutionalized people with disabilities ages 16-64 was 31% and 12 % for those employed and unemployed, respectively [26]. Not surprisingly, securing disability benefits was considered a financial help, and sometimes necessity. However, many expressed concern regarding the ability to adequately provide for themselves and their families on what was perceived as a small amount of money. Several participants indicated that while disability payments were certainly needed, they were simply not enough to live on. When asked if he was able to live comfortably on his disability benefits, David, a 36 year-old father of one said, “Well, yeah, but see it’s not enough, it’s enough-it’s only enough to live comfortably if you understand that it’s not enough. See? You have to use the mentality that this is not enough.” Several participants expressed that they needed to work in order to supplement their disability benefits, but they had to be careful of how much additional work they did, so they would not lose their benefits-benefits, in some cases, it had taken years to procure.

Although loss of opportunities primarily pertained to financial opportunities that participants felt were lost because of their impairment, they also found that this had a circular affect. The lost financial opportunities due to their impairments prevented them from improving their impairments. In other words, their limited financial resources affected opportunities to secure appropriate assistive devices or undergo procedures that they thought might improve their quality of life. For example, Trent, a young man with scoliosis, experienced chronic pain associated with the hardware in place to straighten his spine. Trent felt like he would benefit from decreased pain and was contemplating back surgery to remove the hardware, but said, “the cost has just been too high to consider it.” Sarah described her interactions with an insurance entity as adversarial in nature. Sarah shared her experience in trying to secure a motorized wheelchair: “They switched over my health insurance when I turned 21

and I had to fight to get a wheelchair. Like literally, had to fight to get that wheelchair.” Due to her reliance on the wheelchair for mobility, Sarah's inability to get the insurance to pay for the wheelchair in a timely manner, resulted in her missing classes and exams.

Loss of Social Position—According to Priestley [15], the three key themes in the transition to adult independence are work, housing and family, and disability can interrupt the socially expected achievement of adult social position through the disruption of a typical attainment of these. The loss of social status for these African American young men and women occurred in the context of their established ethnic and individual identity. From this position, the men involved in this study often described their bodies in terms of being “broken” or “fixed.” However, they did not consider the brokenness of their bodies to be a defining aspect of their identity. Colby's sentiment seemed to capture what several participants stated: “I still look at myself as the same person as I was before. Yeah, my body may be broken, but I'm not. I'm still the same person inside, still got my right mind and everything.” For most participants, how they viewed themselves and their potential before and after their impairment did not change. In fact, the factor that changed the most in their opinion was how other people reacted to them.

The participants stated that they were defined and judged by their impairment, which left them without social position. Although they maintained their ethnic and individual identities, other people identified them as “disabled”, which carried stigmatizing connotation. They felt that people made unfair assumptions regarding their abilities to perform adult roles or their potential ability to perform adult roles based solely on their impairment. They stated that few people understood-or even tried to understand-the way they lived their lives and how they viewed their bodies. Trent said, “..I still go through that, where people will make assumptions about what I can or cannot do, if I mention it (impairment). They will be like well he can't do this. He can't do that. I'm like he can't what? I'm right here. You can just ask me if I can do something or not. I'm probably all right.”

The participants' perceptions of lost social position were amplified by the state's lack of recognition of their disabilities. The ability to be exempt from adult roles and receive financial compensation requires that the state “scrutinize the everyday rituals and practices of citizens who maintain they have debilitating physical and mental impairments.” [27, p. 220]. The participants in this study described how their attempts to define their bodies as disabled were met with resistance from the state. For instance, although he was mobile using his cane, Kevin considered himself disabled both mentally and physically. Regardless, he had been denied disability related benefits on several occasions. His experience mirrored those of other participants who had been denied disability benefits. They indicated that they had been turned down multiple times and the process of securing disability benefits had been unnecessarily arduous and long.

Sustained desires

The theme of “sustained desires” describes basic needs that the study participants maintained despite a series of losses. Even when participants experienced significant losses of independence, connectedness, and self-care, the *desire* for those things was unwavering. In some manner, every participant expressed that their self-identity had not been altered by their disablement experience. Therefore, the desires that were present prior to their impairment remained intact in the context of disability.

Desire for Independence/Autonomy—Despite loss of control over many aspects of their lives, including their bodies, every participant expressed a yearning for restored autonomy and independence. More specifically, participants voiced a desire to be mobile, to

make decisions regarding their health, and to be able to function without the help of other people. They were not opposed to the use of assistive devices to aid their mobility, but they did not want to depend on another person or persons.

Several participants voiced their aversion to the chronic use of pain medications to enhance their ability to function independently. The importance of not wanting to be dependent on pain medications was apparent in the responses of Trent, who said, “If I use anything (for pain), I use Arnica gel. It's just something more natural. I'm very much in the idea of not trying to get dependent on anything.” Kevin said, “Yeah, and I was like, that's the kind of thing that I was hoping to get out of reading because psych meds and even meds for my physical condition, I don't want to-I don't look forward to taking that for the rest of my life.”

Desire to Connect with Others—Being connected to others was important. Although participants had established rigid boundaries with others due to shame and mistrust, several of those same participants expressed a longing to share their experiences and themselves with others. Their motivation was frequently based on their desire for people to understand their lives and to gain a richer appreciation for their life experiences. They did not want to be pitied or gawked at. Sarah, like several participants, preferred that people ask her questions than make a spectacle of her disability: “I'm always talking about my, talking about my disability or my life. And a lot of people are afraid to approach me about it. But I'd rather you ask me than stare.” Many participants wanted to share their experiences in hopes of encouraging people and helping them “look at the world differently”—including those with similar impairments. For several participants, this was their motivation for participating in this study.

The desire to connect did not stop at the connection with other people. Instead, participants maintained an emotional connection with their God in order to maintain emotional and spiritual health. Those participants who spoke of spiritual beliefs did not blame their God for their impairment or their life situation. They believed that staying positive had helped them cope with the losses they had encountered. Colby, a young man with only limited movement of his arms, said, “As long as you're alive you should be happy to get up every day and that's how I look at it. As long as I can open my eyes and breathe, I'm happy.” When asked how he was able to maintain the hope of walking in the face of discouragement from medical practitioners, Colby said, “Really what they say is irrelevant because God can do anything. One day you can be down, the next day He could have you walking and they.[sic] And then all of a sudden you're a medical mystery, but really there are no medical mysteries. It's all God doing it.”

Desire to Care for Self—The expressed desire to care for their minds and bodies was a common theme. For all of the participants, caring for oneself emotionally, cognitively, and physically involved focusing on one's strengths, not their limitations. Participants' desire to care for themselves was not tempered by the losses they had experienced. Even when difficult to maintain or improve, several participants indicated that cognitive, emotional, and physical health was important and was something they wanted. Trent said, “Do you dwell on it or do you continue to fight? And you have to make that decision and that's how I look at it. Do I make the decision to dwell on my thoughts and just lay there in the bed, don't do nothing, get bed sores, get sicker? Or do I lay in the bed and try to get up?” Many times, focusing on one's abilities led participants to push themselves beyond their physical limitations. All participants spoke of their need to “keep pushing” or to persevere. Participants shared that they would often end up with pronounced pain and fatigue secondary to this phenomenon.

In order to care for themselves after the onset of their impairments, participants engaged in multiple adaptive strategies such as social comparison with downward comparisons [28-29], and psychological reframing with optimistic tendencies. In other words, participants compared their life circumstances and physical limitations with others and expressed relief that their situation was not “as bad” as the situation of others. David said, “It's a blessing I'm not in a wheelchair, but at the same time, my situation is still unfortunate.” Functioning at the capacity in which they could and recognizing that their limitations could be more severe, seemed to be a way for participants to maintain a sense of optimism. They emphasized that “taking one day at a time” was essential for handling disappointments. The notion of “dealing” with adversity was shared by participants. In order to recover what they had lost, participants felt that they had to “deal” with it or develop a way of coping. Tricia, a young woman with lupus said, “It's better if I just deal with it in my mind because I think the other part, sometimes, is that people can hold themselves back by going, 'I'm suffering. I can't do this. I'm in pain. I'm going through this.' Then you basically told yourself you can't, can't, can't, can't.”

Discussion

According to Priestley [30], “A life course perspective can offer a valuable orientation not only to the dynamics of individual lives in historical and social context but can orient us also to elaborating that context” (p. 17). In this study, the life course perspective served as a framework to assist in contextualizing the disablement experience of our participants. The disablement experience of this group of young adult African American men and women centered on the potential for health and life satisfaction through two overarching themes: “Cumulative Losses” and “Sustained Desires.” The two primary themes identified suggest that despite significant losses of independence, social position, financial resources, and intimacy, several desires remained intact in the context of their impairments. It is important to note that although they experienced losses of independence or intimacy for instance, their yearning for those remained.

Harrison states that, “The intersection between gender and ethnicity can influence the cultural response to disability” (31, p. 681). The likelihood that gender, race, and culture shape the disablement experience, make it a unique experience grounded in a contextualized reality. The authors have found some commonalities among the disablement experience of our participants and that of other groups. As in this study, desires for autonomy and independence along with the desire to care for one's own emotional, physical, and mental health was also seen in a study of young adult White women with disabilities [32]. Like our participants, Crooks and Chouinard [33] found that the Canadian women in their study experienced losses of employment opportunities that impacted their ability to provide for themselves and their families. Our commonality of findings, however, does not negate the interactive impact of gender, ethnicity and disability. Further studies are needed to compare between group differences with larger samples.

While the disablement experience of young adults of different racial and ethnic groups is likely to vary based on cultural and gender influences, additional research is needed to explore how and why differences occur. For example, the majority of participants in this study were unemployed and reported having no or inadequate health insurance due to their limitations. Further research is needed to explore the ways in which cultural and gender based paradigms influence the unequal distribution of societal resources. The compounded effects of limited access to available resources from early adulthood forward can lead to public health problems, such as unequal mortality rates, over the life course if not addressed. This study highlights the perceived impact of early adulthood loss due to functional limitation. At this point in their life course, the men and women voiced their sustained desire

for social participation through employment, marriage and socialization, but researchers must ask: Will there be a developmental point when these young men and women no longer discuss, or most tragically, no longer have those desires?

The evolving definition of disability [34-35] has significant implications for how persons with disabilities are recognized by a society as well as themselves. According to Kelley-Moore and associates [2], disability is associated with negative social stigmas that influence when a person considers his or herself disabled as well as their perceived level of disability. They also found that societal influences that caused higher *perceived* disability resulted in greater morbidity and mortality regardless of the degree of functional limitation. Very often, participants in this study expressed frustration in their attempts to recapture some of the things they had lost, but felt that societal constraints, unfairly assigned labels and low expectations of their potential by others, had limited their ability to do so. Therefore, it is possible that inadequate social support and societal stereotypes and constraints may hasten the advancement towards disability by lowering personal beliefs regarding the probability of goal attainment and achievement. Several of the young adult African American participants in this study may have advanced to disability prematurely or unnecessarily due to societal standards surrounding their disability experience.

The physical limitations experienced by the participants in this study did not change the way that they described their identity. In other words, they did not lose their identity or allow it to be shaped by societal standards of “normality.” Participants maintained that they were still the same person they had always been - both before and after they had developed their impairment. This finding is consistent with what Harrison and colleagues [36] found in their study of how timing of impairment affected health promotion lifestyles in women with disabilities. Like the people in their study with an impairment onset after the age of 25, the self-identity of our participants was not lost or changed. What did change, however, was the way that other people seemed to react to them. According to Garbarski [37], “perceived social position encompasses perceptions of inequality or subordination” (p. 693).

Interestingly, the findings of this study provided a differing perspective on the notion of social position. Several participants recognized their physical limitations and simultaneously believed they could achieve the things they desired if they had the resources and opportunities - resources that often included disability benefits. These participants considered themselves disabled and felt that their impairments warranted disability related benefits and resources. According to the participants, the governmental entities did not consider them “disabled enough” to qualify for said benefits. This was a commonly reported experience, particularly among the young men of this study who had chronic back injuries. They believed people thought they were faking their impairment because it was not visible to others and not an obviously debilitating injury like a spinal cord injury. Essentially, they were unable to satisfy the physical image society expects of a young adult without a disability or a man with a disability. They remained in a liminal state unable to satisfy either physical category [17,38]. This resulted in them being unable to qualify for the social benefit of having a “documented” disability.

For a majority of participants in this study, lost opportunities were frequently discussed in relation to the financial resources needed to adequately provide for themselves and their families. For people who develop a disability early on in the life course, lower educational attainment often results in decreased earning power and limited employment opportunities throughout their lives [39]. Due to these disparities, people with disabilities experience poverty at more than three times the rate of people without disabilities [7,39]. Income level and educational attainment are likely to have implications for the type of jobs that persons with disabilities acquire, thereby influencing the level of insurance available to them [40].

Our findings indicate that limited job opportunities for persons with mobility impairment, difficulty securing disability benefits, and insurance red tape, were perceived barriers to financial independence and the fulfillment of familial roles. It is unclear if the young African American men and women in our study were at a greater disadvantage than other groups in finding employment. The rates of employment for people with disabilities based on race was not reported.

Participants reported that decreased levels of functioning would subsequently contribute to perceived missed opportunities for social interactions, employment, and the fulfillment of familial roles. The tendency of those losses to lead to other losses created the potential for stressors associated with those losses to accumulate as well [41]. Several participants in this study reported that the losses they had experienced resulted in significant distress. Participants voiced that they often felt powerless in their ability to prevent further losses from occurring. We would posit that it would prove valuable for future research to explore the dynamic relationships likely to exist between these losses, stressors, and health in the context of disability.

Among this group, basic desires for independence, shared intimacy, and psychological and physical health were not diminished by physical limitations. The findings of this study describe the high level of motivation that young adult African American men and women with disabilities have to improve levels of health and well-being within the context of their impairments. In the United States from 2004 to 2006, 47% of the 18,562 African Americans with a disability reported their health to be fair or poor, as compared to 37% of the 194,681 Non-Hispanic Whites with disabilities [42]. Their motivation may serve as a spring board for long-term improved health outcomes. This needs further testing with appropriate intervention development.

In conducting this study, the investigators were better able to understand the disablement experience of a group of young adult African American men and women from their perspective. Understanding the contextual factors that influenced the progression from impairment to disability offered some insight into how young African Americans experienced disability in the context of their interaction with their environment as they navigated young adulthood. This understanding provides valuable insights into the underlying factors and experiences that may contribute to the development of worsening impairment and subsequent disability over time. In their study of older Whites, African Americans, and Mexican Americans, Zsembik [43] discovered, "that there is a greater impact of earlier stages of the disablement process on disability among non-Whites." Zsembik [43] and her associates surmised that for African Americans, high rates of chronic conditions in early life resulted in higher rates of disability in later life than Whites. Research exploring racial and culturally based reasons for those disparities is needed.

When compared to persons without disabilities, people with disabilities are less likely to receive the care that they need or they experience significant time delays in receiving needed care [19]. Perhaps increased knowledge of the disablement experience of young African American men and women may assist health care entities and social service providers in improving health care and rehabilitation targeting this group. In order to design effective health promoting interventions, health care providers need foundational knowledge of how the disablement experience for African Americans might be unique to their ethnicity, age, and culture. This insight will assist healthcare providers in understanding the health needs of young African Americans with disabilities as well as facilitate a patient-provider relationship based on a mutual understanding of experience.

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Declaration of Interest

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Table 1

Descriptive Characteristics of the Sample (N = 10)

Variable	<i>M</i>	<i>SD</i>
Age	31.5	6.65
<i>Health insurance type</i>	<i>n</i>	
No insurance	2	
Private pay insurance	1	
Private pay insurance through employer	2	
Medicare	1	
Medicaid	3	
MAP (Medical Access Program) *	2	
Worker's Compensation	1	
<i>Employment status</i>		
Working	3	
Not working	7	
<i>Income level</i>		
No response	2	
Less than \$10,000	1	
\$10,000-15,000	3	
\$15,000-20,000	2	
\$25,000-35,000	1	
\$35,000-50,000	1	
<i>Highest level of education</i>		
High school	2	
Community college, Associate Degree, Technical Degree	5	
College or university equivalent, Bachelor's Degree	2	
Master's Degree	1	
<i>Marital status</i>		
Married	3	
Divorced	2	
Lives with significant other	1	
Never married	4	

* The MAP program is funded by a separate political subdivision of the State of Texas. MAP provides access to health care for residents who meet enrollment criteria

Table 2**Participant Information**

Kevin	36 year-old male with Arthritis, Inguinal hernia
Trent	31 year-old male with Scoliosis
Colby	23 year-old male with cervical spine injury resulting in quadriplegia
David	36 year-old male with Plantar fasciitis, Back injury (and pain) after being hit by a car
Gerald	35 year-old male with low back injury after falling off a flatbed truck, Diabetes Mellitus
Tricia	34 year-old female with severe Sciatic nerve pain, Lupus, Neck/back spasms, Back injury after car accident
Tina	39 year-old female with Degenerative disc disease, Carpal tunnel syndrome
Janet	35 year-old female with Myesthenia gravis
Sarah	22 year-old female with Osteogenesis imperfecta, Asthma
Pam	22 year-old female with Muscle wasting/mild tissue necrosis from untreated Brown recluse spider bites

Table 3

Cumulative Losses

Loss of Independence/Autonomy	Loss of Social Position	Loss of Intimacy with Others	Loss of Employment/Educational Opportunities/Financial
• Negative Feelings Regarding Impairment • Lacking/Loss of Control over Environment/Situation • Loss of Independence/Autonomy • Pain Occurs Whenever • Lifestyle Changes (Unable to work or do activities as before) • Mental Health Issues	• Self Awareness • People's Negative Reactions to Impairment/Disability • Being Misunderstood • Assigned Labels • Self Image (How you see yourself) • Insecurity/Insecurities	• Lack of Support from Others • Distrust of Others • Distancing self from Others/Disengagement • Establishing Boundaries • Isolation • Separated From Loved Ones (Unintentionally)	• Financial Concerns/Issues • Barriers to Employment/Educational Opportunities • Insurance Inadequacies • Feelings of Obligation Regarding Work • Sources of Financial Assistance • Attaining Disability Benefits

Table 4

Sustained Desires

Desire for Autonomy/Independence	Desire to Connect with Others/ Share Intimacy	Desire to Care for Self (Physically/Psychologically)
• Desire to be Mobile • Desire for Success/Accomplishment • Restoring/Gaining Independence/Autonomy • Positive Regard for Insurance	• Making Connections • Support Systems/Getting Support from Others • Helping Others/Being a Help to Others	• Ways of Coping • Pain Management • Things Done to Maintain Health/Improve Health • Keep Going/Pushing • Changing Perspectives/Thinking Differently • Spiritual Beliefs • Beliefs about Gender Roles