5-4-2001

Spirituality and Disability : What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities

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Recommended Citation

Berndt, Michele, "Spirituality and Disability : What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities" (2001). *Theses and Graduate Projects*. 178.
https://idun.augsburg.edu/etd/178

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MASTERS IN SOCIAL WORK THESIS

Michele Berndt

Spirituality and Disability : What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities

2001

Spirituality and Disability:
What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities

Michele Berndt

**Submitted in partial fulfillment of
the requirement for the degree of
Master of Social Work**

**AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA**

2001

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

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Acknowledgment

I want to thank many people for their support and encouragement during this project. First, I would like to express my sincere thanks to Vern Bloom for your constant support. I may have had the concept for this thesis project, but you were there to help me put it all together. Every meeting you and I had was like a meeting of the minds and I will miss that. You gave me a voice. You understand as much as I do how important this subject matter is to the disability community and for that I am grateful. I would also like to extend a big "thank you" to my family for your patience with me during this time. Even though there were times when, I am sure, you did not think I was going to get it done you were there to support me. Thank you. To my peers in the disability community, you all understand better than anyone how important this subject matter is to you personally, as well as the disability community as a whole. Lastly, to the participants in this thesis project, "thank you." Each of you dared to be open and honest and because of you this project has meaning.

ABSTRACT

Spirituality and Disability: What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities

A qualitative study using elements of Hermaneutics

Michele Berndt

May 4, 2001

This qualitative study attempted to explore the significance and dynamics of spirituality in the lives of people with physical disabilities in coping with barriers that are placed on them by society. The goal of this study was to demonstrate the importance of the spiritual dimension in constructing disability. This study was based on a pure qualitative strategy. Data that reveal the participants' experiential point of view have been evaluated and analyzed using elements of Hermaneutics. The data was obtained by conducting in-depth interviews with four physically disabled individuals. The interview questions focused on the psycho-social-spiritual perspectives of disability. The participants were asked to give as much detail from their own lived experiences as they were able.

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Spirituality and Disability
What are the Dynamics and Significance of Spirituality in the Lives of People with Physical Disabilities?

Chapter One

Introduction

The following chapter details the background of the problem, a statement of the problem, the purpose and significance of the research study, the research question and the background of the researcher.

Background of the Problem

There is evidence to suggest that persons with disabilities are not looked upon in society as whole persons, much less spiritual beings. Rather, our society often defines them as persons who are merely physically and/or emotionally broken and needing to be fixed, as the medical model would suggest. It seems challenging for us to accept them as full members in society, worthy of validation as they are, with the inherent potential for contributions to all of society.

Statement of the Problem

The social work profession, in general, has been ambivalent to recognizing and addressing the spiritual issues for all persons; as demonstrated in the lack of text books, research and articles written. This may be even more challenging with regard to persons with disabilities. The "diagnosis" of the disability tends to narrow our definition of "who you are" and to serve as the catalyst for determining the person's needs. In turn, this all encompassing profession neglects to address any issues that the "whole person" may be experiencing. It is difficult for the profession and our society to separate the person from their disability. Consequently, the person with the disability often must struggle on their own with understanding how their spirituality can assist them in dealing with life's challenges and potential.

Purpose and Significance of the Research Study

This research study offers the unique perspectives of four people who have physical disabilities as they discuss the significance in their lives of their spiritual journey and how having a disability has shaped this journey. This study explored the meaning and lived experience of these four people. Qualitative research methodology using elements of Hermeneutics was used to study this problem. This method allows for interpretation of everyday human life experiences. Using this research method allows me as the researcher to be close to the participants and to interject my own lived experience as a person with a disability and it allows others who read this study to have the same closeness.

Empathy and insight are major themes in Qualitative study. It develops, "from personal contact with the people interviewed and observed during fieldwork. Empathy involves being able to take and understand the stance, position, feelings, experiences, and world view of others (Patton, 1990, 56)." Emphasis is placed "on the human capacity to know and understand others through emphatic introspection and reflection based on direct observation of and interaction with people (Patton, 1990, p 57)."

This study also lends itself significantly to the field of Social Work and other professions as well. If the Social Work profession embraces the spiritual dimension as a valid construct of disability, then this new construct can also be the catalyst that changes how the profession works with persons with disabilities, how our educators educate persons with disabilities and how our society makes laws regarding disability.

The Research Question

The research question posed in this study is: What are the dynamics and significance of spirituality in the lives of people with physical disabilities?

The Researcher's Background

As stated earlier, this study was conducted using elements of a qualitative research method called Hermeneutics. Researchers use this method in order to construct, "reality on the basis of their interpretations of data with the help of the participants who provide the data in the study…Thus, one must know about the researcher as well as the researched to place any qualitative study in a proper, Hermeneutic context (Patton 1990, p. 85)." It is inevitable that my lived experience will, to a certain extent, shape the way I interpret the lived experience of the participant's in this study. Therefore, it is important for the reader of this study to know who I am in relation to the people who participated in this study.

This study is conducted from the perspective of a white, middle class, female, in my early thirties, working toward my Master's Degree in Social Work, who was born with a disability known as Spina Bifida. Because I have a physical disability, I have the unique experience of being, not only the researcher in this study, but of being able to relate directly to the experiences of my participants. While it is true that everyone's lived experience in disability is different, both myself as the researcher, and the participants in this study, share a common understanding and empathy toward each of our human experiences.

My professional work in disability has given me a broader understanding of the issues and challenges that face many in the disability community. It has always been an interest of mine to try to understand and find a way to impact the disability community's lived experience. While it is true that this study is not meant to be a representation of the whole disability community, the knowledge that I have gained as a professional combined with the knowledge that I have gained through my human experience, have led me to conducting this study.

Summary

This first chapter reviewed the researcher's interest in spirituality and persons with disabilities, the significance of the study, the research question and the researcher's background. The next chapter will review the literature related to spirituality and disability. The third chapter describes the method that was used in obtaining the data in the research portion of this thesis project. The fourth chapter addresses the findings of the research and the fifth chapter includes a discussion of the findings, the implications of this study and implications for further research.

Chapter Two

REVIEW OF THE LITERATURE

Introduction

The following outlines the current literature relevant to the research question. It is divided into two sections. The first section describes the social construct of disability, societal views and the affect this has on people with disabilities. The second section pertains to the literature on spirituality, how it relates to disability and to the Social Work profession. This section also describes the theoretical and conceptual framework upon which this research is based. The theoretical framework is rooted in Transpersonal Psychology. Literature is discussed to demonstrate the importance of this theory to this thesis project. A conceptual framework is also discussed. The importance of the concept of finding meaning to life is presented and several examples are cited.

Social Constructs of Disability

The International Encyclopedia of the Social Sciences, defines disability as a socially disvalued behavior or state of being. Accordingly, this state of being "assigns one to a socially disparaged role and constitutes a blemish in the self. This blemish, or stigma, is an important constituent of all social encounters in which it is present…and has consequences for the development of personality and for social interaction (p.148-149)."

Although this project is focused on physical disability, there are several statutory definitions of disability that are outlined in very broad terms. The first; P.L. 94-142, Section 121a.5, defines disabled children as "those evaluated as being mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, deaf-blind, multi-handicapped, or as having specific learning disabilities" (Scotch, 1988, p. 243-244). We now use a second type of statutory definition which is more functional. Sec. 504 defines a disabled individual as "any person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment" (Scotch, 1988, p. 244). This article goes on to suggest that the definition of disability is determined by public policy and that disability becomes whatever laws and regulations want it to be (Scotch, 1988). At the same time, public policy is dictated by the attitudes and perceptions of disability within our society. Our society dictates policy, and policy in turn, reinforces the attitudes and perceptions of our society. In this manner, the two work together, to define disability within our society.

Some of the most recent literature argues against the traditional psycho-social perspectives in defining disability which portray it as a person "marked" to be a victim, needing caring for, and as limited in all aspects of human life because of their disability. In their article, Disability Beyond Stigma: Social Interaction, Discrimination, and Activism, Fine and Asch suggest that it is our environment which makes having a disability disabling. They propose reframing disability and defining it in terms of a civil rights issue. They call it the Minority-Group Model. Within the framework, meanings for the state of one's body are played out in psychological, social, and political dimensions. They suggest that traditionally it is society who defines disability, not the person with the disability. They argue that disability would take on a whole new meaning for all people if people with disabilities were not faced with inaccessible buildings and inadequate transportation.

In their article entitled, History of Disability: A History of 'Otherness', two Australian researchers, Jayne Clapton and Jennifer Fitzgerald, describe the evolutionary process of constructing disability in Western society. They explain that the history of disability is characterized by several models of disability: the religious model of disability, the medical/genetic model of disability and the right-based model of disability (Clapton and Fitzgerald, 1998).

In the religious model of disability the Judeo-Christian understanding of disability is rooted in Biblical references which describes this state of being as the result of " evil spirits, the devil, witchcraft or God's displeasure. Alternatively, such people were also signified as reflecting the 'suffering Christ', and were often perceived to be of angelic or beyond-human status to be a blessing for others. Therefore, themes which embrace notions of sin or sanctity, impurity and wholeness, undesirability and weakness, care and compassion, healing and burden have formed the dominant bases of Western conceptualization of, and responses to, groups of people who, in a contemporary context, are described as disabled (Clapton and Fitzgerald, 1998)." Religious communities responded to this group of people in a variety of ways, they either wanted to help "cure" them with the help of exorcisms, purging or other rituals, or by providing care, hospitality and services as some saw this their "Christian Duty."

The medical model of disability followed; with the doctor and the scientists replacing the priests as the highest authority on social values and curing processes.

> " 'Normality,' then, became determined by the ideal of the white, youthful, able, male body and otherness to this ideal became hierarchically placed as inferiority. Therefore, difference became redefined as deviance commanding control... The lives of such people were reduced to little more than a medical label, and their futures defined by a medical prognosis... As sociologist,

> Vic Finkelstein notes, 'this was an era when cripples disappeared and disability was created…' In the post-industrial and post-enlightenment era, disability in Western society has been regarded as an individual affliction predominantly cast within scientific and medical discourses. Therefore, 'disability' has come to be defined and signified as a power-neutral, objectively observable attribute or characteristic of an 'afflicted' person. According to this model, it is the individual, not society, who has the problem, and different interventions aim to provide the person with the appropriate skills to rehabilitate or deal with it. (Clapton and Fitzgerald, 1998)."

Furthermore, in their article entitled, Malady: A New Treatment of Disease, the authors Clouser, Culver and Gert define disability as a malady. They suggest that, "A person has a malady if, and only if, he or she has a condition; other than a rational belief or desire, such that he or she is suffering or at increased risk of suffering, an evil (death, pain, disability, loss of freedom or opportunity, or loss of pleasure) in the absence of a distinct sustaining cause (Clouser et al, 1981 p.36)." The authors apply this to both physical as well as mental disabilities.

Within the rights-based model of disability, "the emphasis has shifted from dependence to independence, as people with disability have sought a political life force." The authors, also say that "the history of disability has been a history of seeking to construct hierarchical differences out of an essential reality of oneness. The challenge is to create the reverse (Clapton and Fitzgerald, 1998)." This will be explained in further detail later.

From the mid 1980's, some Western countries such as the United States and Australia have enacted legislation that embraces a rights-based discourse rather than a custodial discourse and which seeks to address issues of social justice and discrimination. The legislation also embraces the conceptual shift from disability being seen as an individualized 'medical problem' to being about community membership and participation and access to regular societal activities such as employment, education, recreation and so on. Where access is inappropriate, inadequate, difficult or ignored, advocacy processes have been initiated to address situations and promote the people's rights (Asch and Fine, 1988).

In his book, No Pity, Joseph Shapiro writes about the history of disability and describes the civil rights movement that has unfolded as a result. According to Shapiro, "no other group of citizens was so insulted or so removed from the American mainstream. Twenty-five years after Black Americans had successfully won a legal end to their exclusion from public places and jobs, similar segregation was still a fact of daily life for millions of disabled people...For the first time, people with disabilities were asking Americans to recognize that the biggest problem facing them was discrimination. They sought access and opportunity, not charity (Shapiro,1993 p.106)." The result of this was the passage of the American with Disabilities Act on July 26, 1990. It was "the most sweeping civil rights law since the passage of the Rehabilitation Act of 1973 (Shapiro, 1993 p.106)." The law took effect in 1992. "But it was an odd victory; as radical as the ADA's passage would be for disabled people, non-disabled Americans still had little understanding that this group now demanded rights, not pity (Shapiro, 1993 p. 141)."

Yet, rights-based discourse, although employed as a political strategy, has also become a way of constructing disability by locking people with disability into an identity which is based upon membership of a minority group. Entitlements thus become contingent upon being able to define oneself as a disabled person with disability. And the conceptual barrier between 'normal' and 'abnormal' goes unchallenged, so that while one may have entitlements legislatively guaranteed, 'community' which cannot be legislated for, remains elusive…(Fine and Asch, 1988).

Some writers argue that we need to go beyond conceptions of constructed disability to a notion of universalism whereby, according to Canadian writer, Bicknebach, 'disability is actually a fluid and continuous condition which has no boundaries but which is, in fact, the essence of the human condition. And, as a condition which is experienced by us all, at some stage in our lives, disability is actually normal.' This view is also supported by the Indian philosopher, Sakar, who argues that bodily difference is simply a construction of ideology, not a state of reality; since we are all interconnected. The researchers also express their disappointment that past research has failed to acknowledge this (Fine and Asch, 1988).

Authors Scotch and Shriner, suggest an alternative model based on the concept of human variation which implies additional strategies for achieving integration of people with disabilities in society. This concept could quickly tell us how a society would look if disability was not viewed as a handicapping condition. They argue that the outcomes of a rights-based model, such as the one previously discussed, may not be known for quite some time because legislation such as the Americans with Disabilities Act is relatively new (Scotch and Schriner, 1997).

While it is true that literature taken from the most recent journals seems to be focused on disability from a positive perspective that fosters the idea that people with disabilities are people first, the literature also suggests that "within American society, there is the existence of patterned interactions between disabled and non-disabled persons (Phillips, 1990 p. 855)." It does appear, based on this literature, that many of the experiences of people with disabilities in society are consistent with the cultural notion by our society that people with disabilities are, "in effect, damaged goods." Their experiences appear to affirm the prevalence of "language and images that perpetuate the notion of the defectiveness of persons with disabilities. Their experiences also acknowledge the messages perpetuated by society of the wrongness of their bodies (Phillips, 1990 p. 855)." Their experiences also confirm the notion that the disabled experience in our society is one of social minority status (Phillips, 1990 p. 849).

Spirituality

Most authors make a clear distinction between spirituality and religion. The works of Carl Jung, and Ken Wilber give us a framework for understanding spirituality as it relates to human nature. Jung teaches us that the spiritual perspective requires us to look for meaning in life, to look beyond what is easily validated and strive toward a more existential meaning to life (Sermabeikian, 1994). Wilber points to "the Great Chain of Being" which states that reality, "is not one-dimensional; it is not a flatland of uniform substance stretching endlessly before the eye. Rather, reality is composed of several different but continuous dimensions...At one end of this continuum of being or spectrum of consciousness is what we in the West would call 'matter' or the insentient and the non-conscious, and at the other end is 'spirit' or 'godhead' or the 'super-conscious'...Arrayed in between are the other dimensions of being arranged according to their individual degrees of reality, i.e., actuality, inclusiveness, consciousness, clarity, value, or knowingness (Wilber 1993, p. 53)." What Wilber is describing is a "hierarchy of matter to body to mind to soul to spirit (Wilber 1993 p. 53)."

Some authors in Social Work are also present in the literature and define spirituality as, “the individual’s response to the events in life over which they have no control (Coronett, 1992 p. 101).” Derezotes defines spirituality as “a complex, intrapsychic dimension of human development, in which the individual moves towards higher states of connectedness, well-being, consciousness, and/or meaning” (Derezotes, 1995 p.1).” He describes spirituality in terms of one’s relationship with a higher power, as a desire to realize one’s true self and inner potential. He defines religion as a system of beliefs, rituals, and behaviors shared by individuals in an institutional setting (Derezotes, 1995). Other authors suggest that “spirituality is the center from which all other human activity flows (Howard & Howard, 1997 p.181).”

Spirituality and Disability

This literature speaks of various themes that have been identified and describes an overall paradigm and model of “wholeness and reconstitution” (Do Rozario, 1997 p.1). The literature talks also about the entities in society that have played a role in how society defines disability, those being: science, bureaucracy, and organized religion respectively. The literature is critical of how the medical model has adversely shaped how we define disability and how we treat people with disabilities, as well. From the medical model perspective, we see them as broken, incomplete, and imperfect needing our pity and our care (Fitzgerald, 1997).

Consequently, “these constructions operate to define and confine the spiritual journey for people with disabilities (Fitzgerald, 1997 p. 1) and suggests the need for an integrated holistic conception of self. The article by Fitzgerald outlines the barriers to experiencing the spiritual journey for people with disabilities. This article suggests that these barriers are based on the societal constructs of disability (Fitzgerald, 1997).

The literature also takes a look at some contemporary uses of the terms spirituality and disability. It examines the concept of perfection as defined by our society and suggests that this acts to stigmatize disability. It suggests the need to redefine the term dependence to a more interdependent view point (Horsburgh, 1997).

A portion of the literature focuses on the significance of spirituality to the social work profession. Within this there is discussion on how the profession defines spirituality. Concepts that focus on spirituality are also discussed. There is also overwhelming evidence that suggests the need for further education for practitioners on spiritual issues.

Spirituality and the Social Work Profession

The use of spirituality in social work practice is not necessarily a new phenomena, rather one that is beginning to, "reclaim it's spiritual heritage (Holland, 1989 p. 28)." Research suggests that while it is true that Social Work started in the 19th century with some religious commitments, "it has adopted more culturally accepted images of personal success. These changes, some would agree, "have led to emphasis on techniques rather than shared purposes and on self-interest rather than mutual responsibility (Holland, 1989 p. 28)."

An article by David Cox suggests that there is indeed a third dimension to mankind and that Social Work has a responsibility and a unique opportunity to "support individuals' search for the spiritual dimension,... (Cox 1985, p.11)." This is especially true for persons with physical disabilities. In an article entitled, Conceptualizing Spirituality for

Social Work: Insights from Diverse Perspectives, Edward Canda writes, "The professional helping relationship needs to be a genuine expression of the social worker's own spiritual commitment to compassion and social justice...A spiritually-sensitive helping relationship will emphasize client-centered, emphatic, respectful, and caring style (Canda, 1988 p. 43)." Also, studies have been conducted with Social Work professionals that indicates "it is entirely possible and desirable for social workers to maintain personal commitment to their own particular beliefs and values while also affirming the worth of alternate spiritual approaches (Canda, 1988 p. 41)."

The strengths perspective as a concept identifies spirituality as an asset within each of us that can enable us to overcome life's challenges. Some of the literature would indicate that Social Work as a profession must do better to support individuals, families, and communities in this internal process so that they may be empowered when facing their own personal sufferings (Society for Spirituality and Social Work Newsletter, Tice, No Date).

Lastly, the literature suggests an overwhelming need for practitioners to be further educated in the spiritual dimension. There appears to be a particular need when it comes to the cultural issues surrounding spirituality (Sheridan, Bullis, Adcock et al, 1992; Sheridan, Wilmer, & Atcheson, 1994; Stander, Piercy, Mackennon et al, 1994; Krill 1995; Deretzotes, 1995). The profession is criticized for neglecting, omitting, and carefully avoiding this most basic aspect of human nature in its curriculum. The research identifies only one tool as being particularly important to its curriculum, i.e., Wilber's, Full Spectrum of Consciousness Model.

With this model, Wilber describes "a full spectrum view of human growth and development (Wilber 1995, p. 129)." This model incorporates the perspectives of Psychology, Sociology, Theology, Metaphysics and Philosophy to help explain human behavior and cognitive development. It does this by dividing all these schools of thought into four quadrants. Each quadrant is related to the other. Each quadrant has within it three levels of human behavior. No one quadrant is more important than the other. Rather, they are equally important to encompassing all human behaviors. (Wilber, 1995).

Theoretical/Conceptual Frameworks

There are two parts to the theoretical/conceptual framework that form the basis for much of this thesis project. The first part is a theoretical framework identified in the field of psychology. Transpersonal Psychology was developed in the late 1960's by psychologists Carl Jung and later, Ken Wilber. Jung, was one of the first psychologists to speak on transpersonal phenomena which he used interchangeably with his term "collective unconsciousness." It uses such concepts as: values, the unconsciousness, mysticism, the sacredness of everyday life, cosmic awareness, cosmic play, individual and species-wide synergy, the spiritual paths, theories and practices of meditation, compassion, and transpersonal cooperation (Corsini, 1994). "Transpersonal Psychology attempts to understand those experiences in which the sense of identity expands beyond the individual person, personality, or ego to encompass aspects of humankind, life, and beyond (Corsini, p. 549)."

This theory emphasizes the importance of examining our belief systems as they go beyond the self and include identification with the values and goals of groups and societies seeking to define a well developed unselfish human being (Corsini, 1994). Much of the rationale for transpersonal psychology starts with a questioning of the basis for knowledge in traditional scientific psychology. It seeks to answer such questions as, is human knowledge to be confined only to that derived from rational thinking and sensory experiences in the waking state? "The transpersonal position is that there are several ways to obtain and prove knowledge and that there are many states of consciousness. Some psychologists equate the transpersonal with the spiritual and insist that it is important to study and incorporate into practice, mystical, subjective and ephemeral phenomena that are already accepted in many cultures (Corsini, p. 548)."

However, others point out the difficulty in describing and studying the metaphysical aspects of the consciousness. An organized method of research and theory in transpersonal psychology has yet to be developed. "Research needs to be done which compares and contrasts transpersonal to mainstream theory and practice in order to establish what the transpersonal area uniquely contributes to the overall understanding of human functioning above and beyond what is already known via conventional psychology (Friedman and MacDonald, 1997 p. 120)."

The most current literature does seem to indicate that there are several assessment tools being used to measure and assess the transpersonal. However, the question of the validity of these assessment tools is being raised by some researchers. The question seems to be: can an assessment tool that is designed to measure the physical aspect of consciousness also be valid for measuring the metaphysical aspect of consciousness? The literature seems to indicate that, while studying the metaphysical consciousness has proven to be of benefit to the field of psychology, assessment of it does have its limitations (MacDonald, et al, 1994 & 1995).

Transpersonal psychologists argue that the metaphysical aspect has had little attention paid to it in our understanding of the human condition. "As an interdisciplinary and cross-cultural movement, the transpersonal orientation presents many challenges for psychology. Is there a cosmic meaning of life and death? Are there relationships and interactions among all beings? (Corsini, p. 548)." Science has only recently begun to identify with this unconventional phenomena. The discovery of quantum mechanics in physics, for example, has helped to lend support to the idea that everything in the universe might actually be invisibly linked, which is the basic premise for the transpersonal theory. Medicine also, is beginning to validate the metaphysical aspect of consciousness as a mechanism for healing the body.

This theory suggests the importance of the metaphysical to all human kind. However, this is not to suggest that when constructing disability, the physical and psycho-social is not important. We may, however, need to go beyond this and explore the metaphysical as well. As a society, we often choose to look only at the physical and psycho-social constructs. Perhaps a metaphysical construct needs to also be considered in constructing disability, as this theory would suggest.

The manner in which this theory will help determine the direction for this study include: determining the degree to which transpersonal constructs are important in living with disabilities; exploring the connections that may exist between one's view of a disability and the larger cosmic view of God's will; finding one's meaning and purpose in life and determining one's identity. From the psycho-social point of view, a person with a disability is identified by their disability. This theory helps to determine that there is something more that identifies humans as belonging to humanity regardless of the state of their body or mind.

An article by Au-Dean S. Cowley describes transpersonal psychology as, "the only theory to recognize higher levels of consciousness and the spiritual dimension as being exceptionally healthy or as representing the epitome of human potential (Cowley, 1993 p. 527)." There has been much difficulty since the 1960's, when the movement began, to define Transpersonal Psychology. There is not one all inclusive definition. The research does, however, outline several. Transpersonal psychology identifies a fourth force that goes beyond the behaviorist-- classical psychoanalytic theory or humanistic psychology. It is "that orientation within the field of psychology which is concerned with those behaviors and experiences which are perceived to be beyond the personal concerns of social roles, identity, or individual history (Lajoie & Shapiro, 1992 p. 82)." These authors outline five main themes in their attempt to define Transpersonal Psychology: levels of consciousness; highest and ultimate potential; beyond ego or personal self; transcendence; and spiritual. It should be noted that the research argues that these definitions appear to be highly "theory laden" and sometimes "metaphysically laden" and that while they "are not necessarily wrong, their validity should be researched and assessed rather than presupposed (Walsh & Vaughan, 1993 p. 202)." It is suggested that definitions that are more tied to peoples experiences and that describe the focus and purpose of transpersonal disciplines, but make minimal theoretical or metaphysical presuppositions, may be more beneficial because this makes transpersonal psychology, "unique explicitly in adopting an eclectic epistemology which seeks to include science, philosophy, introspection and contemplation, and to integrate them in a comprehensive investigation (Walsh & Vaughan, 1993 p. 205)." However, the ever changing definitions for transpersonal psychology are a reality of its intention to keep the definition open to change and that it will forever be a discipline whose definition will continue to change (Vich, 1992). This is what gives transpersonal psychology its validity as it is continually "shaped by changing historical, cultural and international context (Vich, 1992, p. 100)."

Transpersonal Theory, it is argued, is important to the Social Work profession because of its dual psycho-social thrust. "On the personal level, it is committed to the search for self mastery or the making and finding of a purpose in life larger than the little self or skin-encapsulated ego. On the macro or societal level, transpersonalists…are concerned with the quality of life in families, organizations, and communities (Cowley & Derezotes, 1994 p. 35)."

However, this theory is not without controversy. Psychologists like Kirk Schneider argue that it has no validity because it can not be proven scientifically and that therefore, there is no fourth dimension to the realm of human beings as psychologists like Ken Wilber profess (Schneider, 1989).

Some psychologists, well versed in transpersonal phenomena, are opposed to the idea of using standardized testing to measure the transpersonal domain. As Wilber said in 1990, "...once you have translated the world into empirical measurement and numbers, you have a world without quality guaranteed (MacDonald et al, 1995 p.172)" But, MacDonald et al also say, "we believe that the value of testing for transpersonally oriented research can be better appreciated if it is viewed not as a means of accessing and understanding transpersonal experience directly, but instead as a tool which can be used to explore the 'expressions' of such experiences. By expressions, we are referring to the behavioral, physiological, psychological (cognitive/emotional), and sociological correlates of transpersonal experience as well as the theories (religious and secular) generated to explain these experiences (MacDonald et al 1995)."

The literature does outline several standardized tests that could legitimately be used to explore the transpersonal experience in this manner. (See Appendix D). Each of these have their own individual benefits and limitations to measuring the transpersonal experience.

The second piece which forms the basis for this thesis project, capitalizes on the concept of finding meaning in one's life. For the whole of the disability community, it becomes a matter of not only finding meaning in their lives as individuals, but, for our society to be open to see the meaning that their lives hold, as well. As a disabled individual myself, I see that my life has meaning beyond my physical limitations. But, society looks at me in a very different way than I do. It is customary for our society to hold the belief that, as a human being, I am broken needing fixing and that because my state of being is not the 'norm,' I am rendered useless by societal standards. Several examples of this concept and its importance to the human spirit are discussed here.

In his book, It's a Meaningful Life : It Just Takes Practice, Bo Lozoff states that there are two basic, fundamental teachings at the core of all the major religions. The first is what he terms this "internal spirituality." According to Lozoff, "each of us, in silence and solitude, can touch and eventually merge into the Divine Essence deep within us (Lozoff, 2000 p. 5)." The second is our natural sense of community. Lozoff says that it is through our reaching out to our community that we begin to find meaning in our own lives. He states, "As social animals, we human beings not only depend on each other's support simply to live, but also have a deep-seated desire to communicate with one another to express our feelings and share our experiences (Lozoff, 2000 p.xiii)." He terms this "external spirituality." Lozoff calls this, "a simple ethic about how we are to regard others. We are instructed to love and respect all of creation, to be forgiving and compassionate and generous, and to dedicate our lives to the common good rather than merely to personal success (Lozoff, 2000 p. 5)." We all want to know that we are a part of something bigger than ourselves.

Secondly, in his book, Man's Search for Meaning, Victor Frankl talks of how, even in a concentration camp, one can find meaning in their life by paying attention to the simple things around them: contributing to others; remembering their loved ones; observing the beauty of the land around them; finding humor in their situation and to visualize what their lives will be like when they are freed. Frankl says that a sense of vision is important as it lends itself to finding meaning for one's life (Frankl, 1984). Thus, it is for someone who lives with a physical disability. To find meaning to their lives regardless of their current situation, allows them to appreciate their state of being and live the experience fully.

In his book, Flying Without Wings, Arnold Beisser speaks about his experience of contracting polio and how he learned to find meaning in his new found and totally unexpected state of being. He talks about learning to recreate himself to reflect who he is presently versus who he had been. He says, "We must be open to every aspect of who we are in order to be able to respond appropriately to the changing contexts that develop in life (Beisser, 1992 p. 109)." He goes on to talk about the stereotypic images that society holds as truths about disability: the wounded warrior who is defeated and rendered helpless in all future endeavors. He says that by "accepting that the loser is in each of us, we learn something important about the meaning of life--that it is not limited to the successes and failures of any one individual, but that together we all are part of the sweep of evolution (Beisser, 1992 p. 111)."

The process of acceptance and ultimately finding meaning is a long one. Beisser calls this the "stages of acceptance," and believes that these stages take place simultaneously with the stages of grief described by others.

In the last stage in this process, we are told, there is acceptance. Beisser adds that there needs to be an acceptance of something that can replace that which is lost. To him, "the more important acceptance is not the reality of what has been lost, but the acceptance of something new that is valuable and can take the place of the loss. Without something new, one clings to the past, for the fantasy is more palatable than the present (Beisser, 1992 p. 146)."

The process of acceptance which Beisser suggests, has several stages. "First, one rejects the familiar options. Second, one looks for something new. Thirdly, one grudgingly accepts something new. Then, one behaves as if they accept it. Next, one begins to discover some of the same satisfaction in the new that one had with the obsolete. Lastly, one surrenders with dignity and grace or embraces the new as if they had chosen it (Beisser, 1992 p. 153)." It is through this very gradual process that one finds meaning in their life *as it is*, and not as it was.

In her book, Joni, Joni Eareckson writes about her journey toward finding meaning in her life after a diving accident suddenly changes her life and forces her to find a new vision for her life. She has this to say about her life after becoming disabled. "I saw that my injury was not a tragedy but, a gift God was using to help me conform to the image of Christ, something that would mean my ultimate satisfaction, happiness, even joy (Eareckson, 1976 p.118)." She talks about the realization that she finally came to about her worth as a person, not as she was, but as she is now. She says, "in the days that followed, I thanked Him for "me"-whatever I was in terms of mind, spirit, and personality, and even body. I thanked Him for the way I looked and for what I could and could not do. As I did, the doctrine of His sovereignty helped everything fall into place, like a jigsaw puzzle (Eareckson, 1976 p.120)." This realization helped give her life purpose. She continues to inspire others with her story of how the events of her life helped her find meaning.

In the book, Tuesdays with Morrie, Morrie Schwartz has this to say about finding meaning in life. "So many people walk around with a meaningless life. They seem half-asleep, even when they're busy doing things they think are important. This is because they're chasing the wrong things. The way you get meaning into your life is to devote yourself to loving others, devote yourself to your community around you, and devote yourself to creating something that gives you purpose and meaning (Albom, 1997 p. 43)." For Morrie, the meaning of life was discovered through his process of dying from ALS. As he mourned the loss of his body functions and the things he could no longer do, he discovered a meaning to his life as it was and not as it had been.

Summary

The literature outlined previously is grouped into several areas. First, the social construct of disability is discussed. The focus is on how society defines disability. Next, models of disability are discussed, which in turn reflect how our society defines disability.

The literature on spirituality in Social Work and Psychology is minimal at best and serves to merely define it There is some literature on spirituality and disability but, again, the literature is minimal. It does, however, discuss the barriers to the spiritual journey that are often experienced by people with disabilities. The literature talks about how these barriers reflect our social construct of disability. The literature also talks briefly of the relationship between these concepts.

Lastly, the literature on spirituality speaks of the need in the field of Social Work for more education as the profession is recognizing their role in helping people address their issues of spirituality. Ironically, although the profession is rooted in religious traditions, it has moved away from this way of thinking and favors a more clinical approach to people in their attempts to understand the things that happen to them.

There is both a theoretical framework and a conceptual framework that is pertinent to this thesis project. Transpersonal, be it somewhat controversial, relates to this subject because of its psycho-social thrust. The concept, which is a main thrust throughout this project, is the idea of finding meaning in one's life. Several examples are outlined to illustrate this concept and its relationship to this thesis project.

Chapter Three

METHODOLOGY

Introduction

When deciding on a research design for a study, the researcher must first ask what kind of information is to be obtained from this study and what is the best method for obtaining this information. Qualitative research methods allow the researcher to obtain pertinent data in a manner that is flexible enough so as to obtain the most accurate first hand information.

In her article entitled, Emerging Criteria for Quality in Qualitative and Interpretive Research, Yvonna Lincoln states that, "Qualitative research is conducted not to confirm or disconfirm earlier findings, but rather to contribute to a process of continuous revision and enrichment of understanding of the experience or form of action under study (Lincoln, 1995 p. 278)."

She outlines several criteria that she views as important elements in evaluating qualitative research. She calls them, Positionality or Standpoint Judgments, Community as Arbiter of Quality, Voice, Critical Subjectivity, Reciprocity, Sacredness, and Sharing the Perquisites of Privilege. What Lincoln says is that issues of rigor and ethics found in quantitative research are not an issue in qualitative research. Rather, qualitative research is a research "grounded in the recognition and valuing of connectedness between researcher and researched, and between knowledge elites and the societies and communities in which they live and labor (Lincoln, 1995 p. 287)." Hermaneutics was the qualitative research method used to conduct the research for this thesis project.

Hermeneutics "attempts to capture everyday skills, habits, and practices by eliciting narratives about the everyday and observing action in meaningful contexts…The Hermeneutics tradition derives from the phenomenological work of Heidegger (1926/1962) and Kierkegaard (1843/1985) (Benner, P.A., et al., 1996, p. 351)." The basic question that Heideggian philosophy asks is: What does it mean to be human? Present-day interpreters include Dreyfus (1979, 1991a), Taylor (1985a) and Rubin (1984).

Research Question(s)

The research question that this thesis project seeks to answer is, What are the dynamics and significance of spirituality in the lives of persons with physical disabilities? This question was operationalized with the following questions and probes that were asked of the participants. Each participant was asked to talk about their support system, to describe the extent they are aware of themselves as spiritual beings and what have been the barriers and/or supports in their spiritual journey. The discussion also centered around such questions as: where they are presently, in terms of their spirituality; how have they been treated by people in society; and the extent to which they have experienced any barriers in their attempts to integrate into society. Each participant was asked the following probing questions:

1. What was that like for you?
2. Can you tell me more about that?
3. Can you describe more of your experiences?
4. How do you feel about that?

5. Is there more you would like to add to this discussion?

Research Design

The research design used in this thesis project was a qualitative study using elements of Hermaneutics as the research method. Four persons with physical disabilities were interviewed. Each interview was audio taped. All the questions were as in-depth and open-ended as possible to allow the researcher to get as much information from each participant as possible.

Definitions

For purposes of this study, spirituality is defined as metaphysical experiences that one feels which moves them toward a sense of wholeness as an individual and their connectedness to other human beings. Disability is defined as that which limits a person physically and socially to such a degree that they are not considered to be among the mainstream of society. However, it is important to recognize that these definitions are merely preconceived ideas. The participants themselves will define spirituality and disability and they may choose to redefine them.

Participants

The participants in this study are composed of people who have physical disabilities. For purposes of this study, this includes three participants who were born with their disability and one who acquired it later in life. They are all between the ages of 20-50 years.

Population

This study is meant to explore the lived experience of four disabled individuals with regard to their spiritual journeys and report the findings. The data will be obtained by conducting in-depth, open-ended interviews with participants recruited from acquaintances that the researcher has, both personal and professional, within the disability community.

Data Collection

The questions asked will be generated from the responses given by each participant. The interview schedule will serve to guide the discussion. The questions asked will pertain to what the participant is saying so as to create the most informative dialogue about their spiritual journeys and experiences as a disabled person living in our society and how they are impacted by this. Where appropriate, the researcher will also interject her own experiences as a disabled person to help guide the discussion.

Data Analysis

This study is based on qualitative methodology and contains elements of Hermeneutics. Qualitative Data will be gathered from the in-depth interviews of each participant. The content of this raw data will be analyzed to find common themes and meanings. Data will be gathered that reflects the participants' perspectives and personal experiences. The researcher's task is not only to listen but to pursue in-depth questioning.

Data Analysis Procedure

The interviews will be analyzed by relying on elements of Hermeneutics. The researcher will gather the data in an environment that is non-manipulating, unobtrusive, and non-controlling, open to whatever is said with no preconceived notions or judgments about the results. The researcher will be looking for common themes, ideas, and descriptions among the raw data and any relationships to concepts derived from the literature (Patton, 1990, p. 40).

Protection of Human Subjects

To assure confidentiality, each interviewee will be randomly assigned a code which corresponds with their perspective interview schedules. A consent form will be designed that will assure informed consent and authorize the interviewer to audio tape the interview. The consent form will also authorize the limited use of the data for publication and will also state that it respects the privacy and sensibility of the participants at all times.

Summary

This chapter discussed the methodology that was used in the research portion of this thesis project and included the research question, research design, definitions, characteristics of the participants, data collection and analysis procedures. The protection of human rights issues were also addressed.

Chapter Four

FINDINGS

Introduction

The participants in this research project consisted of two males and two females. The age range was from 33 to 47. Three had disability onset at birth; one acquired their disability at 35 years of age. Their disabilities were Cerebral Palsy, Spina Bifida, blindness and above the knee amputee.

For a majority of the participants, societal barriers were the most troubling for them. These barriers were experienced in several different areas of their lives. However, the most prevalent were the medical profession and the religious community. Societal attitudes about disability were also the lived experience of three of the participants and had a major impact on all aspects of their lives. One participant, however, seemed to be an exception. This participant did not feel that societal attitudes had an impact on her life in any way.

For all of the participants, the dynamics and significance of spirituality is clearly demonstrated as they defined spirituality and their spiritual journeys. Each participant defined it in a somewhat different way, but there were some similarities. Spirituality for two of the participants included their relationships to other people. For one participant, her spirituality includes a process of redefining who she is and developing a stronger sense of self. Lastly, one participant defines her spirituality as grounded in a deep-rooted belief in God and the teachings of the Bible. Most of the participants identified a major conflict between their view of themselves and the way others view them. They view themselves as spiritual beings first and other people tended not to. Therefore, society can not separate their disability from who they are as people. The result is that most of these participants experience social barriers. The significance of spirituality, regardless of how each participant defined it, is that it helps them find meaning in their lives and feel that they are a part of something that is larger than themselves.

Barriers

The Medical Model

One participant feels that the Medical Model was a barrier. When asked to elaborate, the participant said,

> They are trained to deal with a part, or a piece of you, and they have lost the ability to see you as a person. They put you in a category. After my accident, a medical professional told me "not to worry my pretty little head about it, we will make these decisions for you" (1).

She went on to relate a story about seeing her doctor when she was pregnant and seeing that the doctor had written, AKA and AMA on her file. When she asked her doctor what these meant, she was told that it stood for Above the Knee Amputee and Advanced Maternal Age.

This relates directly to what Clapton and Fitzgerald and Vic Finkelstein have written about the Medical Model reducing the lives of people with disabilities to a medical diagnosis and their futures and indeed their whole identity are determined by a medical prognosis (Clapton and Fitzgerald, 1998).

Organized Religion

It is important to distinguish between spirituality and religion. Spirituality is a dimension of the human experience in which individuals connect with a higher state of consciousness and meaning to their lives. Organized religion on the other hand, is a well structured set of religious beliefs and rituals adopted by a group of people to worship a higher power. In theory, religion is a way for people to fulfill their innate desire for belonging and fellowship with others. However, for people with physical disabilities, this sense of fellowship and belonging is complex and can be difficult for them to obtain.

One participant concurred with Clapton and Fitzgerald when they talk about the Judeo-Christian understanding of disability being rooted in the Biblical reference, which describes this state of being as a result of evil spirits, witchcraft, or God's displeasure. This participant believes that he has been judged by the religious community because of their belief that,

> we are disabled because of the sins of our parents, we are not whole beings and if only you would believe harder, you would not be blind. How do you argue against the attitudes, how do you argue against prejudice especially when people are not going to acknowledge it as such (3)?

He has also felt that it has been difficult for him to feel a sense of inclusion when it comes to organized religion.

> A true Christian church would be inclusive of all people regardless of what their physical conditions are, and they are not. I've actually had one go so far as to say, when I requested that things be enlarged, "we are not going to do that because a majority of the people don't read that way." Now, that was a number of years ago, but it was enough to cause one to become pretty disillusioned (3).

He goes on to state,

> If churches model themselves after society, why should they be (all inclusive). If the social attitude in regard to people with disabilities is to keep us out of the way,

> put us in institutions and get us off the street, why should churches be any different? They are just mimicking society (3)..

This contradicts what Bo Lozoff, in his book It's a Meaningful Life:it just takes practice, would say about religions. Lozoff says that all religions have two primary entities. Each one teaches about communing with a higher power. But, they also teach us about reaching out to our community and that relationships with other people help us to feel a sense of inclusion which sustains us. However, the lived experience of this participant is that he has not always felt a sense of inclusion from the religious community.

Societal Attitudes

One participant felt that the struggles they encountered in education, employment, housing, economics and religion happened as a direct result of the attitudes that people had about their abilities because they are disabled.

> They were not allowing me to participate fully in my education and isn't that what education is all about, to allow a person to develop their abilities rather than put up barriers keeping them from developing their abilities (3)?

One participant talked about their frustration with being identified by their disability.

> I was really struggling with, do I pull out my trump card, or do I talk about the things that I identify myself with. But, I fell into it too by telling them (the nurse), I am the mother who is the amputee. Society does not support the roles that it values, for instance, being a mother. God help you if you have a disability and are a mother (1)!

Another participant made a few comments about stereotypes that society has about people with disabilities.

> There is more to me then what you see. In a restaurant, the waitress or waiter will see me, they will move the chair away for me and when it comes time to order the food, they will ask someone else what I would like to eat. It does not mean that I am mentally challenged because I am in a chair.

> The chair is an extension of me and my service dog is an extension of me, too. I am a person first and a person with a disability second (4).

I asked one participant for his reaction to societal attitudes stemming from the premise that people with disabilities are broken and needing fixing. They had this to say,

> We don't need fixing. The biggest challenge that we in the disability community have is to break through or change that thought. I have people who tell me that they forget that I am in a chair and I take that as a complement because those are people who have really understood me (4).

For another participant the challenge was to overcome obstacles when she initially became disabled.

> It hit me when I got carried through the door of my house that I was not the same person. I realized that everything I *had* done, I was either not going to do anymore, or I was going to have to figure out another way of doing it. But, I truly believe that you create your own reality (1).

All the participants agreed that there is a difference between the way they view themselves and the way society views them. One participant stated,

> I really do not feel less than. Most of my friends are able-bodied friends. But, societies' expectations of me are different. They either place me on a pedestal or they lower their expectations of me. Early on, in my accident and recovery, I would have people say, "Oh no, you shouldn't do that, don't worry about that." Some of that is really seductive, you really suck into that and at some point, you begin to feel like "this is not who I want to be." These are things that I would expect of myself as an able-bodied person. Why shouldn't I expect to do it now. People do not really understand the things that would be of help to me, they offer things that they should not be offering, things that I should be able to do for myself. There are people in the profession who do not know how to treat you either. My co-workers tend to place me on a pedestal as though having a disability validates me in my position (1).

Another one stated that she sees that there is a difference in the way that she views herself and the way society views her, too, but only initially.

> Society would initially see me as not generally competent, not generally able to care for myself, not generally able to handle life because of my

> disability which is a fairly typical and understandable perspective. I mean, when non-disabled people see someone with a disability, they put it in their own perspective and say, "I couldn't handle it, therefore, that person can't either." But, I can turn this around on them fairly quickly and fairly easily. I can show them in three sentences that I am competent, I'm intelligent, I have value in society. All I have to do is say, Hello, my name is,____________, I am a college graduate, I'm married, I have two kids and I have a good job. I've done all the things that our society considers to be standard of a normal life (2).

To this participant, her disability is not her primary identification. She sees herself as a worker, a wife and a mother first. She sees herself as a disabled individual last. This participant views herself as part of the disability community, but not really a member of the community. This viewpoint can be compared to how the disability community as a whole feels about society. They feel they are a *part* of society, but not really *members* of society from the standpoint that they often find it difficult to be considered as full participants in society.

However, this participant feels that the disability community,

> allows the outside world to define who they are far too much. We have to, by our example, integrate into society rather than set ourselves apart from it and say no, you have to accept us just the way we are. There are certain things where we have to be the ones to adjust. If we choose to accept how our society defines us, then that is *our* problem, not theirs (2).

I told this participant that I thought that when you have grown up with a disability, it is easier to buy into the judgments that people make about you and how they define you. It requires a strong sense of self to defy that. When you are thrown into it from the moment you are born and people are making judgments about your abilities, whether you will walk or talk or what kind of a "normal" life you will have, it is much more difficult to develop a strong sense of self that defies that.

This has not been the lived experience of this participant. This same participant, when asked if she ever experienced any barriers that hindered her participation in community life, had this to say,

> I don't think so, but I think that this might be because of my attitude toward my disability rather than because there aren't any; because I have a personality style that is like a bull in a china shop. So, I can see where there might be barriers, but I've always been able to ignore them and generally by ignoring them, I've always gotten to do what I wanted to do. I'm not so concerned with what other people are thinking about me or what kind of barriers they put in front of me. It's more what kind of barriers do I want to live with and if I do, than that's fine, but if I don't then I don't pay any attention to it. I've been so mainstreamed in my life, that I just don't see the barriers. I've always been able to compensate no matter what it is (2).

This participant's attitude toward her disability and how it effects her, is similar to the attitude that one would find among the deaf community and the blind community. Each of these disability groups view their situation as a state of being and not as one that creates any limitations for them. They have a clear understanding that their deafness or blindness is a way of life and not a disability.

One barrier she did experience however, was when she was raising her children when they were babies and toddlers.

> Obviously, there are certain aspects of parenting that are not easy for a person with a disability. There just aren't any resources. I had to figure all that out for myself. I see the barriers and I deal with them (2).

Spirituality

Each of these participants identified their support system in the following ways:

> My biggest support system is my husband, my colleagues and the students that I work with (1).
>
> My biggest support system is God and my family (2).

> My support system is God (3).
>
> My support system is my family, my friends and the community organizations I belong to (4).

Each of the participants in this study defined Spirituality in the following ways;

> Spirituality to me means choices. I can not afford to have others tell me how things will go or that they will take care of it for me, because then things won't turn out the way I need it to (1).

This participant goes on to say,

> It's interesting, at the time of my accident, a lot of things were going on in my life. The accident literally cut a piece of me away and in a sense cut those things away from me, too. I was forced to redefine who I am. This took awhile for me. I wasn't teaching at the time, so I couldn't define myself as a professional. I wasn't looked upon as a woman so I couldn't define myself as a sexual being. It took me awhile to redefine who I was. Now, my sense of self is stronger and my belief in myself has become stronger than my disbelief from other people (1).

Another participant defines spirituality as a well-defined set of religious beliefs which she believes to be the truth. To her, real truth comes from the Scriptures and belief in God. She believes her spiritual journey is from the cradle to the grave.

> Spirituality is more of a new-age term and has more to do with us then with God. The word, "spirituality" demeans the whole experience of God. God is experienced through the Scriptures and by faith only. However, we all have a soul and it is possible to experience your soul while you are living (2).

She believes that she does not experience any barriers to her spirituality because,

> it can only be experienced through God. My disability has nothing to do with defining my spirituality, because my spirituality comes from God (2).

Another participant defines spirituality as,

> One's relationship with God, friends, family and your journey in life...my disability plays a part in that because, I'm not going to lie to you and say that there aren't days where I say I'm really sick of this crap. The only thing that keeps me going is that this is the hand that I was dealt and I have to figure out a way to find meaning in that. Spirituality exists in every aspect of human life (4).

One way that he finds meaning in that is to not take "no" for an answer, being willing to stop and answer questions when people, especially kids, stop him on the street and ask him questions about his disability and by belonging to disability groups.

Another participant defines spirituality exactly as the author, Bo Lozoff would. Lozoff defines spirituality as having two parts: (1) commune - understanding and experiencing spirituality from within and (2) community - being able to share and connect with others and your environment. This participant says that spirituality is defined as,

> being part of a larger community and with that being spiritually self aware of what God expects of us and to live that and to share that with our community, but also to be strong enough to endure challenges set forth by the community (3).

This participant does not believe that there are negative spiritual experiences

> Spirituality is a constant journey, there is always the potential for growth, the negative is that we only have this life to experience it. There is life after death, but I won't be aware of it. As long as I live and breathe, no spiritual experience is negative because one person's negative is another ones positive. There could be barriers to this journey for me, but only if I allow it. Spirituality has been the main driving force in helping me get ahead. If a person is not well grounded in their spirituality, they are not going to make it (3).

Chapter Five

DISCUSSION OF FINDINGS AND IMPLICATIONS

In this study, four people with physical disabilities discussed their lived experiences of having a physical disability. They also were very open in discussing the dynamics and significance that spirituality has for them and how having a physical disability shapes their spiritual journey.

While it is true that the perceptions and experiences of these four people are not a representation of the entire disability community, there is much that can be learned from the lived experiences of these four individuals. This chapter begins with a discussion of the major findings of this study, its strengths and limitations are discussed, as well as the implications to the practice of Social Work, implications for research and implications to society as a whole.

Discussion

There were several themes throughout the findings of the study that coincided with the literature. The common themes that surfaced in both the literature and the interviews were: social construct of disability, attitudes and barriers, and spirituality.

The literature discusses the ways in which our society defines disability and it tells us that the disability experience in our society is consistent with our cultural ideations that people with disabilities are, in effect, "damaged goods." The literature also states that their experiences appear to affirm the prevalence of "language and images that perpetuate the notion of the defectiveness of persons with disabilities. Their experiences also acknowledge the messages perpetuated by society of the wrongness of their bodies

(Phillips, 1990 p. 855)." Also the literature states that the disability experience in our society is one of societal minority status (Phillips, 1990 p. 849).

It is clear from the interviews conducted that for these four people with physical disabilities, the societal attitude which stems from the way society constructs disability, is the main obstacle to barriers in their lives. All the participants, except one, could very clearly describe the barriers that each of them faced in society and they were very clear that societal attitude led to those barriers.

Derezotes defines spirituality as "a complex, intrapsychic dimension of human development, in which the individual moves towards higher states of connectedness, well-being, consciousness, and/or meaning" (Derezotes, 1995 p. 1). He describes spirituality in terms of one's relationship with a higher power, as a desire to realize one's true self and inner potential. The literature talks also about the entities of society that have played a role in how society defines disability, those being: science, bureaucracy and organized religion respectfully. The literature is critical of how the Medical Model has adversely shaped how we define disability and how we treat people with disabilities. From the Medical Model perspective, we see them as broken, incomplete, and imperfect needing our pity and our care (Fitzgerald, 1997).

For people with disabilities as a whole, and especially people with physical disabilities, I think spirituality becomes the path to wholeness that they seek. It offers a way out of that fragmentation of the person. Spirituality takes away the disconnectedness that they experience in society. Spirituality is the only thing that we have that goes beyond the state of the body or mind. Our society can not do that. The findings seem to confirm this.

Each of the four participants, like the literature, defined their spirituality in different ways. Three of the participants felt that their experiences as people with physical disabilities helped to shape their spirituality. To each of them, the relationships that they had with other people, disabled and non-disabled, and the task of finding meaning to their lives, was an important part of their spiritual journey. The other participant believed that her spirituality was based solely on the Bible and that her disability had no impact on how she defined her spirituality or her spiritual journey. She was clear, however, that this spiritual dimension in her life was very important.

Two of the participants were also critical of organized religion and the Medical Model as they described their experiences with both of these entities. None of the participants spoke of their spirituality as being negative in any way. Each one seemed to view it as a strength and they rely on it to help them define who they are. But, for one participant, a negative aspect was in their relationship with organized religion. They told about how they were blatantly not included as a member of this community as a direct result of their having a physical disability. From the Medical Model one participant describes how she was treated as broken, needing fixing and taking care of and the profound impact that this had for her as she redefined who it is she is now versus who she was before she was disabled.

From the findings of this study, we learn several things about the dynamics and significance of spirituality for people with physical disabilities. Three of the participants concurred with the literature that social barriers are a reflection of how our society views them and that this is different from how they view themselves in society. From their comments, they seem to concur that our society does not view them as spiritual beings and therefore, can not view them as *people* separate from their disability. All four of the participants reject the societal view that they need fixing or curing of their disabilities. They view disability as a state of being, rather than something that limits them.

Most of the participants seem to feel that their spirituality is an extension of themselves that defines who they are: people, *not people with disabilities.* They view their spirituality as a tool to finding meaning in their lives *as they are*.

One participant has a different view of her spirituality than the rest. She does not think that her disability impacts her spiritual journey in any way. Perhaps this is because her spirituality is grounded differently than the other participants. She believes that her spiritual journey is rooted in her relationship with God and she relies on the Bible and her religion to bring meaning to her life.

This study is evidence that people in the disability community can create the social change that they desire. Each one of these participants has a voice and they use their voice to create change. Perhaps the real issue is that there are not enough people listening. There is hope for the future if people are willing to listen and to be open to a new way of constructing disability.

Strengths and Limitations

This study has several strengths. The flexible research design, allows the researcher to conduct in-depth interviews which can be modified to get as much raw data as possible with each interview. The literature review suggests that the data collected will be new and innovative and potentially useful and beneficial for many, including major changes in Human Service practice and policy.

It also has a limitation. This study is not culturally diverse in nature. Cultural factors may change how people understand their spirituality and their sense of self as disabled individuals.

Implications for Research

More research in the area of spirituality and disability needs to be conducted in order for our society to understand the dynamics and significance of spirituality to the disability community and for their understanding of how the current social construct of disability impacts the whole disability community. This lack of research could lead one to ask some questions. Why does our society insist on this construct of disability as our only frame of reference when thinking about the inclusion of people with disabilities into our society? Are we, as a society, ready to embrace a new frame of reference?

Another area of study that could be important to the inclusion of people with disabilities into our society is to explore the impact that organized religion has on disability. Exploring how their value system versus their practices impacts disability and how this is yet another reflection of our social construct of disability, could prove beneficial to the idea of embracing a social construct of disability that includes spirituality.

This study does not address children as participants and their understanding of disability. To explore how children construct disability and how their lived experiences impact their understanding of disability, could prove important in demonstrating how our social construct of disability is beginning to change.

Implications to Society

The current construct of disability embraced by society impacts the disability community by setting up a hierarchy. The idea that people with physical disabilities are part of a minority social status, leads to their overall isolation in our society. To embrace a social construct of disability that includes spirituality would have a significant impact on all of society. For example, this new construct of disability can be the catalyst that continues to change how our society makes laws regarding disability. Our societal attitude about disability would become one of complete inclusion and full participation rather than a hierarchical viewpoint.

Although there have been significant changes, we still have a long way to go in our society with regard to what we understand about disability and how we construct it. One example of this is the efforts being made in our school systems to educate children about disability and the efforts that have taken place with the passage of IDEA; (Individualized Education Act) that integrates children with disabilities into mainstream education.

Implications for Social Work Practice

Addressing the spiritual issues of all persons is a relatively new and innovative emphasis in the practice of Social Work. To address the spiritual issues for persons with disabilities is even more so. Even the profession, as all encompassing as it is; at present, is only beginning to recognize the importance of a construct of disability that includes spirituality and the spiritual journey. We, as a profession, would do well to embrace a construct of disability that includes the spiritual dimension and emphasizes the idea that persons with disabilities are human beings first, with a human spirit worthy of being recognized and validated *as they are* and as they are capable of becoming.

There is evidence that we are moving in this direction in social work education. Social work education teaches about the inclusion of all human beings into our society, the strengths perspective, social justice for all human beings, and it is beginning to teach about concepts like spirituality and resilience and about the values of postmodernism. This theory suggests that all people are individual with their own story to tell. For people with physical disabilities, this means that each person is more than the “diagnosis” or assessment that is placed on them. They, too, have a story to tell that is important and valid in its own right.

However, these ideas are less obvious in the practice of Social Work. For example, in hospital Social Work people are viewed from more in a Medical Model prospective. On the other hand, social work in a community-based program is conducted within a more person-centered perspective. It is here that the profession has made the greatest strides in viewing people in a holistic manner. It is imperative that we recognize the significant role that the practice of Social Work plays in continuing the conversations about the implications of our social construct of disability, as it continues to uphold the values of social justice and equality for all people.

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APPENDIX A

MEMO

April 19, 1999

TO: Ms. Michele Berndt

FROM: Dr. Lucie Ferrell, IRB Chair

RE: Your IRB Proposal

Thank you for your response to the IRB conditions for approval. You have met these conditions and your study, "Exploring the Significance of Spirituality in the Lives of People with Disabilities," is approved, IRB approval number 99-35-3. Please use this number on all official correspondence and written materials relative to your study. Your voice mail number will be 612-330-1568. Please call me at 612-330-1215 for the password and for instructions for use.

Your research should prove most interesting and valuable. We wish you every success.

LF:lmn

c: Mr. Vern Bloom

APPENDIX B

IRB 99-35-3

Spirituality and Disability: What are the Dynamics and Significance of Spirituality in the Lives of Persons with Physical Disabilities

Consent Form

You are invited to be in a research study exploring the significance of spirituality to persons with disabilities. You were selected as a possible participant because of the add that you saw in the Access Press Newspaper. I ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Michele Berndt as part of my master's thesis at Augsburg College.

Background Information:

The purpose of this study is to explore the significance of spirituality in the lives of persons with disabilities and how spirituality assists that person in coping with their lives.

Procedures:

If you agree to be in this study, I would ask you to do the following things. I have prepared an interview guide that will ask you statistical questions such as your age, what your disability is, and when the onset of your disability was. You will also be asked to discuss in-depth, your current support system, any barriers that you have experienced in society because of your disability and where you think these barriers come from and the significance that spirituality has in your struggle with these barriers.. You will also be asked to describe your sense of your own spirituality, and your spiritual journey. Lastly, you will be asked to explain the significance that spirituality has for your life as well as to describe any barriers to this spiritual journey that you have encountered.

The interview is expected to take 1-1 ½ hours. The researcher may need to ask you additional questions not on the interview guide as a means of clarifying something that you have said or to allow you to elaborate on what you have stated. The additional questions will not contain any additional content not outlined on the interview guide. However, you can refuse to answer any or all questions at any time during the interview that you wish to not answer. This will in no way effect the pay that you will receive for your participation.

The researcher will be writing down your answers as you speak. You will also need to agree to have the interviews audio taped. This allows the researcher to get all the information as accurately as possible.

Risks and Benefits of Being in the Study:

The study has one risk; because the questions being asked are potentially of a sensitive nature, this may cause you some unintended psychological discomfort. Therefore, the researcher reserves the right to end the interview if it becomes apparent that continuing would be detrimental to you.

In the event that this research activity results in emotional injuries, treatment will be available, including; counseling, and follow-up care as needed. If you require it, a referral will be made to Walk-In Counseling Center, 2421 Chicago Ave., 612-870-0565. They can assist you in dealing with any emotional concerns you may have as a result of this study. However, payment for any such treatment must be provided by you or your third party payer, if any, such as health insurance, Medicare, etc.

Direct benefits to participation include the contribution of knowledge to the field of Social Work as this is an area not researched in the past.

Confidentiality:

The records of this study will be kept private. In any sort of report that might be published, no information will be included that will make it possible to identify you. Research records will be kept in a computer and on diskette. All diskettes will be kept in a locked file. Only the researcher, the thesis advisor, Vern Bloom, will have access to any of the data including audio tapes which will be made as a part of the interview process. These tapes will be erased upon approval from the thesis committee.

Raw data will be destroyed by Summer2001.

Voluntary nature of the Study:

Your decision whether or not to participate will not affect your current or future relations with the College. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

Contacts and Questions:

The researcher conducting this study is Michele Berndt. You may ask any questions you have now. If you have questions later, you may contact me at Augsburg through the thesis advisor, Vern Bloom at 612-330-1133

You will be given a copy of the form to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participation in the study.

Signature____
Date______________________________

Signature of investigator____________________________
Date______________________________

I consent to be audiotaped

Signature________________________________
Date___________________________________

I consent to the use of direct quotations with in the final analysis

Signature________________________________
Date___________________________________

APPENDIX C

IRB 99-35-3

Interview Guide

Statistical Information:

1. What is your age?

2. What is your disability?

3. When was the onset of your disability?

Please answer the next questions with as much detail as possible.

4. Please describe what barriers you have encountered, if any, as a result of your disability; which have hindered your ability to participate fully in community life.

5. What significance, if any, has spirituality had in your struggle with these barriers?

6. Where did these barriers come from, ie; attitudes of people in society, employers, educators, organized religion, etc. Please explain in detail.

7. Describe your support systems, if any, you may have had or may currently have such as; family, friends, any religious organizations, etc.

8. Now I want to ask you some questions about your spirituality.

    a. How do you define spirituality?

    b. Explain the significance, both positive and negative, of spirituality in your life and the forms that it takes.

    c. Describe with as much detail as you can, what is your spiritual journey and where are you now in that journey?

    d. Tell me what were some of the more important positive or negative spiritual experiences that you have had, what effect they have had on you and why?

    e. Describe any barriers to this spiritual journey that you have encountered.

APPENDIX D

IRB 99-35-3

"The Self-Expansiveness Level Form (SELF; Friedman, 1983), the Myers-Briggs Type Indicator: Form G, the Neo Personality Inventory-Form S, the Marlowe-Crowne Social Desirability Scale, the Spirituality Assessment Scale (SAS Howden 1992), the Spiritual Orientation Inventory (SOI Elkins, Hedstrom, Hughes, Leaf & Saunders, 1988), the Index of Core Spiritual Experience (INSPIRIT; Kass, Friedman, Leserman, Zuttermeister, Benson, 1991), the Mystical Experiences Scale (M-Scale: Hood, 1975), the Peak Scale (PES: Maths, Zevon, Roter & Joerger, 1982), the Intrinsic Religious Motivational Scale (IRMS; Hoge, 1972), the Transpersonal Orientation to Learning (TOTL; Shapiro & Fitzgerald, 1989), the Ego Grasping Orientation (EGO; Knoblauch & Falconer, 1986),the East-west Questionnaire (EWQ; Gilgen &Cho, 1979a), the Paranormal Belief Scale (PBS; Tobacyk & Milford, 1983), the Assessment Schedule for Altered States of Consciousness (ASASC; van Quekelberghe, Altstotter-Gleich & Hertwick, 1991), the Integration Inventory (II; Ruffing-Rahal, 1991), the Boundary Questionnaire (BQ; Hartmann, 1991), the Personal Philosophy Inventory (PPI; Persinger & Makarec, 1987, 1993), the Holistic Living Inventory (HLI; Stoudenmire, Batman, Pavlov & Temple, 1985), the Death Transcendence Scale (DTS; Hood & Morris, 1983), the Temperament and Character Inventory (TCI; Cloninger, Svrakic & Przybeck, 1993), the Phenomenology of Consciousness Inventory (PCI; Pekala, Steinberg & Kumar, 1986), and the Spiritual Well Being Scale (SWBS; Ellison, 1983; Paloutzain & Ellison, 1982) (MacDonald et al 1994, 1995 & 1997)."