2009

The effect of disability type and severity on personal identity and acceptance of a cure

Carley Inez Butler

Recommended Citation

Butler, Carley Inez, "The effect of disability type and severity on personal identity and acceptance of a cure" (2009). *Theses Digitization Project*. 3802.
https://scholarworks.lib.csusb.edu/etd-project/3802

THE EFFECT OF DISABILITY TYPE AND SEVERITY ON PERSONAL IDENTITY AND ACCEPTANCE OF A CURE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Carley Inez Butler
June 2009

THE EFFECT OF DISABILITY TYPE AND SEVERITY ON PERSONAL IDENTITY AND ACCEPTANCE OF A CURE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Carley Inez Butler
June 2009

Approved by:

[redacted]
Dr. Rosemary McCaslin, Faculty Supervisor
Social Work

5/26/09
Date

[redacted]
Dr. Beth Jaworski, Services to Students
with Disabilities

[redacted]
Dr. Janet C. Chang,
M.S.W. Research Coordinator

ABSTRACT

While the Americans with Disabilities Act has paved the way for inclusion of people with disabilities multitudes of previously forbidden arenas of American society, negative attitudes about the disabled persist, along with the pervasive belief that if given the opportunity, any disabled person would choose to take a cure for their disability. This is simply not the case for scores of people for whom their disability has become a critical aspect of their identity. Fifty- seven disabled college students were asked questions that gauged the type and severity of their disability, how positively or negatively they identify with their disability and their desire for a cure, in order to determine whether the type or severity of ones disability is correlated with desire for a cure. The study finds that while severity is not strongly correlated with desire for a cure, certain types of disability may have a greater influence on a disabled person's desire for a cure than others. Additionally, the findings point to other personal variables, that may influence desire for a cure such as age and age at which a person becomes disabled.

ACKNOWLEDGMENTS

I would like to thank Dr. Beth Jaworski, Director of the Services to students with Disabilities office for graciously allowing me to survey students who receive services through the Services to Students with Disabilities office, and for advertising my project through the office's listserv. Also, thank you to Sean Snider, Administrative Support Assistant, for helping to collect raffle tickets from the participants. Finally, thank you to Tim Thelander, for helping format the thesis, and everything else you do and don't get credit for.

DEDICATION

I would like to dedicate this to my family, who has stood by me, in good times and in bad, over the last two years, providing endless support and encouragement. Thank you Dr. McCaslin. Your wisdom and no nonsense approach have helped me get through this process relatively unscathed. Also, I would like to dedicate this to all the people with disabilities in my life, who have inspired me to pursue this topic and to spread awareness of disability related issues wherever I go.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION

CHAPTER TWO: LITERATURE REVIEW

CHAPTER THREE: METHODS

CHAPTER FOUR: RESULTS

CHAPTER FIVE: DISCUSSION

LIST OF TABLES

CHAPTER ONE

INTRODUCTION

This chapter will outline the problem of ableism and negative stereotypes of people with disabilities. It will look at how pervasive the problem is not only in the broader society, but in the medical profession as well and how the problem of ableism within the medical profession leads doctors to make false assumptions about a disabled person's desire for a cure. It will also outline the purpose of this study and its significance for social work practice.

Problem Statement

Negative stereotypes of people with disabilities are pervasive in American society. In years past, "people with disabilities were thought to be helpless, indigent citizens, and were forced into institutions and asylums without equal opportunity or equal protection under the law" (Anti-Defamation League, 2005, para. 1). McDonald, Keys, and Balcazar (2007) contend that these negative stereotypes have been used by society to lock people with disabilities out of "community life, including neighborhoods, schools, employment and leisure activities" (McDonald et al., 2007, p. 146). Today, people with disabilities make up thirteen percent of the California population, and many outward signs of institutional ablism, "a system of discrimination and exclusion [which includes], denying people with disabilities equal access to education, health care, housing, and employment" (Allies for Change, n.d.) continue to vanish (United States Census Bureau, 2006). However, "cultural narratives of disability [continue to] include assumptions that people with disabilities are pathological and incompetent" (McDonald et al., 2007, p. 146).

Negative stereotypes and false assumptions about people with disabilities are not limited to the broader society. Recent advancements in technology continue to change the face of the medical field, bringing with them new stereotypes and assumptions about the disabled community. For example, where once amputees faced life-altering changes in their mobility, new bionic limbs offer these people new hope of returning to a life they may have feared lost forever. Such advances are at the center of a debate as to whether athletes with bionic limbs should be able to compete in the Olympics. It is feared, in this instance that such technology will allow amputee athletes to surpass their non-amputee competition.

These advancements have also begun to impact the lives of persons living with congenital defects. Artificial bladders have been grown in laboratories and successfully transplanted into humans with defective bladders. New surgical procedures are on the horizon that will allow doctors to re-route severed nerve connections, also making bladder function possible for those who never had it before, such as those born with spina bifida.

Those born with spinal cord injuries, such as spina bifida, as well as those with some acquired conditions, now have hope of living a normal life. However, there is evidence to suggest that some people with such conditions, if offered a cure that would take away their medical conditions would refuse. Hahn and Belt (2004) for example, point to members of the deaf community, "who fear that striving to rid themselves of their disabilities might result in the loss of valuable assets including sign language and deaf culture" (p. 453).

While it may be hard for the non-disabled world to fathom, along with the disabled rights movement has come an acceptance of one's disability and an incorporation of that disability into one's identity (Hahn & Belt, 2004, p. 453). For many, taking away their disability may be tantamount to taking away their gender or sexual orientation. Yet, on the other hand, there are also many chronically ill and disabled people who, if given the opportunity, would gladly be rid of their illness.

Researchers and others in the medical field are no doubt eager to uncover further advances and to help untold numbers of chronically ill and disabled persons live a more normal life. However, while these men and women may see their advances in a purely positive light, they may neglect to take into account the negative effect that these advances may have on a person whose illness or disability is an importance piece of his or her identity. Failing to take this into account, doctors and other professionals may push treatments or procedures on a person without preparing that person for the emotional or psychological impact they might have. They may also discount the viewpoint of a patient who states that he or she does not want such measures to be taken, continuing to push for a procedure that the doctor believes can only improve the patient's quality of life.

Purpose of the Study

The purpose of this study was to attempt to discern whether or not relationships exist between type and severity of ones disability and ones desire for a cure. This study focused on the association made by researchers such as Hahn and Belt (2004), that "individuals with stronger positive affirmation of personal identity as being disabled are more likely to reject a cure" (p. 460). The question this paper addressed is whether or not the type of disability a person has and the severity of it affects his or her identity, and ultimately, acceptance or rejection of a cure.

Questions surrounding what motivates some in the disabled community to actively pursue a cure for their illness, while others are seemingly content with their current situation, have been a concern of this author, as well as others in the disabled community and researchers such as Hahn and Belt (2004). It is imperative for those working with the disabled, social workers and doctors alike, as well as the broader society, to understand that the decision to accept treatment by a disabled or chronically ill person is a personal decision, one that must be accepted and respected by those around the disabled or chronically ill person.

The population sampled for this study was California State University San Bernardino students, who utilized Services to Students with Disabilities (SSD) office services. The study was quantitative, in order to identify correlations between disability type, perceived severity and acceptance or rejection of a cure. Questions regarding integration of disability into one's personal identity were based on questions from the Hahn and Belt (2004) study. Additionally, this study drew from Belgrave's (1991) study, which found that, compared to other demographic and psychosocial factors examined "the perception of disability was the strongest contributor to adjustment to disability" (p. 39), and utilized the Illness Intrusiveness Rating Scale, which Devins et al. (2001) assert has uncovered "substantive differences in the relative intrusiveness of each diagnosis" (p. 1102) for the measure of perceived severity.

Significance of the Project for Social Work

Social workers practice in a wide variety of venues, interacting with professionals from numerous disciplines, including the medical field. While doctors and researchers focus on the physical and biological functioning of a human being, it is social workers that focus on the mental and emotional aspects. As such, it is crucial that social workers uncover factors that contribute to a disabled or chronically ill person's decision to accept or reject treatments or procedures that may improve or cure their conditions.

Understanding the interaction between the type of disability one has, its severity and desire to be cured, will help social workers account for a variety views held among people with differing disabilities. This knowledge will assist social workers in planning and implementing their interventions in an informed and more culturally competent manner, sensitive to not only the differences between the genders and different ethnic groups, but to differences between groups with varying diagnoses and to differences in individual perceptions of severity as well. Additionally, an understanding of the importance of a person's disability in the formation of their identity and the decision to accept or reject a cure will help social workers advocate on behalf of disabled clients, both in healthcare settings, and in the community as well, where stereotypes and misconceptions run rampant.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will explore the relevant literature regarding persons with disabilities. It will specifically look at the formation of the disabled identity and the implications type and severity of disability have for various aspects of the disabled person's life. Additionally, this chapter will investigate the various aspects of disability that may impact a disabled person's desire for a cure.

Disability And Society

Advancements in medicine and technology have drastically impacted the disabled community. Disability has been on the decline in the United States, with "6.2% of American's age five and over living with one disability as in 2007, down from 6.9% in 2005" (United States Census Bureau, 2006). Yet, while the numbers of disabled are shrinking, there are those for whom treatment and a cure is not a choice. It is this reality, that the disabled community is still very much a part of American society today, which creates an urgency to undo the negative stereotypes of the disabled that have persisted throughout history.

Vash (1981) states that the disabled have experienced alternating periods of visibility and invisibility throughout history (p. 11). One constant, however, has been the disabled person's status as second-class citizen (Vash, 1981, p. 11).

Early in America's history, "manufacturing of goods and materials was carried out in an individual's home, and products were bought and sold on a small scale in local markets" (Swain, Finkelstein, French, & Oliver, 1993, p. 12). Swain et al. conjecture that during this simpler time, it may have been easier for people with disabilities to adapt to their environment and find a niche within it (Swain et al., 1993, p. 12). The industrial revolution, however, led to these same jobs being done by machines designed to be operated by the average individual, leaving no room for those who deviated from the norm (Swain et al., 1993, p. 12). Massive unemployment of disabled people followed, along with questions regarding who would take care of these people (Swain et al., 1993, p. 12). This led to the division of the poor into two groups, "the deserving, those who could not work through no fault of their own and deserved assistance and the undeserving, those regarded as lazy" (Swain et al., 1993, p. 12). Doctors were charged with determining disability status and later with developing treatments and cures that would make them "normal" productive citizens (Swain et al., 1993, p. 13). Those who could not be cured, were housed in alms houses and institutions (Swain et al., 1993, p. 12). Thus began the division between the disabled and non-disabled, the negative stereotypes and the assumptions that all disabled people want cures for their disabilities rather than face what must be a tragic existence.

The disability rights movement, which began to evolve in the 1970's along with other civil rights movements, has led to increased visibility of the disabled in American society (Hahn & Belt, 2004). While this increased visibility has decreased oppression experienced by people with disabilities, they are often still devalued, "seen as inferior, not very capable, not very useful, possibly burdensome [and] unaesthetic" (Vash, 1981, p. xvii). It is this attitude, which leads many in society to believe that disabled people "want improvements in their functional abilities, or complete cures" (Hahn & Belt, 2004). It is important that people, especially those in the medical field, who develop and implement cures for various disabilities, are aware of their able-bodied biases and understand the varying views of disability cures.

Identity and Attitudes towards a Cure

Identity formation is something with which everyone must struggle. Most, Wiesel, and Blitzer (2007), state that this occurs "through interactions with others" (p. 68). With each interaction one adopts a different role, from child, to student to adult, and it is from each of these social roles that a person's identity emerges. Having a disability, or becoming disabled, adds another layer to the identity formation process, one more thing that a person will either accept and integrate into his or her identity, or reject and separate from his or her identity.

The integration of one's disability into his or her identity has been shown to impact the disabled person in numerous ways. Several studies have examined the impact of violently acquired spinal cord injuries in men of color (Hernandez, 2005; Ostrander, 2008). Ostrander

(2008), found that the disability for the most part had a negative effect on the men's lives, "violat[ing] social understandings of what it means to be a man in their environmental context" (p. 82).

In contrast, an earlier study by Hernandez (2005) found that while the men of color surveyed "felt like less of a man since their injury," they also viewed it as a positive, life changing experience (Hernandez, 2005, p. 130). Hernandez investigated how men of color fit into the four types of integration at the heart of Gill's (1997) model of identity development (Hernandez, 2005, p. 118). These types include "integrating into society...integrating with the disability community...internally integrating one's similarities and differences with others [and] integrating how one feels with how one presents oneself" (Hernandez, 2005, p. 119). Hernandez's (2005) study found that the men did show signs of integrating into one's society, which "reflects an assertion that one has the right to be included in all aspects of mainstream culture" and integrating with the disabled community, which "highlights the comfort and enjoyment felt by people with disabilities when they associate with disabled peers" (p. 118).

Ostrander points to a key distinction between those surveyed by Hernandez and by himself in order to explain the differing conclusions. Those men surveyed in Hernandez's study were taking part in a peer-mentoring program, while those in Ostrander's study were not part of such a group (Ostrander, 2008, p. 81). The main limitation of both studies is that, while the qualitative nature of the studies provides in depth knowledge about the men's experiences, it is difficult to generalize the studies' findings (Hernandez, 2005, p. 131).

O'Connor, Young, and Saul's (2004) findings fall somewhere in between those of Hernandez (2005) and Ostrander (2008). The researchers interviewed both paraplegic men and women about their experiences (O'Connor et al., 2004). Many of the participants identified themselves according to their disability, "using medical terms and jargon," however they also made it clear that they want to be seen as more than just a diagnosis (O'Connor et al., 2004, p. 210). Hope was identified by all of the participants as having helped them through the initial shock of their diagnosis and most said that, they dealt with feeling different from others by identifying with people like themselves (O'Connor et al., 2004, p. 212).

A study by Hahn and Belt (2004) investigated the assumption that many people with disabilities would take a cure to their disability if given the chance. Basing their study on previous findings that "group identity is associated with participation in other social and political movements," (Hahn & Belt, 2004, p. 455), the researchers surveyed members of the disability activism group, American Disabled for Accessible Public Transit/American Disabled for Attendant Programs Today (ADAPT), measuring the "degree to which disabled respondents would want to be cured" as well as the degree to which the disability was a part of the person's identity (Hahn & Belt, 2004, p. 455). The findings showed that the more positively the disabled person identified with his or her disability, the less likely he or she was to want a cure for it (Hahn & Belt, 2004, p. 460). However, Hahn and Belt admit that there are limitations in the generizability of their findings (Hahn & Belt, 2004, p. 460). The sample subjects in this study were all members of a disabled activism group, thus it is unknown whether the same conclusions would be reached in a survey of the general disabled population (Hahn & Belt, 2004, p. 461). Furthermore, the majority or those surveyed in this study (80.1%), were white, thus the conclusions reached cannot be generalized to other ethnic groups (Hahn & Belt, 2004, p. 455).

Yet, while there are several limitations in this study, its results are worth further investigation in order to be able to generalize to other populations. The study also poses additional questions for future study, including whether the perceived risk of living with a particular illness influences a desire for a cure and whether the severity of a persons illness influences their desire for a cure, the focus of this study (Hahn & Belt, 2004, p. 462).

Most et al. (2007) investigated identity and attitudes towards cochlear implants in deaf and hard of hearing adolescents (p. 68). While the study found that many of the adolescents "held mostly positive attitudes towards cochlear implants," it also revealed a negative correlation between deaf identity and attitudes towards cochlear implants, meaning that a "stronger deaf identity was associated with more negative attitudes towards cochlear implants" (Most et al., 2007, p. 79). This agrees with the earlier findings of Hahn and Belt (2004), supporting the idea that people with disabilities who more strongly identify with their disability are less likely to want a cure for it. Like the Hahn and Belt (2004) study, Most et al., (2007) did not address diversity issues, a major limitation.

Disability Type

Studies of the disabled community reveal that the type of disability one lives with has numerous implications for the person. For example, Antonak and Livneh (1995) reviewed literature relevant to the "psychological adaptation to disability among persons with multiple sclerosis" (p. 1099). Their review of previous literature included a discussion of "phase theories of adjustment" (Antonak & Livneh, 1995, p. 1099). These theories state that the disabled person goes through the phases of "shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement and final adjustment" (Antonak & Livneh, 1995, p. 1099). The research has found that the type of disability a person has, effects how the person transitions through these stages (Antonak & Livneh, 1995, p. 1099).

The shock phase is differs greatly depending on a persons disability (Antonak & Livneh, 1995, p. 1100). The research shows that while persons with sudden traumatic injuries experience short bursts of shock, someone with a threatening condition may experience prolonged periods of less intense shock and someone with a gradually deteriorating disease may not experience shock at all (Antonak & Livneh, 1995, p. 1100). The differences in experience continue through all of the phases and thus result in differences in adjustment depending on the condition a person experiences (Antonak & Livneh, 1995, p. 1100). For example, in a person with a chronic illness, the adjustment involves facing the possibility of death, depending on the illness, whereas a person who experiences a traumatic injury must adjust to permanent changes in functioning in many areas (Antonak & Livneh, 1995, p. 1100).

In contrast to Antonak and Livneh's (1995) findings, Hicken, Putzke, Novack, Sherer, and Richards (2002) explored life satisfaction of people with spinal cord injuries and traumatic brain injuries. The researchers found that when they compared persons with similar functional ability, there was no difference in life satisfaction between the group with spinal cord injuries and the group with traumatic brain injury (Hicken et al., 2002, p. 364). The researchers point to several limitations of their study that may have impacted the results. First, the "samples were taken from only two sites, both in the southeast United States" (Hicken et al., 2002, p. 364). This, along with the fact that all of the participants were only one-year post-injury, makes generalization of the results difficult.

Research has shown that the type of disability one has impacts more than just the person's adjustment to the disability. Yanchak, Lease, and Strauser (2005) compared career development in people with cognitive and physical disabilities. Their research was based on evidence that people with disabilities "are more susceptible to vocational identity and career decision-making problems" than non-disabled people (Yancheck et al., 2005, p. 130). The study in fact showed that there are "significant differences" (Yancheck et al., 2005, p. 134) between the two groups, and that people with cognitive disabilities "have more dysfunctional career thoughts than individuals with physical impairments" (Yancheck et al., 2005, p. 134). Limitations of this study include the fact that "the sample consisted of individuals with a diagnosable physical or cognitive impairment who obtained services from a state vocational rehabilitation agency" (Yancheck et al., 2005, p. 136). This means that those surveyed in this study may have more severe disabilities than those not receiving such services (Yancheck et al., 2005, p. 136). Another limitation was that the study was "self-report, and subject to bias" (Yancheck et al., 2005, p. 136). However, the study does illustrate that the type of disability one has does affect numerous areas of the person's life.

Disability type has not only been shown to impact the disabled person, but the person's family as well (Pelchat, Richard, Bouchard, Perreault, Saucier, Berthiaume, & Bisson, 1998). Pelchat et al. (1998) studied how the type of disability an infant has impacts the parents' adjustment to the infant (p. 377). When examining parental adaptation, previous research has emphasized the importance of the type of disability, because the unique characteristics of each disability "are believed to define the stressful situation, before the families' resources and coping strategies can be gathered to adapt to it" (Pelchat et al., 1998, p. 378). Pelchat et al studied parents of children with congenital heart disease, Down's syndrome, and cleft lip or palate, and compared their adaptation to parents of children without a disability. The results showed that "parents of children with disabilities rated higher parental-stress appraisal and psychological distress than parents of non-disabled children" (Pelchat et al., 1998, p. 388). Furthermore, "parents of children with Down's syndrome and congenital heart disease scored higher in these areas than the parents of children with cleft palate" (Pelchat et al., 1998, p. 388). Additionally, the study showed that parents of children with Down's syndrome and congenital heart disease "reported more difficulties accepting their child's disability" and "felt more threatened by their disability" than the other parents (Pelchat et al., 1998, p. 388). As with many of the other studies cited here, this study has some limitations. The study was conducted in Montreal and Quebec, Canada, so the results cannot be generalized to families in the United States (Pelchat et al., 1998, p. 388). Also, the researchers state that because of the sample size, they were unable to "perform analysis that would have controlled for variables such as parents' age, which could affect the results" (Pelchat et al., 1998, p. 388). Nevertheless, the results are important, because they shed light on the fact that the type of disability one may have has implications not only for the disabled person, but for the family as well.

Disability Severity

Along with the type of disability one has, the severity of that disability also has implications for the person. Hicken et al. (2002), explored the life satisfaction of persons with spinal cord injury and traumatic brain injury. In addition to examining the differences between the two groups, the researchers also explored the differences within the groups (Hicken et al., 2002). It was discovered that while the severity of the disability had little impact on life satisfaction for the people with spinal cord injuries, it was "a more consistent predictor of life satisfaction among persons with traumatic brain injuries" (Hicken et al., 2002).

Similarly, Uppal (2006) studied the "impact of the severity of one's disability on his or her subjective well-being" (Uppal, 2006, p. 525). Uppal states that "subjective well-being is defined as either life-satisfaction or happiness" (Uppal, 2006, p. 525). For his study, Uppal used data from the 1991 Health and Activity Limitation Survey (HALS), a survey which included, "persons with a physical, sensory, or psychological disability" (Uppal, 2006, p. 528). Uppal found that "about 24% of those with mild disabilities, 19% of moderately disabled and 12% of the individuals with severe disabilities, reported being very happy" (Uppal, 2006, p. 528). Additionally, "eight percent of those with mild disabilities, 17% of those with moderate disabilities and 23% of those with severe disabilities reported being 'not too happy'" (Uppal, 2006, p. 528). Thus, Uppal's findings suggest that the greater the severity of a person's disability, the less likely they are to report being very happy (Uppal, 2006, p. 528). As with Hicken's work, the primary limitation in Uppal's (2006) study is generalizability. The data used was from a survey of disabled Canadians, so the results cannot be generalized to disabled persons in the United States. However, these findings do lend support to those of

Hicken, that the severity of one's disability impacts their life satisfaction.

Severity of one's disability has not only been shown to impact life satisfaction, but adjustment to disability as well. While Jopsen et al. (2003) investigated adjustment in Australians with multiple sclerosis, including those of European, Maori and Asian descent, Belgrave (1991), examined adjustment in African Americans with a variety of disabilities. Both studies revealed that a person's perception of the severity of their disability had an impact on their adjustment. In the case of Belgrave's study, when perception of severity was compared with the person's self esteem and social support as predictors of adjustment "perception of disability was the strongest predictor accounting for 25% of the variance in explaining adjustment to disability" (Belgrave, 1991, p. 39). Jopsen et al. (2003) also found that " illness severity accounted for the majority of the variance in physical and role dysfunction" (Jopsen et al, 2003, p. 503). The significant limitation of both of these studies is their lack of generalizability. However, they are helpful in identifying one possible consequence of the severity of a person's disability that is remarkable and worth further investigation.

Theories Guiding Conceptualization

This chapter contains a discussion of the changing roles of people with disabilities throughout our society's history, however, a discussion of specific theories and conceptualizations related to disabilities is needed to fully understand the issue of ablism and how disability identity is formed. One such theory is person-in- environment. This framework sees the relationship between a person and his or her environment as a reciprocal one: "each influences the other over time, through exchanges" (Payne, 2005 p. 150). Germain and Gitterman's life model is based on the person in environment theory and says that each person's life has its own unique "life stressors, transitions, events and issues that disturb their fit with the environment" (Payne, 2005, p. 150). The model states that each person has their own resources to deal with life stressors, such as "relatedness, the ability to form attachments and self concept, one's overall evaluation of themselves" (Payne, 2005, p. 150). Person- in- environment and related theories and models have traditionally been used to describe a person's social environment, however Saleeby suggests that "such a focus ignores the impact of the person's own body in such interactions" (Payne, 2005, p. 150; Saleebey, 1992, p. 112).

One study, conducted by Coulton (1979), did in fact examine the person-environment fit as it relates to those with chronic illnesses and disabilities. Coulton found that many of her study participants "lacked social and emotional support," that those who had become disabled later in life had "difficulties performing their roles as they had before their illness" and "lacked opportunities for activities" (Coulton, 1979, p. 11-12). Additionally, many participants noted a "discrepancy between their financial resources and demands" and "between their physical environment and their ability to navigate it" (Coulton, 1979, p. 14).

Coulton's study sheds light on dimensions of environment that are important when examining the person-environment fit of the disabled and chronically ill (Coulton, 1979). However, because it focuses on those with acquired illnesses such as diabetes and arthritis, it does not capture the full spectrum of experiences that would include those of persons with congenital disabilities. Additionally, Coulton does not isolate the severity of one's illness as a variable, thus it is unknown whether this study addressed a full range of experiences from the mildly disabled to the severely disabled.

Viewing Hahn and Belt's (2004) study through the person-in-environment perspective for example, a person's disability could be seen as a life stressor. The researchers found that their subjects developed an identity that incorporated their disability and person in environment and the life model would say that the subjects did so as a way to cope (Hahn and Belt, 2004). Thus, it might be said that those who identified more with their disability were less likely to accept a cure for it because they are better able to cope with it than those who would accept a cure. Continuing this line of thought within the context of this study, the severity of one's illness appears to be one factor that contributed to whether persons with disabilities use such resources as embracing their disability as part of their identity (Payne, 2005).

However, an analysis of the impact of the severity of one's illness on their desire for a cure should also be viewed in context of the type of disability. The life experiences of those who are profoundly deaf for example, vastly differ from the experiences of those who become paralyzed later in life, shaping their environments and possibly their acceptance of their disability and ultimately their desire for a cure.

While person-in-environment is one theory that guides this study, there are others in need of further consideration. One such theory is role theory. This theory deals with "our interactions with others and how their expectations and reactions cause us to respond in characteristic ways" (Payne, 2005, p. 168). Viewed through the lens of this theory, a disabled or chronically ill person's acceptance of their disability and lack of desire for a cure, could be explained by the fact some disabled people, especially those born with their disabilities, have been socialized, through interactions, to take on the disabled role and thus might be reluctant to give it up for a cure (Payne, 2005). Conversely, a person who acquires their disability later in life may then be less accepting of their disabled role, as it may conflict with roles they held before they became disabled, such as star athlete. This being the case, such a person might then be more likely to accept a cure for their illness.

The social model of disability shifts the focus of a person's disability away from the person and onto society (Crow, 1996). This model sees the level of disablement that a person with any impairment experiences as "a product of how well the society he or she lives in accommodates the individual", not a "product of how impaired the person is or how well the person fits his or her environment" (Crow, 1996, p. 55). Examined through this framework, those surveyed in Hahn and Belt's (2004) study may have been less likely to accept a cure because they were disabled activists who had over time, acquired methods of achieving the societal change needed to remove the societal barriers that may have impacted their participation in society. Furthermore, variability's in desire for a cure in this study may have been impacted by the societal barriers faced by the individual and their ability to and success in advocating for the removal of those barriers.

Summary

This chapter first placed the current research focus, disabled persons' desire for a cure, in a historical context. It then delved into previous research relating to disability identity and desire for a cure and the impact of type and severity of disability for the disabled person. While the literature provides useful information in terms of the implications of disability type and severity, there is a gap in terms of a connection between type, severity and desire for a cure. More research needs to be conducted in order to discover whether there is such a connection. Additionally, much of the literature appears to lack generalizability. Thus, further research is needed in order to determine the extent to which the current research is generalizable.

CHAPTER THREE

METHODS

Introduction

This chapter details the steps that were followed throughout the research process. The chapter also explains how the confidentiality of participants was protected and how the data was analyzed.

Study Design

This study was designed to explore whether type and severity of one's disability are correlated with a disabled person's desire for a cure. The researcher surveyed disabled students at California State University San Bernardino about perception of their disability, its severity and intrusiveness, the extent to which their disability is integrated into their identity and their desire for a cure.

The data was collected and analyzed using a quantitative survey, consisting of questions from previous studies that while they examined either type of disability, severity of disability or desire for a cure, did not attempt to integrate the three variables. The question regarding perceived severity of disability was taken from a study of psychosocial predictors of disability adjustment, by Belgrave (1991). The reliability and validity of this question are unknown. Questions about disability intrusiveness came from a study of lifestyle interruptions caused by illness, conducted by Devins et al. (2001). When analyzing the reliability of this measure, the researchers found that "coefficients consistently exceeded 0.80," display[ing] high internal consistency with few exceptions" (Devins et al., 2001, p. 1101). Finally, questions relating to disability identity were taken from Hahn and Belt's 2004 study, "based upon an adaptation of concepts of ethnic identity developed by Phinney (1990) and upon indexes of collective and individual self-esteem created by Major, Sciaccitano, and Crocker (1993)," which the researchers combined to create an eight question instrument measuring personal identity instrument (Hahn & Belt, 2004, p. 456). The researchers found that the questions could be divided into two personal identity factors (Hahn & Belt, 2004, p. 458). Questions 1 through 4 measured "affirmation of disability", while questions 5 through 8 measured "denial of disability" (Hahn & Belt, 2004). The overall study cannot be determined because it combines questions from the previously mentioned studies to create a new, previously untested, instrument.

The strength of this survey is that it allowed the researcher to assess correlations between variables, such as disability type and desire for a cure. Also, while the survey was somewhat lengthy, it was easy to understand. Limitations included the quantitative nature of the survey, which did not allow the researcher to ask follow-up questions of the participants and seek more in-depth understanding. For example, the researcher did not have the opportunity to ask participants in what ways their disability impacts such things as their health and financial situation.

Sampling

The sample for this study consisted 57 disabled college students at California State University San Bernardino. Disabled students were chosen because only the disabled can provide insight into personal perceptions of disability and desire for a cure. Furthermore, students were chosen because the researcher attends California State University San Bernardino, and thus was easily able gain access to this particular population. An additional reason for choosing to conduct this study at California State University San Bernardino is that the school draws a diverse student population.

The participants in this study were receiving services currently from California State University San Bernardino's Services to Students with Disabilities office. This office helps disabled students receive appropriate accommodations, (testing, note taking, mobility, etc.) which allow the students to participate fully in the academic experience. The office is located in University Hall at California State University San Bernardino. It is within this office that students were recruited. The participants varied in age, all being over the age of 18. The director of this office was contacted and asked if students could be surveyed and the director granted the researcher access to the students.

Data Collection and Instruments

The survey (Appendix A) the disabled students completed consisted of questions regarding demographics, disability background, illness intrusiveness, and disability identity. Demographics included asking participants their age, sex, ethnicity, and marital status.

Disability background information included the age at which the person became disabled and the category(ies) of disability they have, either physical, learning/ intellectual, emotional, psychological, visual, auditory or other and to name their disability(ies) which are nominal. Additionally, participants were asked how severe they think their disability is, either very severe, severe, somewhat severe or not at all severe.

The third section of the survey measured the intrusiveness of one's illness by asking participants to rate how much their illness interferes with various aspects of their life. Categories included health, diet and recreation and the participant was asked to rate the intrusiveness on a scale of 1, or not very much, to 7, or very much. The number scores for each item on this scale were summed to create an interval scale.

The final section of the survey asked questions regarding how positively or negatively the participant identifies with his or her identity. Questions asked participants to rate how strongly they agree or disagree with several statements regarding having a disability, such as "In general, I am glad to be a person with a disability," (Hahn & Belt, 2004). Disability identity questions were divided into two separate scales, with the ratings on items one through four added to create an interval score representing disability "affirmation" and the ratings on questions five through eight added to create an interval score representing disability "denial", the positive and negative aspects of disability identity (Hahn & Belt, 2004).

Procedures

Participants were recruited through advertisement in the Services to Students with Disabilities (SSD) office. This advertisement directed students to the surveygizmo.com website, where the survey was posted to be completed on-line. Additionally, the director of SSD sent this advertisement to its students through its Listserv. Furthermore, the researcher left several copies of the survey in the SSD office where students completed them and returned them to a designated SSD staff member.

Since a large number of disabled students filter in and out of the SSD office at various times, and because the office would not grant the researcher access to contact information for its students, availability sampling was appropriate. Posting information for the on-line version of the survey took no more than 10 to 15 minutes.

Students who participated in the survey were asked to bring their debriefing statement to the Services to Students with Disabilities office. There, each student who participated in the study received a raffle ticket on which they will wrote their name and email address. Raffle tickets were kept separately from surveys to ensure the anonymity of each participant's answers. At the end of the survey period, four tickets were drawn and those people were contacted by email and asked to go to the SSD office to receive a $25 Starbucks gift card.

Protection of Human Subjects

Prior to beginning the survey, students filled out consent forms (Appendix B). The consent form explained the survey and its purpose. By signing the form, the student was stating that he or she understood the survey, and the fact that they could withdraw from the survey at any time. The consent form also explained that the students' confidentiality would be protected, meaning that their name and other identifying information would not be shared with others. At the end of the survey, students were given a debriefing statement (Appendix C), thanking them for their participation and advising them of where the results of the study could be located.

Data Analysis

As previously stated, quantitative analysis was used to determine whether correlations exist between the type and severity of one's disability and their desire for a cure. Univariate analysis was used, as well as bivariate analysis to examine differences between different demographic groups in regard to disability identity and cure seeking.

First the researcher ran the descriptive statistics, finding frequencies, means, medians, and standard deviations. Next, Pearson's correlations were run to look at correlations between perceived severity and desire for a cure and the disability intrusiveness score and desire for a cure. This testing was also used to examine correlations between other pairs of interval data, such as scores on the identity, severity or cure scales. Finally, t-tests were run to explore correlations between type of disability and desire for a cure, as well as to determine whether correlations existed between other interval variables, and two category nominal variables, such as gender.

Summary

Chapter three explained the design, sampling, data collection, the survey and procedures to be followed. The informed consent to be provided was discussed, as was data analysis.

CHAPTER FOUR

RESULTS

Introduction

This chapter begins by describing the sample demographics. Additionally, the chapter addresses the study frequencies and percentages, as well a presents the results of t-test and Pearson correlation analysis of the variables.

Demographic Information of Participants

Following are the quantitative outcomes of this study in table format. This is a brief overview and the findings from this study will be discussed in greater detail in Chapter Five. This study asked whether the type or severity of ones disability affects their desire for a cure for it.

The first table contains demographic information, including gender, marital status and ethnic background. The next table addresses the participants' current age and age at which they first became disabled.

The study consisted of 57 participants all of whom were students at California State University San Bernardino, and were receiving services through the

Services to Students with Disabilities office at the time of the study. Of the respondents, 38.6% were male and 61.4% were female.

A large number of participants, 43.9%, stated that the have never been married. Following closely behind were those who are currently married, with 38.6%. Next were those who were divorced, 14.0%, followed by those who were widowed and those who were separated, each with 1.8%.

The largest percentage of participants, 34%, identified themselves as white or Caucasian. Other ethnic groups were not as well represented, with nine participants checking off that they were of Latino decent, eight African-Americans and six chose other. Surprisingly, no one of Asian decent participated in this study.

Table 1. Demographic Characteristics

Variable	Frequency (N)	Percentage (%)
Gender (N = 57)		
Females	35	61.4%
Males	22	38.6%
Marital Status (N = 57)		
Never Married	25	43.9%
Married	22	38.6%
Divorced	8	14.0%
Separated	1	1.8%
What is your ethnic background? (N = 57)		
White/ Caucasian	34	59.6%
Latino	9	15.8%
African- American	8	14.0%
Other	6	10.5%

Participants ranged in age from 19 years old, to 64 years old. The mean age was 39.32 and the median was 39.00. The standard deviation was 11.945. The question regarding age at which the participants became disabled was answered by 54 people. The age ranged from birth to 53 years old. The mean was 20 years old and median was 20.5. The standard deviation was 16.207.

Table 2. Age and Age When First Disabled

Variable	Frequency N	Min	Max	Mean	Median	Std. Deviation
Age	57	19	64	39.32	39.00	11.945
Age First Disabled	54	0	53	20.00	20.5	16.27

The survey asked participants to circle which categories of disabilities they identified themselves as having, giving them the opportunity to check off or circle several categories. All 57 participants answered this question. The largest percentage of participants, 61.4%, stated that they had a physical disability. The next highest percentage of students were those with a learning or intellectual disability, 38.6%, followed by, psychological disability, 28.1%, emotional disability, 21.1%, visual disability, 10.5% and auditory, 7.0%. Additionally, 12.3% stated that they had some other category of disability not previously mentioned.

Table 3. Disability Type

Variable	Frequency (N)	Percentage (%)
Disability Type		
Physical	35	61.4%
Learning/Intellectual	22	38.6%
Psychological	16	28.1%
Emotional	12	21.1%
Other	7	12.3%
Visual	6	10.5%
Auditory	4	7.0%

Disability Severity

Next, participants were asked to rate how severe they believe their disability or disabilities to be, either not at all severe, somewhat severe, severe or very severe. Few responded in either extreme, with eight people stating that they perceive their disability as not at all severe, and only three stating that they perceive their disability to be very severe. The responses were almost evenly split between somewhat severe, with 25 responses, and severe, with 21 responses.

Table 4. Perceived Disability Severity

Variable	Frequency (N)	Percentage (%)
Severity	57	100.0%
Not at all severe	8	14.0%
Somewhat severe	25	43.9%
Severe	21	36.8%
Very severe	3	5.3%

After rating the perceived severity of their disability, participants were asked to rate how much their illness interferes with several different areas of their lives, from one or not very much, to seven, or very much. The scores for these twelve items were then added to create an overall disability intrusiveness score, with higher scores indicating greater intrusiveness. The lowest score was 12 and the highest score was 76. The mean score was 44.91 and the standard deviation was 17.587.

Table 5. Disability Intrusiveness

Variable	Frequency N	Min	Max	Mean	Median	Std. Deviation
Disability Intrusiveness Score	57	12	76	44.91	46.00	17.587

Disability Identity

Part four of the survey consisted of statements that reflect opinions about having a disability, with the first four questions representing positive feelings about disability and the next four question representing negative feelings. The participants were asked to rate how strongly they agreed with each statement, with one being strongly disagreed and 7 being strongly agree. The scores on the individual items were then added together to give an interval score. The higher the score on the "affirmation scale", the more positively the participant identifies with his or her disability; the higher the score on the "denial scale", the weaker the identification (Hahn & Belt, 2004, p. 458). The lowest score on the "affirmation scale" was 4, while the highest was 28. The mean score was 14.75 and the standard deviation was 5.488. The lowest score on the "denial of disability scale" was 4, while the highest was 28 (Hahn & Belt, 2004, p. 458). The mean score was 16.93 and the standard deviation was 6.886.

Table 6. Disability Identity

Variable	Frequency N	Min	Max	Mean	Median	Std. Deviation
Affirmation Of Disability	57	4	28	14.75	14.00	5.488
Denial of Disability	57	4	28	16.93	18.00	6.886

Desire for a Cure

Finally, participants were asked to rate how strongly they agreed with the statement "Even if I could take a magic pill, I would not want my disability to be cured," from one, or strongly disagree, to seven, or strongly agree (Hahn and Belt, 2004, p. 459). The highest percentage, 66.7%, stated that they strongly disagreed with the statement, 1.8% somewhat disagreed, and 5.3% somewhat disagreed meaning that might take a cure if one were available. Ten and a half percent of respondents were in the middle, while 1.8% agreed with the statement, 3.5% somewhat agreed and 10.5% strongly agreed, meaning that they may be less likely to take a cure if one was available.

Table 7. Desire For a Cure

Variable	Frequency (N)	Percentage (%)
Desire for a cure	57	100.0%
1 (Strongly Disagree)	38	66.7%
2	1	1.8%
3	3	5.3%
4	6	10.5%
5	1	1.8%
6	2	3.5%
7 (Strongly Agree)	6	10.5%

Bivariate Results

This study sought to determine whether the type or severity of one's illness is related to his or her desire for a cure. The researcher first utilized Pearson's correlation to determine whether a relationship exists between severity and desire for a cure. There was found to be a significant negative correlation of -.287 between perceived severity and the positive component of disability identity, "disability affirmation", with a significance (two-tailed) of .031, and a positive, yet not significant, correlation between perceived severity and the negative component of disability identity, "denial", 0.297, with a significance (two- tailed), of .26 (Hahn & Belt, 2004, p. 458). Perceived severity was found not to be significantly corralled to desire for a cure. Similarly, participant's disability intrusiveness scores were found to negatively correlate with "disability affirmation", (-.451, 2 - tailed with a significance of 0.57), and positively correlate with "denial", (0.561, two-tailed with a significance of .000) (Hahn & Belt, 2004, p. 458). As with perceived severity, the disability intrusiveness score was found not to significantly correlate with desire for a cure (-.243, two-tailed with a .069 significance).

Table 8. Severity Correlations

Variable	Perceived Severity	Disability Intrusiveness Score
Affirmation		
Pearson's Correlation	-.287	-.451
Sig (2-Tailed)	.031	.000
N	57	57
Denial		
Pearson's Correlation	.297	.561
Sig (2-Tailed)	.026	.000
N	56	56
Desire for a Cure		
Pearson's Correlation	-.204	-.243
Sig (2-Tailed)	.128	.069
N	57	57

An independent- samples t-test was conducted to compare differences in desire for a cure between those who reported having a particular type of disability and those who did not. There was a significant difference in the desire for a cure score between those who reported having an emotional disability (M = 1.42, SD = .996) and those who did not (M = 2.56, SD = 2.272); t(55) = -2.563; p = .014 (two-tailed). However, when examining the scores for desire for a cure of those with other categories of disability, and comparing them to those who did not report having that category of disability, i.e. physical disability, no significant difference in scores was found.

Table 9. T-Test for Disability Type and Desire for a Cure

Variable Disability Type	Mean	Std. Deviation	t	p 2-Tailed
Emotional disability			-2.563	.014
Yes	1.42	.996		
No	2.56	2.272		
Physical disability			.248	.805
Yes	2.37	2.276		
No	2.23	1.875		
Auditory Disability			-.552	.583
Yes	1.75	1.500		
No	2.36	2.158		
Leaning/Intellectual Disability			-.121	.904
Yes	2.27	1.907		
No	2.34	2.261		
Psychological Disability			-.701	.486
Yes	2.00	1.897		
No	2.44	2.203		
Other			-1.911	.077
Yes	1.43	1.134		
No	2.44	2.196		

While the relationship between both type and severity of disability, and desire for a cure is unclear, there was found to be a relationship between both the participants' current age and the age at which they became disabled and desire for a cure. Using Pearson's correlation to examine these variables, there was found to be a negative correlation of -.298, with a significance of 0.025 (2-tailed), between the age at which the participant first became disabled, and the participant's desire for a cure. The participants' current age was also found to negatively correlate with desire for a cure, with a correlation of -0.388, with a significance of 0.003. Additionally, current age had a significant correlation with the disability intrusiveness score (0.313 with a significance of .018 at the 0.05 level) and "affirmation of disability" (-0.278 with a significance of 0.36) (Hahn & Belt, 2004, p. 458).

Table 10. Age and Age When First Disabled Correlations

Variable	Current Age	Age When First Disabled
Affirmation		
Pearson's Correlation	-.278	-.125
Sig (2-Tailed)	.036	.231
N	57	57
Denial		
Pearson's Correlation	.133	.163
Sig (2-Tailed)	.329	.231
N	56	56
Desire for a Cure		
Pearson's Correlation	-.388	-.298
Sig (2-Tailed)	.003	.025
N	57	57

Summary

In this chapter, results from both univariate and bivariate analysis of the variables were presented. Information from the survey was analyzed to reveal whether or not correlations exist between type and severity of disability and desire for a cure. Additionally, correlations between desire for a cure and other variables were examined and significant relationships were discussed in this chapter.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will include a discussion of the study, and conclusions reached through the statistical analysis of the independent and dependent variables. Additionally, the chapter explores the limitations of the study and makes recommendations for social work practice, policy and future research.

Discussion

This study was an extension of an earlier study, conducted by researchers Hahn and Belt (2004), in response to the "growing influence of the disability rights movement" (p. 453). The Hahn and Belt (2004) study, examined variables that correlate with desire for a cure, specifically in a group of disabled activists. At that time, the researchers found that how strongly the person positively identified with their disability was correlated with his or her desire for a cure (Hahn & Belt, 2004). Additionally, the study uncovered a correlation between age at which the participant became disabled and his or her "affirmation of disability," or positive disability identity (Hahn & Belt, 2004). The current study sought to generalize these findings to the broad disabled community, by surveying college students who may or may not be involved in disabled activism. It was also the intension of the researcher to explore questions posed by Hahn and Belt (2004) at the conclusion of their study, regarding whether or not a correlation exists between the type of disability one has and desire for a cure as well as the severity of that disability and desire for a cure.

In order to answer these questions, this study collected demographic information from the participants, including disability related information, such as the age at which the person became disabled and the category or categories of disability that the participants' identify themselves as having. Questions from the Hahn and Belt (2004) study regarding the positive and negative aspects of disability identity, as well as the question aimed at discerning whether participants would take a cure for their disability if one were available, were also utilized (Hahn and Belt, 2004). Additionally, questions from Devins et al. (2001) factor analysis of the "Disability Intrusiveness Rating Scale," were incorporated in order to quantify the severity of the participants' disabilities, as was a question posed in a study by Belgrave (1991), asking participants to rate how severe they believe their disability to be.

Research indicates that the type of disability one has, has numerous implications for the individual, from adjustment, to career choices (Yanchak, Lease, and Strauser, 2005, Antonak and Livneh, 1995). After conducting t-tests to explore desire for a cure among those who identified themselves as having a particular type of disability, such as a physical disability, compared to those who did not report having that particular category, only those identifying themselves as having emotional disability, were found to have significantly different scores compared to those who did not identify themselves as having an emotional disability. The fact that the mean score on the desire for a cure scale was lower for those who identified themselves as having an emotional disability than for those who did not identify themselves as having an emotional disability, suggests that persons with emotional disabilities may desire a cure for their disability more than those without emotional disabilities. When comparing desire for a cure among those with other categories of disability, with those who did not have those categories, there was little significant difference in desire for a cure. While the results are mixed, it points to the possibility that in some cases, disability type may be related to desire for a cure.

Previous studies have indicated that like type of disability, severity impacts numerous aspects of a person's life, from "subjective well-being, to adjustment to disability (Uppal, 2006 Jopsen et al., 2003, Belgrave, 1991). However, this study found no significant relationship between either the participants' perceived severity, or their score on the disability intrusiveness scale, and their desire for a cure. Still, both methods for rating disability severity were found to negatively correlate with positive "affirmation of disability" (perceived severity had a negative correlation of -.287, significance of .031, while the disability intrusiveness score had a negative correlation of -.451, significance of .000), and positively correlate with "denial of disability" (perceived severity had a positive correlation of .297, with a significance of .026, while the disability intrusiveness score had a positive correlation of .561, with a significance of .000) (Hahn & Belt, 2004, p. 458). This indicates that as the severity of one's illness increases, they identify less positively and increase negative feelings towards the disability.

While the findings of this study did not definitively support a correlation between either type or severity of disability and desire for a cure, there were some interesting findings worth noting. The mean age at which the participants first became disabled was 20 years old. This is important, because Vash (1981), states, "Self-concept may be influenced by whether a disability was present from birth or happened later to a previously 'normal' individual" (p. 9). The current study supports this assertion, because while there was not found to be a significant correlation between positive or negative aspects of disability identity and age at first disabled per se, the age at which participants first became disabled was found to have a negative correlation with desire for a cure (-.298, with a significance of .025). This means that the older the person was when first disabled, the less strongly the person agreed with the statement that they would not want a cure if one were available.

Vash also highlights the fact that individual characteristics play an important part of one's reaction to disability (Vash, 1981, p. 14). One such characteristic found to be important in this study was the current age of the participant. The mean age of participants was approximately 39 years old, and when a Person's test was run to examine the relationship between current age and desire for a cure, a significant correlation of was discovered, revealing that as the age of the participants went up, the less strongly they agreed with the statement that they would not want a cure if one was available. Thus it would appear that, many personal as well as disability related variables interplay to determine one's desire for a cure.

Limitations

One limitation of this study is the sample size. It was predicted that with access to the entire Services to Students with Disabilities population, the researcher would receive a greater number of responses, and thus the results of the statistical analysis could have greater statistical significance. However, while the researcher utilized both email notification as well as placing surveys in the office itself, participation was limited to 57 people. The origin of the sample was another limitation. The study sought to generalize and expand on the findings of the earlier study regarding desire for a cure among disabled activists, conducted by Hahn and Belt. While the disabled student population may better represent the general disabled population, it also misses large segments of the population, namely those whose disabilities prohibit them from attending a college or university. An additional limitation was that the survey allowed participants to identify whether they had a category other than the ones listed, however did not ask participants to specify what that category was, leaving the results of correlations between "other" disabilities and other variables unclear.

Recommendations for Social Work Practice, Policy and Research

Further research should focus on examining the personal characteristics that are collated with one's desire for a cure. Areas of focus might include the individuals "interests, values and goals" (Vash, 1981,

p. 15). This would best be done through a qualitative survey that would allow participants to explore the topic more in depth than was possible in the current study.

Additionally, research should concentrate on the awareness of social workers and other professionals that work with people with disabilities of the wide variety of opinions regarding desire for a cure. It is crucial that those who work people with disabilities be aware that these diverse opinions exist, in order to effectively advocate for clients. This is especially true within the context of complex medical structures, where clients are often left disimpowered.

Conclusions

This study reached several conclusions. First, it was discovered that for these participants, the more severe the disability is, the less positively they identify with their disability. In answer to the question of whether severity of one's disability is correlated with one's desire for a cure, however, the study found that this is not the case. Regarding a correlation between type of disability and desire for a cure, results were mixed, with only those with emotional disabilities scoring significantly differently on the desire for a cure question than those without emotional disabilities. However, this study did conclude that as both age and the age at which a person increase, desire a cure also increases.

APPENDIX A

QUESTIONNAIRE

Disability and Personal Identity

Part 1 **Demographic Information**

1. Current age_______

2. Sex
   Male
   Female

3. Ethnicity. Circle all that apply
   White
   Latino
   African-American
   Asian
   Other

4. Marital Status
   Married
   Never Married
   Divorced
   Widowed
   Separated

Part 2. **Disability Background Information**

1. At what age did you become disabled? ________

2. What category(ies) of disability do you have? Circle all that apply
   Physical
   Learning/ Intellectual
   Emotional
   Psychological
   Visual
   Auditory
   Other

3. What is/are the name(s) of your disability(ies)?____________________

4. In general, how severe do you think your disability is? (Belgrave, 1991)
   Not at all severe
   Somewhat severe
   Severe
   Very severe

Part 3. **Illness Intrusiveness Ratings Scale**

"The following items ask about how much your illness and/or its treatment interfere with different aspects of your life. Please circle the one number that best describes your current life situation. If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you. How much does your illness and/or its treatment interfere with your:" (Devins et al, 2001)

1. Health
   Not Very Much Very Much
   1 2 3 4 5 6 7
2. Diet (ie, the things you eat and drink)
   Not Very Much Very Much
   1 2 3 4 5 6 7
3. Work
   Not Very Much Very Much
   1 2 3 4 5 6 7 N/A
4. Active recreation (eg, sports)
   Not Very Much Very Much
   1 2 3 4 5 6 7
5. Passive recreation (eg, reading, listening to music)
   Not Very Much Very Much
   1 2 3 4 5 6 7
6. Financial situation
   Not Very Much Very Much
   1 2 3 4 5 6 7
7. Relationship with your spouse (girlfriend or boyfriend if not married)
   Not Very Much Very Much
   1 2 3 4 5 6 7 N/A
8. Sex life
   Not Very Much Very Much
   1 2 3 4 5 6 7 N/A
9. Family relationships
   Not Very Much Very Much
   1 2 3 4 5 6 7
10. Other social relationships
    Not Very Much Very Much
    1 2 3 4 5 6 7
11. Self-expression/self-improvement
    Not Very Much Very Much
    1 2 3 4 5 6 7
12. Religious expression
    Not Very Much Very Much
    1 2 3 4 5 6 7
13. Community and civic involvement
    Not Very Much Very Much
    1 2 3 4 5 6 7

Part 4. **Disability Identity**

"The following items ask about your opinions about having a disability. Please circle the one number that best describes your current life situation" (Hahn and Belt, 2004).

1. In general, I am glad to be a person with a disability

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

2. Being a person with a disability is an important reflection of me

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

3. I have a clear sense of what my disability means to me

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

4. I feel proud to be a person with a disability

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

5. My disability sometimes makes me feel ashamed

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

6. I do not feel good about being a person with a disability

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

7. I regret that I am a person with a disability

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

8. I do not have a sense of belonging to the disability community

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

Part 5. **Desire for a cure**

1. "Even if I could take a magic pill, I would not want my disability to be cured." (Hahn and Belt, 2004)

   Strongly disagree Strongly agree

   1 2 3 4 5 6 7

APPENDIX B

INFORMED CONSENT

Informed Consent

The study in which you are being asked to participate is designed to explore the effect of disability type and severity on personal identity and acceptance of a cure among disabled college students. The student researcher, Carley Butler, MSW student is conducting this study under the supervision of Dr. Rosemary McCaslin, Professor of Social Work at California State University San Bernardino (CSUSB). This study has been approved by the Department of Social Work Subcommittee of the Institutional Review Board, CSUSB.

In this study, you will be asked to answer questions about the effect of disability type and severity on personal identity and acceptance of a cure among disabled college students. This will be asked and completed during a survey process. This should take about 20 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses to the various survey questions. You may receive the results of this study upon completion after September 2009 at the Services to Students with Disabilities office at California State University San Bernardino

Your participation in this study is totally voluntary. Each participant will enter a drawing and four will receive a $25 Starbucks gift card. There are no foreseen risks in participating in this study. Should you experience any discomfort, you may contact the Services to Students with Disabilities office for further assistance. You are free not to answer any questions and withdraw at any time during this study without penalty or coercion.

If you have any questions or concerns about this study, please feel free to contact, Dr. Rosemary McCaslin, at (909) 537-5507.

By placing a check mark in the box, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I am 18 years old or older.

Today's Date: ______________

☐ Place a check mark here

APPENDIX C

DEBRIEFING STATEMENT

Debriefing Statement

Thank you for participating in this study conducted by Carley Butler, MSW student from the California State University San Bernardino (CSUSB). The purpose of this study is to investigate the effect of disability type and severity on personal identity and acceptance of a cure among disabled college students. It is hoped that the results of this study will contribute to a better understanding of how the type and severity of one's disability impact their desire for a cure.

The research data were collected through the survey, which you completed. All data collected will be kept confidential and anonymous. The results of this study will be available at The Services to Students with Disabilities office at California State University San Bernardino by September of 2009. If you have any questions or concerns regarding this research project you may contact my research faculty supervisor, Dr. Rosemary McCaslin at the CSUSB Department of Social Work at (909) 537-5507.

Thank you again for your participation and
cooperation in this research project.

REFERENCES

Allies for Change. (n.d.). *What allies for change offers.* Retrieved February 01, 2009, from http://alliesforchange.org/programs.html

Anti-Defamation League. (2005). Equal treatment, equal access: raising awareness about people with disabilities and their struggle for equal rights. Retrieved September 28, 2008 from http://www.adl.org/education/curriculum_connections/fall_2005/default.asp

Antonak, R. F., & Livneh, H. (1995). Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science & Medicine, 40*(8), 1099-1108.

Belgrave, F. Z. (1991). Psychosocial predictors of adjustment to disability in African Americans. *Journal of Rehabilitation, 57,* 37- 40.

Coulton, C. (1979). A study of person-environment fit among the chronically ill. *Social Work in Health Care, 5*(1), 5-17.

Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In C. Barnes & G. Mercer (Eds.), *Exploring the divide,* (pp. 55-72). Leeds: The Disability Press.

Devins, G. M., Dion, R., Pelletier, L.G., Shapiro, C.M., Abbey, S., Raiz, L.R., Binik, Y.M., McGowan, P., Kutner, N.G., Beanlands, H., Edworthy, S.M. (2001). Structure of lifestyle disruptions in chronic disease: A confirmatory factor analysis of the illness intrusiveness ratings scale. *Medical Care, 39*(10), 1097- 1104.

Hahn, H. D., & Belt, T. L. (2004). Disability identity and attitudes toward a cure in a sample of disabled activists. *Journal of Health and Social Behavior, 45,* 453-464.

Hernandez, B. (2005). A voice in the chorus: perspectives of young men of color on their disabilities, identities, and peer-mentors. *Disability and Society, 20*(2), 117-133.

Hicken, B. L., Putzke, J. D., Novack, T., Sherer, M., & Richards, S. (2002). Life satisfaction following spinal cord and traumatic brain injury: a comparative study. *Journal of Research and Development, 39*(3), 359-366.

Jopsen, N. M., Moss-Morris, R. (2003). The role of illness severity and illness representation in adjusting to multiple sclerosis. *Journal of Psychosomatic Research, 54*(6), 503-511.

McDonald, K. E., Keys, C. B., & Balcazar, F. E. (2007). Disability, race/ethnicity and gender: themes of cultural oppression, acts of individual resistance. *American Journal of Community Psychology, 39*(1/2), 145-161.

Most, T., Wiesel, A., & Blitzer, T. (2007). Identity and attitudes towards cochlear implant among deaf and hard of hearing adolescents. *Deafness and Education International, 9*(2), 68-82.

O'Connor, D. L., Young, J. M., & Saul, M. J. (2004). Living with Paraplegia: tensions and contradictions. *Health Social Work, 29*(3), 207-218.

Ostrander, N. R. (2008). Meditations on a bullet: violently injured young men discuss masculinity, disability and blame. *Child & Adolescent Social Work, 25*(1), 71-84.

Payne, M. (2005). *Modern social work theory* (3rd ed.). Chicago: Lyceum Books Inc.

Pelchat, D., Richard, N., Bouchard, J-M, Perreault, M., Saucier, J-M, Berthiaume, M., & Bisson, J. (1999). Adaptation of parents in relation to their 6-month-old infant's type of disability. *Childcare, Health and Development, 25*(4), 377-397.

Saleebey, D. (1992). Biology's challenge to social work: Embodying the person-in-environment perspective. *Social Work, 37*(2), 112-118.

Swain, J., Finkelstein, V., French, S., & Oliver, M. (Eds.). (1993). *Disabling barriers- enabling environments.* London: Sage Publications.

United States Census Bureau. (2006). 2006 American Community Survey data profile highlights. Retrieved October 11, 2008 from http://factfinder.census.gov/servlet/ACSSAFFFacts?_event=&geo_id=04000US06&_geoContext=01000US%7C04000US06&_street=&_county=&_cityTown=&_state=04000US06&_zip=&_lang=en&_sse=on&ActiveGeoDiv=&_useEV=&pctxt=fph&pgsl=040&_submenuId=factsheet_1&ds_name=null&_ci_nbr=null&qr_name=null&reg=null%3Anull&_keyword=&_industry=

Uppal, S. (2006). Impact of the timing, type, and severity of disability on the subjective well-being of individuals with disabilities. *Social Science & Medicine, 63*(2), 525-539.

Vash, C. L. (Ed.). (1981). *Springer series on rehabilitation: The psychology of disability* (Vol. 1). New York. Springer Publishing Company Inc.

Yanchak, K. V., Lease, S. H., & Strauser, D. R. (2005). Relation of disability type and career thoughts to vocational identity. *Rehabilitation Counseling Bulletin, 48*(3), 130-138.