

The Life Experiences of Women With Cerebral Palsy Who Have Experienced Mistreatment

by
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ABSTRACT

TITLE: The Life Experiences of Women With Cerebral Palsy Who Have Experienced Mistreatment

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RATIONALE: Abuse and mistreatment of women with disabilities is a complex problem that affects their health and well-being. Previous studies have focused on heterogeneous groups of women with disabilities, with only small numbers of women with cerebral palsy (CP) included. It has been suggested by Hassouneh-Phillips and McNeff (2004) that specific disabilities may play different roles in relation to abuse. Exploring mistreatment of women with cerebral palsy is the first step in determining the relationship between mistreatment and a specific disability.

PURPOSE: To describe the life experiences of women with CP who have experienced mistreatment and to describe how these women understand the meaning of their disability and their mistreatment experiences relative to gender, culture, social class, and power.

METHOD: The feminist biographical method was used to promote an in-depth exploration of women's storied lives, uncover the meaning of women's lives from their own personal perspective, and provide understanding of women whose stories seldom have been told. A criterion sample of eight participants took part in two in-depth, audio-recorded interviews. Data analysis involved: 1) transcribing interviews verbatim, 2) ongoing analysis throughout and after the interviewing process, 3) use of the hermeneutical procedure of comparing the part to the whole and the whole to the part, 4) identification of themes within each narrative and across all of the narratives, and 5) identification of exemplars of themes and categories.

RESULTS: Two major categories emerged from the participants' narratives: 1) mistreatment, and 2) living with cerebral palsy. Subthemes of mistreatment include: 1) the meaning of mistreatment, and 2) outcomes of mistreatment in their lives. In the second category participants described living with CP at four different stages of development: 1) childhood through adolescence, 2) higher education years, 3) young adulthood, and 4) later adulthood.

IMPLICATIONS: Addressing the issue of mistreatment is essential in providing appropriate health care for girls and women with CP. The first step in preparing this population for the challenges of living with their disability is to understand the significance of mistreatment and the meaning of CP in their lives.

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CHAPTER ONE

Introduction

Coming too early I was very small

But I didn't give up, not at all.

I fought to live and grow and grow

But cerebral palsy became my foe.

My parents had problems, so you see

They didn't know how to take care of me.

They left me alone and the police soon came.

I want you to know this is not a game.

Moving from home to home was sad,

But then something happened that made me glad.

My mother that I have now found me,

Gave me a home and set me free.

Even though my life was hard

Thanks to my mom I got this far.

I can do lots of stuff like read and swim.

Sometimes I even sing a hymn.

I learn through trial and error and stuff.

Even though things can be very tough,

Never give up even though you're too small

Because in the end, your spirit will grow tall.

By 15 year-old Danielle Freeborn

Personal Story

I adopted a three-year old girl with blonde hair, blue eyes, and spastic quadriplegia cerebral palsy. In an instant, I entered the world of cerebral palsy (CP). Our twenty years together have been fun, fulfilling, and challenging. I have learned about the challenges of mobility, education, and growing up with a disability; also, that, while architectural barriers are a nuisance, attitudinal barriers are profoundly disabling. Months before it was time for Danielle to enter kindergarten, I approached the school administration about her special needs. The kindergarten rooms were not accessible, which had to be remedied. Danielle would need a mobility aide to assure her safety as she used her walker in the classroom and on the playground. The principal snidely commented that it was unfortunate so much money would be used for only one student. This was my first, but not last, encounter with blatant prejudice and ignorance.

I soon learned that having a child with CP affected nearly every activity of daily life. Simple events needed to be thought out and planned so Danielle could feel like an ordinary girl doing ordinary things. Decisions about transportation and equipment were constant and have become more important as Danielle has grown, since I am no longer able to carry her and can barely lift her when needed.

As a registered nurse, family nurse practitioner, and certified nurse midwife, I thought I was fairly knowledgeable about CP. After all, I not only knew about impaired muscle control and abnormal posturing, I had significant understanding about appropriate interventions. It didn't take long, however, for me to see CP within a greater social context and realize that my prior knowledge was woefully insufficient. Danielle had the same spunk and tenacity that any child might have, but she couldn't get her body to do the things she wanted it to do. This, I learned, was the impairment of CP. I learned that

the disability of CP comes from architectural and attitudinal barriers. The impairment of CP may require a child to walk with a walker, but the presence of curbs or other obstacles turns the impairment into a disability. Attitudinal barriers are even more challenging and reflect a disability-phobic society's belief that those with disabilities are less than human (Fine & Asch, 1988; Neath, 1997; Wendell, 1996). While my formal education taught me specific, technical aspects of CP, my informal education taught me holistic, human aspects. Twenty years with Danielle have shown me that nurses, doctors, physical therapists, occupational therapists, speech therapists, teachers, and others need to truly understand the humanness of those with CP in order to approach them in a manner that can assist them to achieve and maintain their health and well-being. Professionals and others need to realize that children, adolescents and adults with CP have the same wishes, wants, personalities, and other traits of children, adolescents and adults without CP. Taking a holistic approach to understanding the experience has led me to the biographical method, in which participants share their life histories, thus allowing readers to find commonalities to promote a true understanding of the humanness of people with CP (Finger, 1988).

As Danielle grew from a child to a young woman, I began to see the role that gender plays in disability. In her high school there were three students in wheelchairs: Danielle and two boys. Assistance, such as classroom aides, provided to the boys was denied Danielle, and I saw that being female was also disabling (Harris & Wideman, 1988; Hillyer, 1993; Neath, 1997; Wendell, 1996). Just as gender increased Danielle's vulnerability to discrimination, it also increased her vulnerability to sexual abuse. At age 16, she was sexually assaulted by the man I brought into our lives as her stepfather. We have become survivors of violence by enduring the psychological, physical, and legal

stressors associated with this violation. While the overt sexual assault occurred just once, there was at least one other occasion when he likely molested her under the guise of providing personal care when I was not available to do so. I watched as Danielle tried to cope with the aftermath of the abuse, and wondered if her coping was more difficult because of her disability. Danielle is unable to walk independently or even stand unaided, thus being sexually assaulted was not just a physical trauma, but an assault on her dreams and hopes to be independent and able to care for herself. She believes her disability made her powerless and vulnerable, and she has struggled for the last eight years to overcome the emotional consequences of abuse.

While feminism has traditionally viewed violence against women as a problem of male dominance (De Beauvoir, 1989), hooks (2000a) describes the social construction of violence as occurring between the powerful and the powerless or the dominant and the dominated. The focus for many feminists is to uncover the societal conditions that allow women to be the targets of abuse (Okun, 1985). This concern can and should be expanded to include women with disabilities (Neath, 1997). By combining the biographical method with a feminist approach, this study explored the experience of women with CP who have been mistreated or abused and the role gender may play. The use of the feminist biographical method allowed me to identify the assumptions I brought to this research. Because of my experiences with Danielle, I assumed that, in addition to citing disability-related experiences with discrimination, physical, and perhaps sexual, abuse, they would identify gender as a significant factor in mistreatment experiences. I also assumed that childhood experiences, both positive and negative, would prepare them for adulthood and that their disability would play a less significant role in their adult lives. However, I wondered if mistreatment and abuse in childhood increased their risk

for mistreatment in adulthood. I became interested, therefore, in research that would explore the life-long experiences of women with CP who have experienced mistreatment in order to address the issues inherent in these assumptions.

As I immersed myself in studies concerning abuse of women with physical disabilities, I identified a significant gap in the literature. Although 15 articles were found addressing abuse of women with physical disabilities, none focused on women with CP or on women with a lifetime disability, but combined women with both congenital and acquired disabilities as participants. The studies did not delineate differences in disability experiences, and therefore, provided little information about abuse of women with any specific type of disability and no information about the role lifelong disability may play in the abuse experience.

A secondary analysis of data from a larger study examining abuse experiences of community-dwelling women with physical disabilities became a catalyst for this work. In the pilot study, I conducted a secondary analysis of narratives of five women with CP who had experienced abuse (Hassouneh & Freeborn, 2006). Since this was a secondary analysis, I was unable to conduct follow-up interviews to clarify or expand the narratives. However, the women's stories described the role early childhood experiences had on later adult abuse situations and stimulated my desire to understand better the lives of women with disabilities who experienced abuse. An investigation into the relationship between childhood experiences and adult mistreatment experiences of women with CP must begin with the life stories and experiences of the women themselves. The feminist biographical method includes obtaining life histories of participants and exploring the female life-cycle experience (Alpern, Antler, Perry, & Scobie, 1992; Denzin, 1989).

Understanding the abuse phenomenon of women with CP mandated exploring not just the social conditions creating an abusive environment but also the interaction of those conditions with the unique vulnerabilities of women with CP. Feminists believe women have an innate ability to understand their lives, abilities and vulnerabilities (Nilsen, 1992; Olesen, 2000). Women with disabilities who have been mistreated or abused not only understand the female condition, but its relationship with disability; and, unfortunately, with abuse (Hillyer, 1993). By listening to the stories of women with CP who have been abused, we gain a better understanding of the confluence of abuse and disability in women's lives within a greater societal context. As women tell their stories, they not only bring their experiences to life, but create meaning and allow each of us to make sense of our world and experiences (King, Brown, & Smith, 2003).

Cerebral Palsy

CP is the most common physical disability of children, with approximately 9,500 new cases each year in the United States (UCP, 2005). It is characterized by abnormal motor control and/or posture, ranges from mild to severe, and may or may not involve communication difficulties (Turk, Scandale, Rosenbaum, & Weber, 2001; Wichers, Odding, Stam, & Van Nieuwenhuizen, 2005). Due to increasing survival rates of premature and low birth weight infants and higher frequency of multiple births, the prevalence of CP has increased worldwide over the last 40 years to about 2.5 per 1,000 live births (Behrman & Kliegman, 2002; Odding, Roebroek, & Stam, 2006).

With increasing numbers of children who have CP, 85-90% of whom will reach adulthood, there will be ever increasing numbers of women with CP (Ansari, Sheikh, Akhdar, & Moutaery, 2001; Hemming, Hutton, & Pharoah, 2006; Hutton & Pharoah, 2005). These women grow up facing issues not encountered by children who do not have

a disability (Harrison, 2003). One of these issues is poor socialization (Pimm, 1996), which different researchers attribute to the child's actual physical limitations and to the stigma of the physical disability itself. Physical limitations of CP range from mild to severe, but even mild physical limitations disrupt recreational habits and result in poor social integration (Lepage, Noreau, Bernard, & Fougereyrollas, 1998; Pimm, 1996). In fact, the stigma of CP is significant in the lives of children and adults with the condition and in their families, schools, society, and work environments (Green, 2003; Green, Davis, Karshmer, Marsh, & Straight, 2005; McLaughlin, Bell, & Stringer, 2004; Mweshi & Mpofu, 2001). This stigma seems to be more significant for adolescent girls with CP who were found to have lower self-esteem than their non-disabled peers, whereas boys with CP did not differ from their peers in self-esteem (Magill & Hurlbut, 1986).

In addition to general low self-esteem, girls and young women with CP also have poor body esteem (Hassouneh-Phillips & McNeff, 2005; Taleporos, Dip, & McCabe, 2002). Body esteem goes beyond body image, which is the mental representation of body shape, size and form, to the self-evaluation, positive or negative, of one's body (Taleporos & McCabe, 2001). The association between social integration, stigma, self-esteem, or body esteem and the risk for abuse is unclear. Researchers are, however, beginning to look at these associations. Low self-esteem is cited as one of many factors contributing to abuse in the ecological model of abuse of disabled women developed by Curry, Hassouneh-Phillips, and Johnston-Silverberg (2001). Poor body esteem is also associated with an increased vulnerability to intimate partner violence for women with physical disabilities (Hassouneh-Phillips & McNeff, 2005; Taleporos et al., 2002).

Abuse of Women with Disabilities

The vulnerability for abuse is significant for women with or without disabilities. For example, each year 1.9 million women endure an estimated 5.3 million incidents of intimate partner violence resulting in nearly two million injuries (National Center for Injury Prevention and Control, 2003). Even though these statistics do not differentiate between women with or without disabilities, some studies suggest 40%-72% of women with disabilities are abused at least once in their lifetime (Beck-Massey, 1999; Gilson, Cramer, & DePoy, 2001; McFarlane et al., 2001; Powers, Curry, Oschwald, & Maley, 2002; Ridington, 1989; Young, Nosek, Howland, Chanpong, & Rintala, 1997). If these estimates are correct, using United Cerebral Palsy data citing approximately 400,000 women with CP in the United States, 160,000 to 288,000 women with CP have been abused (UCP, 2005).

Other than the pilot study I conducted, no studies were found that explored abuse of women with CP, except within the larger context of all women with physical disabilities. Therefore, the exploration of abuse of women with CP required an exploration of the broader issue of mistreatment or abuse of women with any type of physical disability. For these purposes, abuse was defined broadly as any behavior deemed coercive, oppressive, harsh, cruel, or domineering toward a woman with CP which may lead to oppression or disadvantage, and/or harm her physically, mentally, emotionally, or socially (Mays, 2006; Yllo, 1993). Consistent with feminist views of abuse, the ultimate determination of whether a woman has been abused must be made by each individual woman, who truly is the only person who knows what behaviors have been harmful to her well-being (Bograd, 1990; Collins, 1990). In order to minimize the possibility that potential participants would consider abuse to be only physical or sexual,

and therefore exclude themselves from the study, it was determined that mistreatment would be a more appropriate term. The terms mistreatment and abuse, therefore, were used interchangeably in this study.

Mistreatment of women (both with and without disabilities) has serious health effects, including not only actual physical injuries, but subsequent physical complaints such as fatigue, chronic pain, sexual dysfunction, gastrointestinal disturbances (Barrier, 1998), and psychological problems (Coker et al., 2002). Compared to women who have never been abused, there is a 50-70% higher incidence of gynecological, central nervous system, and stress-related problems in women who have been abused (Campbell et al., 2002; Wathen & MacMillian, 2003).

In addition to intimate partner and other types of abuse suffered by women with and without disabilities, women with disabilities experience care-related abuse. Care-related abuse occurs in settings in which, due to her physical disability, a woman must rely on another individual to meet her daily needs such as hygiene, nutrition, and mobility. Care-related abuse may include withholding medication, forcing a woman to stay in a wheelchair for long hours, and refusing to meet essential personal care needs (Gilson et al., 2001; Nosek, Foley, Hughes, & Howland, 2001; Powers et al., 2002; Saxton et al., 2001).

Reliance on others to provide essential daily care complicates the ability of women with disabilities to leave an abusive relationship. Those who provide services and shelters for abused women are seldom equipped to provide for the physical, communication, or emotional needs of those with disabilities (Gilson et al., 2001). Many women feel trapped in an abusive situation because of their need for personal assistance

or their fear that there is not an accessible shelter available (Gilson et al., 2001; Hassouneh-Phillips, 2005; Powers et al., 2002; Saxton et al., 2001).

The nature of the disability itself may also put women with disabilities at an increased risk for abuse. Increased dependency on others, perceptions of powerlessness, difficulty being believed, social isolation, lack of education about appropriate sexual behaviors, desire to be “normal,” or having learned her body is “public” from years of health providers touching her while providing physical therapy or other physical care all have been cited as potential risk factors for abuse (Andrews & Veronen, 1993; Curry et al., 2001; Hassouneh-Phillips, 2005; Nahmiash, 2002).

While women with CP share many of the above risk factors with women with other disabilities, it is not known how the nature of CP itself may increase or decrease a woman’s vulnerability for abuse. However, three studies have examined abuse experiences of individuals with specific disabilities (women with neurologic disorders, women with spinal cord injury, and both men and women with multiple sclerosis). A study investigating domestic violence against women with chronic neurologic disorders demonstrated that those with behavioral changes such as impulsiveness and aggression were more likely to be abused (Diaz-Olavarrieta, Campbell, Garcia de la Cadena, Paz, & Villa, 1999). Women with spinal cord injuries experience increasing vulnerability to abuse after their injury and experience significant abuse related to dependency and healthcare needs (Hassouneh-Phillips & McNeff, 2004). Finally, a review of court records in Massachusetts demonstrated that while men and women with multiple sclerosis represent only 1% of the population, they represented 12% of the cases of abuse (LaRocca, 1999). Only the first study implicated specific disability manifestations as increasing the vulnerability for abuse. The other studies imply that there may be specific

vulnerabilities to abuse, depending on a person's particular disability, but do not explain how the unique manifestations of a disability may increase a woman's risk for abuse. If disabilities do put women at greater risk for abuse, then the task is to tease out those vulnerabilities within specific populations so appropriate interventions can be implemented to decrease the incidence of abuse (Nosek, Howland, & Hughes, 2001).

The literature on abuse of women with disabilities provides evidence to raise the question of vulnerability and actual mistreatment of women with CP. With the increasing incidence of CP, it is crucial to tackle the significant problem of mistreatment for this population. Unlike acquired disabilities, women with CP live their entire lives with physical and social limitations that are unique to CP. The literature on abuse of women with disabilities has provided valuable information for all women with disabilities. This feminist biographical study provides insights about the experience of lifetime disability and mistreatment within social, political, and historical contexts by utilizing in-depth interviews and the participant's own written texts. This is the first step toward alleviating suffering related to this important unaddressed health care issue.

The overall aim of this study was to explore the life-long experiences of women with CP who have experienced mistreatment. The feminist biographical method promotes an in-depth exploration of women's storied lives, uncovers the meaning of women's lives from their own personal perspective, and provides understanding of women whose stories have seldom been told (Popadiuk, 2004a; Thomas, 1999). Since mistreatment of women with disabilities includes aspects of gender, culture, social class and power, a critical feminist approach is appropriate for studying the phenomenon (Fonow & Cook, 1991; Reinharz, 1992). The biographical method integrates participants' perspectives with written textual depictions from their cultural backgrounds (Denzin, 1989; Erben, 1996).

A feminist biographical method focusing on women's life histories allows for the investigation of the social, political, and historical constructs of women's lives, issues, disability and mistreatment, and results in a rich, holistic investigation of the lives of women with CP (Gutierrez, 1992; Popadiuk, 2004a). The utilization of the feminist approach also allowed me to include autobiographical origins of my research, which is consistent with the feminist principle 'the personal is the political' (Mann, 1994), characteristic of feminist research (Reinharz, 1992), and allows the reader to understand my position and critique my interpretations based on my assumptions (Thomas, 1999). I have come to appreciate CP, and I know it can affect every aspect of childhood and adulthood. It is truly a disability with physical, emotional, and societal ramifications. While I believe CP may increase a woman's risk for mistreatment, I also believe there are positive aspects, such as learning to overcome challenges, which affect how a woman views her life experiences.

Specific Aims

The specific aims of this study were:

1. To describe the life experiences of women with CP who have experienced mistreatment.
2. To describe how these women understand the meaning of their disability and mistreatment experiences relative to gender, culture, social class, and power.

CHAPTER TWO

Review of the Literature

Theoretical Background

Exploring the experiences of women with CP who have been mistreated begins with a review of research focused on women who have been abused. To date, there have been only a few studies that focused exclusively on the abuse experiences of women with physical disabilities, and no studies about women with CP who have been abused. Although women with CP belong to the larger group of women with physical disabilities, they are distinct in many aspects. CP manifests itself in very early childhood when physical milestones such as sitting and rolling over are not met. Gross and fine motor abilities, speech and articulation may all be impaired.

This section begins with a review of pertinent literature focusing on society's attitudes toward those with disabilities. Descriptions of stigma, oppression, marginalization, powerlessness, disablism, and violence provide a background for exploring feminist views of abuse and disability, which provided the lens through which this study was conducted. Further literature regarding patterns and causality of CP and how CP influences a woman's vulnerability to abuse is discussed. Finally, since there is no specific literature on the abuse of women with CP, general literature regarding abuse of women with physical disabilities will be presented.

Societal Attitudes toward Women with Disabilities

Women with CP must live within a society that views them as socially unacceptable. This stigmatization was demonstrated when Goffman (1963), whose landmark work intended to shed light on the social devaluation of those with disabilities, but actually devalued those with disabilities by referring to physical disabilities as

abominations of the body. While Goffman referred to physical disabilities as abominations, he described dishonesty as only a “blemish of character.” The use of a derogatory term, such as abomination, in professional literature demonstrates society’s acceptance of such terms and underscores the oppression, marginalization, powerlessness, disablism, and potential for violence that women with CP may face on a regular, if not daily, basis. This section explores these phenomena and the disability experience.

Stigma is the social disapproval of an individual or group whose appearance or behavior is not consistent with mainstream society. When society stigmatizes those who are different, the physical impairment or difference (which is only one aspect of an individual’s life) becomes the defining element of that person (Asch & Fine, 1988; de Klerk & Ampousah, 2003; Gill, 1996; Thomson, 1997a; Wendell, 1996). When one dimension of human difference becomes the defining element of a group of individuals, that defining element is then utilized to polarize groups into opposing categories, such as the disabled versus the non-disabled, or the abnormal versus normal. This categorization is often compared to racial categories, which traditionally have been used to justify segregation and deny basic human rights to specific groups (Neath, 1997; Wendell, 1996). However, the comparison is imperfect because children born into families of a racial group different from the dominant group are surrounded by family members of the same racial group. A child with a disability, however, is most frequently raised in a family with able-bodied members who do not share the challenges of having a disability (Olkin, 2006). In other words, although those with disabilities may face discrimination and oppression similar to those in minority social groups, they probably face it without the association of others with disabilities. Although family members may mentor the

child in many ways, they may be limited in helping the child adapt to and accept a physical disability.

A child with a disability may never know another person with the same disability or may seldom see disabled children or adults portrayed in the media. This reinforces their marginality, as they exist on the fringes of the dominant group. Roberts (1983) discussed the characteristics of oppressed groups and of individuals who give up their personal identities in order to assimilate into the dominant culture. She stated these individuals must reject their own characteristics, which leads to self-hatred and low self-esteem. Children and adults with disabilities may have no group other than the dominant cultural group with which to identify and thus no choice but to try to assimilate into the dominant culture. As they attempt to assimilate, they are confronted with the oppressive, discriminatory practices of those who believe they are inferior to those without disabilities. When those with disabilities internalize society's disablism and realize they are prevented from becoming full members of society, they may feel a sense of loss, grief, and oppression, which adds to feelings of low self-esteem (Bevan & Thompson, 2003; Neath, 1997; Roberts, 1983).

Oppression of women with disabilities may take several forms, including exploitation, marginalization, powerlessness, cultural imperialism, and violence (Northway, 1997). For example, exploitation occurs when an oppressed group is allowed to enter the labor market only in menial, low paying jobs. In the United States in 2004, the employment rate of working-age people without disabilities was 77.8%, compared to 19% for people with disabilities. Men with disabilities had an employment rate of 20%, while women with disabilities had the lower rate of 18% (Houtenville, 2006).

Marginalization refers to the exclusion of an oppressed group from full participation in society or to the process in which certain persons are relegated to the periphery of society (Northway, 1997). These peripheral boundaries serve as barriers that help maintain distinct identities separating those within society's mainstream from those who are marginalized (Hall, Stevens, & Meleis, 1994). Feminists have been concerned about the marginalization of all women in a society that is designed for men. For women with disabilities, this marginalization is more pronounced, when, for example, the ever increasing pace of life excludes them from meeting performance expectations they may not have trouble achieving in a slower paced or more accommodating society (Wendell, 1996).

Powerlessness is the result of other individuals having positions of power over the oppressed group (Northway, 1997). Since powerlessness is often associated with silence (Hillyer, 1993), oppressed groups have little voice in what is done to or for them (Ferguson, Ferguson, & Taylor, 1992). Silence not only perpetuates the powerlessness of women with disabilities; it also forces their experiences to remain unspoken and their lives to move further into the margins of society (Wendell, 1996).

Cultural imperialism reflects a society's disablism which is the belief that an individual or a group is of less worth than the dominant group (Northway, 1997). When Franklin D. Roosevelt was paralyzed by polio in 1921, he would not risk his political future by acknowledging his disability to the American people—and so began an elaborate deception that allowed him to become governor of the state of New York and then president of the United States. Roosevelt's son, James, spent many days surveying physical facilities in order to plan how his father could give a speech without being seen in his wheelchair. This often required Roosevelt to laboriously walk to the podium with

his braces locked, using a cane in one hand and gripping James so tightly with the other hand that James struggled to keep from crying in pain. Although he was the most powerful man in the most powerful nation in the world, Roosevelt's obsession to keep his disability a secret indicates he feared a society that would deem him unfit and perhaps unworthy to hold political office (Gallagher, 1985).

Finally, violence against those with a disability, as a symptom of oppression, may be threatened or actual. Emotional abuse often takes the form of threats of bodily harm, while domestic violence and child abuse are examples of violence to an individual. Violence occurred at the societal level when Nazi Germany exterminated thousands of people with disabilities (Lifton, 1986). Murder techniques eventually utilized against the Jews were actually tested and used on thousands of Germans with mental or physical disabilities, whom some viewed as useless consumers of resources who were not worthy to live (McFarland-Icke, 1999).

American law has a long tradition of oppressing individuals with disabilities. Fear that people with disabilities, considered "genetically inferior," would promote the deterioration of the dominant, "normal" race caused 28 states to pass sterilization laws in the 1920s and 1930s. These laws allowed sterilization of those deemed deficient and thus a "menace" to the state (Phillips & Rosenberg, 1980). Other laws considered oppressive to those with disabilities include "ugly" laws, which prohibited individuals considered "unsightly or disgusting" from appearing in public; transportation laws, which required individuals with physical or mental disabilities to have an attendant in order to use public transportation; and "intercourse" laws, which threatened imprisonment for a man who was "epileptic, imbecile or feeble-minded" having sexual intercourse, or an able-bodied man from having intercourse with a woman who was "epileptic, imbecile, feeble-minded

or a pauper” (Phillips & Rosenberg, 1980). Some may argue these laws reflect outdated social norms and our society has progressed well beyond that type of thinking. However, while these laws no longer exist, some of the “ugly laws” were not repealed until 1975 (Thomson, 1997a).

While the Americans with Disabilities Act improved the legal status of individuals with disabilities, it has not changed how disabilities are viewed in Western culture. Men with disabilities are often seen as being disabled because of war or some other external cause, which is deemed socially acceptable (Fine & Asch, 1988; Wendell, 1996). However, women with disabilities are viewed as being disabled because of disease or some internal cause, which is not only socially unacceptable but also is perceived as making them more deserving of their fate (Fine & Asch, 1988). In addition, both people with and without disabilities view individuals with CP more negatively than they do individuals with other disabilities (Deal, 2003; Gordon, Minnes, & Holden, 1990; Thomas, 2000; Tringo, 1970). In fact, Tringo’s (1970) hierarchy, which ranked the social acceptability of disabilities, placed CP 15th out of 21 disabilities, above only hunchback, tuberculosis, ex-convict, mental retardation, alcoholism, and mental illness. Thirty years later, Thomas (2000) found Tringo’s hierarchy was stable, with only cancer advancing in rank. Deal’s (2003) metasynthesis of the literature looked at the hierarchy of disability among those with disabilities and found that a hierarchy does exist and that those with disabilities rank others with disabilities by how impaired they are and how impaired they appear. Those with CP, therefore, may rank higher, which reflects being more acceptable to others, if their impairment is less visible; but they would rank lower, and thus not acceptable to others, if their impairment were visible and deemed to make them less

attractive. In addition to the stigma and hierarchy of disability, Ewing (2002) explored how gender puts women with disabilities at an additional disadvantage.

Stigma, oppression, marginalization, powerlessness, and violence affect not only women with CP and other disabilities, but have historically been part of all women's lives. While feminists have focused on these concepts and their interrelations with gender, they have not included the additional concept of disability and the role it may play in the marginalization of women with disabilities. However, the philosophical approach utilized by feminists in the evaluation of women's lives is useful for evaluating lives of women with disabilities.

Feminism

As previously discussed, there is a dearth of literature concerning women with disabilities who experience abuse. From a feminist perspective, this "un-knowing" of the experience of women with disabilities who have been abused hinders our ability to respond appropriately when abuse occurs. One goal of feminism is to reveal the unrevealed, or in this case, the ignored and often invisible lives of women with CP who have experienced abuse.

Using a feminist lens in research permits the exploration of gender, culture, social class, and power in the lives of women. This acknowledges not only their place in society but also the influence society, and the social construction of abuse and disability, have on their lived experiences. Feminist writings on abuse of all women, and disabilities help to frame the discussion of abuse of women with CP.

Feminist Views of Abuse

Feminist views of violence against women focus on the social construction of gender and gender inequality within societies (Bograd, 1990; Neath, 1997). The social

construction of gender creates patriarchal or authoritarian societies in which one gender (male) has power and social status while the other gender (female) is relegated to the margins (Andersen, 1993; Beechey, 1979; Ferraro, 1988; Gordon, 1988; hooks, 2000b; Smith, 1990). When a society supports male domination on the familial, political, economic, and social levels, violence is the byproduct of maintaining male power and control (Goodman, Koss, & Browne, 1994). For example, in the 19th century, women were viewed as property of either their father or their husband, who were allowed to inflict corporal punishment on the woman as long as the stick was not larger than the man's thumb (Freeman, 1995).

While patriarchy is associated with the oppression of women, sexism, which can be hostile or benevolent, has been cited as the basis for hostility toward women. Benevolent sexism includes protective paternalism and the idealization of women, while hostile sexism includes dominating paternalism, disparaging beliefs and heterosexual aggression (Glick & Fiske, 1997). The division between hostile and benevolent sexism can be blurred with subtle discrimination such as patronizing gallantry or considerate domination (Benokraitis & Feagin, 1995). Both types of sexism perpetuate the social construction of gender by relegating women to lower status roles and positions.

Within a patriarchal, male-dominated society, powerful men are held in high regard, while powerless women are relegated to positions of low status. The role low status plays in abuse has been explored by feminists. For example, Yllo (1983) examined gender inequality with rates of wife abuse in the 50 United States and found the highest abuse rates occurred in states embracing traditional, clearly differentiated gender roles, as reflected by lower rates of women receiving higher education or being employed in middle to upper paying jobs. As gender inequality decreased and the status of women

improved, rates of abuse dropped with the exception of the most egalitarian states where rates of abuse were the second highest. This paradox, according to Yllo, may be due to male insecurities triggered by the rapid improvement of women's social status.

Feminist views of abuse against women often have focused exclusively on gender as the central explanation for oppression and abuse. However, many African-American feminists feel this view excludes minority women, and they have actively expanded feminist theory of violence to include women of all ethnic backgrounds (Collins, 1990; hooks, 2000b). These feminists propose race, gender, and class are interlocking systems which form an oppressive Matrix of Domination (Collins, 1990). Within the matrix, each woman brings her own personal history, group identity, and cultural experiences, which enhance or buffer her level of oppression or domination. Expanding the matrix to include disability as a fourth system of oppression is useful in the exploration of abuse of women with disabilities. The feminist biographical method promotes this exploration within the context of gender, culture, social class, and power.

Feminist researchers studying abuse often cite the inferior or even invisible position of women's experiences in a society that views men's lives as the norm. Without exploring abuse experiences from the viewpoint of women, many theorists revictimize women by portraying them as helpless, provocative victims, responsible for their own abuse. To counteract this approach, feminists emphasize the need to understand abuse experiences from the viewpoint of the women (Bograd, 1990), which is a major justification for this study. Women with CP are a silent, even invisible group of women whose experiences with abuse have never been explored. Understanding their experiences is the first step in bringing their stories out of the shadows and addressing a serious problem.

Feminist Views of Disability

Feminists concerned with disability focus on the social construction of disability. This includes social situations in which disability is an outcome, such as war, terrorism, or violent crimes. Societal problems, such as the lack of food and clean water, poverty, and abuse are also social situations resulting in temporary or permanent disabilities (Neath, 1997; Wendell, 1989, 1996).

A more subtle, yet just as debilitating form of socially constructed disability occurs when societal views, or disablism, handicap or disable those with physical impairments. Disablism, society's belief that those with disabilities are inferior to others, leads to discrimination, oppression, and abuse (Garland-Thomson, 2002; Gerschick, 2000; Mays, 2006; Neath, 1997; Thomas, 1999). An example of a societal factor that can handicap an individual with an impairment, but may be too subtle for people to comprehend, is pace of life. While a woman with an impairment may be able to function at her own pace, the time constraints and deadline demands imposed by society may exclude her participation in the workforce. The inability to meet society's demands becomes the disability, not the impairment itself. Many women with disabilities function well within the private world of home, where rest breaks are allowed, but are denied the opportunity to work in the public world of work where employers are not as accommodating (Garland-Thomson, 2002; Gerschick, 2000; Mays, 2006; Neath, 1997; Thomas, 1999; Wendell, 1996).

Society's demands that women meet cultural norms of attractiveness also can handicap women with or without disabilities, but these demands often provide another justification for stigmatizing behavior against those with disabilities (Garland-Thomson, 2002; Meekosha, 1998; Neath, 1997; Thomson, 1997a, 1997b). As cited earlier, Goffman

(1963) utilized terms such as *deformities* or *abominations of the body* when referring to physical disabilities. Using negative, insensitive words not only reflects society's devaluation of women with disabilities but also contributes to these women's "otherness" (Wendell, 1989, 1996).

The distinction of "others" in society means women with disabilities are not represented in the social system but must live in a society designed for and run by the non-disabled others. Often, however, society thinks it accepts those with disabilities because it has raised some, such as Christopher Reeves, Helen Keller, or Stephen Hawking, to "hero status." This designation of "hero status" may appear to some to eliminate stigma or "otherness." Since those chosen by society are not chosen by the disabled community, many people with disabilities resent and reject these celebrities and feel even more stigmatized and alienated. They worry they are expected to achieve an unrealistic standard and will be further marginalized if unable to do so (Wendell, 1989, 1996).

The experience of women with disabilities can be isolating, and the goal of research was not only to bring their experiences into the public or political world, but also to empower them on a personal and societal level (Morris, 1992, 1993). For women with CP, stigma and oppression render their lives invisible. Exploring the lives of women with disabilities is cited by Linton (1998) as "a prism through which one can gain a broader understanding of society and human experience" (p. 118). This validated the experiences of these women, by giving voice to their stories, and allowing us to gain a broader understanding of the society where they lived, while showing how society influenced their disability and abuse experiences.

Cerebral Palsy

Understanding the mistreatment experience of women with CP requires a basic knowledge of CP and its physical limitations. This section explores patterns, causality, and manifestations of CP, followed by an exploration of growing up and living with CP and how it may affect a woman's vulnerability to mistreatment.

Patterns, Causality, and Manifestations of Cerebral Palsy

CP is a nonprogressive condition, present from birth or infancy, including various neurological patterns of dysfunction. It is characterized by abnormal motor control and/or posture and is not diagnosed until the child is several months or even years old. Motor control problems can be spastic (muscular rigidity), dyskinetic (involuntary movements), spastic and dyskinetic mix (a combination of hyper- and hypo-tonicity with involuntary movements), or ataxic (poor coordination and hypo-tonicity), and may be hemiplegic (involvement of one side of the body), diplegic (involvement of legs more than arms) or quadriplegic (involvement of both legs and arms). Motor dysfunction ranges from mild to severe and may or may not involve communication difficulties (Turk et al., 2001; Wichers et al., 2005).

The neuropathology of CP is complex, and in many cases unknown. Traditionally, CP is attributed to trauma or problems occurring around the time of birth. In fact, William Little, who in 1862 identified a condition of spastic muscles of young children, explained the condition was caused by hypoxia during birth. However, only 6 - 10% of CP cases can be linked to an intrapartum hypoxic episode (Boccon-Gibod & Khong, 2004; MacLennan, 1999; Odding et al., 2006). While postnatal acquisition can occur due to meningitis, near-drowning, or shaken-baby syndrome, the most common causal pathways include antenatal factors, multiple births, prematurity, and low-birth

weight (Boccon-Gibod & Khong, 2004; Mikkola et al., 2005; Wilson-Costello, Friedman, Minich, Fanaroff, & Hack, 2005; Winter, Autry, Boyle, & Yeargin-Allsopp, 2002). The multiple causations of CP result in different patterns of injury to various brain structures, providing a range of symptoms. In addition to the obligatory motor impairments described above, individuals with CP may experience cognitive impairments, learning disabilities, behavioral problems, epilepsy, sensory impairments, chronic pain, speech impairments, ophthalmic abnormalities, feeding difficulties, dental abnormalities, impaired growth patterns, reduced bone-mineral density, and urinary incontinence (Odding et al., 2006; Rosenbaum, 2003).

The Experience of Persons with Cerebral Palsy

Clearly, the experience of growing up with CP is unique as these children face issues not faced by children without disabilities (Blum, Resnick, Nelson, & St. Germaine, 1991; Harrison, 2003). While several researchers have investigated the experience of raising a child or having a sibling with CP, there is a paucity of studies exploring this experience from the standpoint of those with CP. The eight participants in a study examining the experience of growing up with CP described frustration, isolation, and loneliness arising from daily confrontations with attitudinal barriers, and the need to focus on daily successes leading to in self-acceptance, coping, and hope (Tscherne, 2003). The ability to develop coping strategies, or a sense of coherence (SOC), is associated with well-being and good health outcomes and was investigated in a quantitative study of 766 adults with CP. Utilizing Antonovsky's SOC scale (Antonovsky, 1993), which scores an individual's manageability of problems, meaningfulness of life and comprehensibility of life events, the study revealed adults with CP had lower SOC than the reference group. This disparity was attributed to the

complex challenges of living with physical limitations in an unfavorable environment (Jahnsen, Villien, Stanghelle, & Holms, 2002).

King, Cathers, Miller Polgar, MacKinnon, and Havens (2000) focused their qualitative study of 10 adolescents with CP on how the adolescents defined success in their lives and what factors helped or hindered their success. Success was defined as being happy and was linked to meeting personal goals, feeling fulfilled and enjoying activities. Being believed in by others, believing in yourself, and being accepted by others were crucial elements for attaining success. However, being successful was hindered when these three factors were not present (King, Cathers, Brown, & MacKinnon, 2003; King et al., 2000).

The importance of being accepted by others and having a best friend was cited by respondents in a quantitative study of 162 adolescents with spina bifida or CP. While the majority of the adolescents had a best friend, best friends were often considerably younger, they seldom had social contact in each other's homes, and few respondents had ever dated. Reliance on a mobility device was cited as setting respondents apart from their peers and limiting their social interactions (Blum et al., 1991). Limited social interactions for children with CP and other physical disabilities are generally attributed to physical limitations disrupting recreational habits and social rejection by a society stigmatizing those who are different from the norm (Green, 2003; Green et al., 2005; Lepage et al., 1998; Pimm, 1996; Wadsworth & Harper, 1993). Social isolation occurring during childhood results in a lack of social skills in adolescence because social situations are avoided. This avoidance perpetuates loneliness and further hinders development of age appropriate social skills (Blum et al., 1991; Liptak & Accardo, 2004; Wadsworth & Harper, 1993). In his landmark work on loneliness, Moustakas (1961, 1975) described

how loneliness leads to isolation and depression for some, but self-awareness and creativity for others. Isolation and lack of social skills become an obstacle when individuals desire romantic or sexual relationships, but find even though they are “adults chronologically,” they are “more like adolescents socially” (Chance, 2002, p. 197).

Society’s negative view of women with disabilities contributes to the labeling and stereotyping of disabilities. The stigmatization of disability results from labeling a woman as being different in a way that is socially unacceptable, or promoting stereotypes of dependence or helplessness (Green et al., 2005). For women with CP, this stigmatization begins in childhood. For example, Green (2003) investigated mothers of young children with CP and found mothers described incidents they interpreted as stigmatizing toward themselves and their child, which increased the burden of caring for their child. The expectation of encountering stigmatized reactions from others resulted in the mothers’ avoidance of social interactions and increased the children’s social isolation. Other parents of children with CP described how the stigma of CP had a negative social effect on their children and correlated directly with how noticeable the disability was (Pimm, 1996).

The negative aspects of CP appear to have a greater impact on adolescent girls, who were found to have lower self-esteem than their non-disabled peers. On the other hand, boys with disabilities did not differ from their peers (Magill & Hurlbut, 1986). However, as adolescents with CP became young adults, their self-esteem increased and, though women with CP still had lower self-esteem than their peers, it was no longer statistically significant (Magill-Evans & Restall, 1991).

Positive Aspects of Disability

While much attention is given to the negative aspects of disability, there are some scholars and researchers who have explored positive aspects of disability. Murray (2003) described how youth with high-incidence disabilities, such as learning disabilities and mobility impairments, transition to adulthood. While many of these youth have poor adult outcomes, he found individuals who developed resilience could overcome difficulties and have positive outcomes. Other protective factors included self-determination and parents who were warm but demanding.

King and associates (2000) looked at how adolescents with CP identified success, and found participants who considered themselves successful based their success on being happy. These participants explained they found happiness in their internal characteristics of attaining personal goals, feeling fulfilled, and enjoying what they did in life. Happiness as an inner strength became a protective factor allowing them to detach their own self-worth from stigmatizing societal barriers.

King, Cathers, Brown, and MacKinnon (2003) looked at the positive aspects of physical disabilities and identified turning points that became crucial experiences in the lives of the study participants. While a turning point did not necessarily have a positive outcome, it was often cited by participants when they realized they could accomplish something, when they gained a greater understanding about themselves, or when they finally had a sense of belonging. Their newly found sense of accomplishment, self-understanding, or sense of belonging allowed them to develop long-term protective qualities such as perseverance and determination.

Abuse of Women with Disabilities

The exploration of abuse of women with disabilities has been undertaken in both quantitative and qualitative studies. Many of these studies have focused on men, women, and children with developmental delays and/or physical disabilities, with only a few studies limited exclusively to women with physical disabilities, and no published articles specific to women with CP. It is necessary, therefore, to review both quantitative and qualitative studies about abuse of women with physical disabilities, because these studies not only provide important descriptions of this phenomenon but are the foundation for the further exploration of mistreatment of women with CP.

Quantitative Studies

There are few quantitative studies examining abuse of persons with disabilities. However, this literature does include studies of the prevalence of abuse, abuse by personal caregivers, uniqueness of abuse for women with disabilities, and characteristics of abused women with disabilities.

An early study exploring sexual abuse and assault of children and adults with disabilities by Sobsey and Doe (1991) revealed important information concerning women with disabilities. Contact with random sexual assault treatment centers yielded 162 case reports of sexual offenses against children and adults with cognitive and other disabilities. Of interest to this study, over 20% of the victims had mobility impairments; 95.6% of the adult victims were women; 79.6% were abused more than once; and in 44% of the cases, the relationship between the abuser and the victim was specifically due to the individual's disability. While the study was limited by the use of nonprobability sampling, self-reporting by the treatment centers, and a lack of information about how

their instrument was developed, it was the first to document the significance of sexual assault of individuals with disabilities.

The first published study examining the prevalence of abuse of women with physical disabilities was conducted by Young et al. (1997). This national study of 439 women with physical disabilities and 421 women without physical disabilities revealed that while 62% of both groups experienced some type of abuse in their lifetime, women with disabilities were abused for significantly longer periods of time and were more likely to be abused by a care attendant or health care provider than women without physical disabilities.

Identification of unique vulnerabilities of women with physical disabilities is an important step in understanding the experience of mistreatment of this population. A unique vulnerability that increases the risk of mistreatment of women with disabilities is their reliance on personal care providers. Powers et al. (2002) explored abuse by personal care providers of women with disabilities by administering a survey to 200 women with either physical disabilities or physical and cognitive disabilities. While focusing on abuse by personal care providers, the researchers also asked about lifetime abuse by *any* perpetrators. Findings indicated 67% of the women experienced physical abuse and 53% experienced sexual abuse, confirming Young's et al. (1997) findings. These researchers also examined abusive behaviors by personal care providers deemed hurtful to the participants. These behaviors ranged from actual physical abuse, threats of abuse, sexual abuse, verbal abuse, care providers not showing up for work and neglect, to poor job performance that endangered the women's well-being. While not showing up for work would not be considered abusive in other settings, for a woman with a physical disability it may mean not receiving personal care or meals, which could endanger her physical

well-being. The investigators also identified factors such as a shortage of care providers, lack of back-up providers, lack of knowledge about resources, embarrassment, and fear of providers as barriers to receiving help when abuse occurred. This study clearly identifies the problem of personal provider abuse and highlights some of the unique aspects of abuse experienced by women with disabilities.

Understanding the mistreatment experience is different for women with disabilities than for women without disabilities was the first step in realizing screening for abuse in women with disabilities may also differ from screening for abuse in women without disabilities. Consequently, McFarlane et al. (2001) explored the need for a disability-specific instrument and developed the Abuse Assessment Screen-Disability (AAS-D). This instrument included four questions; the first two were designed to identify abuse of *any* women, while the last two were designed specifically to identify abuse of women with disabilities. In response to the first two questions, 7.8% reported abuse during the previous 12 months. The disability-specific questions identified an additional 2% of participants were abused during the previous 12 months. This study clearly highlights the usefulness of screening procedures designed specifically to identify abuse of women with disabilities.

The need for an abuse screening tool for women with disabilities was validated by Curry, Powers, and Oschwald (2003) who field-tested a refined abuse screening tool with 47 women who experienced physical and/or cognitive disabilities. Their refined screening tool revealed that 70% of participants experienced abuse in the past year, which was greater than the findings in the previous study. This difference was attributed to modifications in the disability-specific questions and underscores the complexity of abuse of women with disabilities.

Understanding characteristics of women with disabilities that increase their risk for abuse is another aspect of screening for the potential for abuse. Nosek, Hughes, Taylor, and Taylor (2006), surveyed 415 predominantly minority women with physical disabilities. They found five characteristics of participants predicted 84% of participants who had experienced abuse. These characteristics included younger age, more education, less mobility, more socially isolated, and higher levels of depression. Researchers explained how the interaction of age, mobility, social isolation and depression increased participants' vulnerability for abuse but were unsure about the finding that those with higher education levels were abused more often. They acknowledge that, although their model had a sensitivity of 84% and specificity of 73% for study participants, more research is necessary before it can be used along with the AAS-D in clinical and social service settings.

One study utilized the 2005 Behavioral Risk Factor Surveillance System (BRFSS) to compare the incidence of intimate partner sexual and physical abuse experienced by women with disabilities, women without disabilities, and men with and without disabilities. The BRFSS is a survey developed by the Centers for Disease Control and Prevention (CDC) and is conducted annually on a state-wide basis. The database consisted of 356,112 subjects: 219,911 men with and without disabilities, 86,445 women without disabilities, and 49,756 women with disabilities. The study found that women with disabilities were more likely to experience all forms of abuse when compared to women without disabilities or men with disabilities. Risk factors increasing the incidence of abuse of women with disabilities included younger age, less education, unemployment, and not being in a committed relationship (Smith, 2008).

In order to explore the role a specific disability may play in the vulnerability for abuse, Diaz-Olavarrieta et al. (1999) limited their participants to 1,000 women with chronic neurologic disorders, randomly selected from neurology and neurosurgery outpatient clinics in Mexico. They found women who exhibited functional symptoms, including essential epilepsy, headache, migraine, trigeminal pain, sleep disturbances, and vertigo, were significantly more likely to be victims of domestic violence than women with a structural brain abnormality but no functional symptoms. Even though the results may not be generalizable to populations in other countries, there may be aspects of the findings common to women with disabilities who live in other countries. The researchers also suggested studying women with specific disabilities, since they may have unique vulnerabilities and risks for abuse.

These quantitative studies contribute to our knowledge of abuse in women with disabilities. Indeed, research clearly demonstrates women with disabilities are at risk for the same types of abuse as other women in addition to disability-related abuse. However, since women with disabilities are a heterogeneous group, these studies fail to address the vulnerabilities and risks women with specific disabilities might have. Therefore, it is important to conduct research with more homogeneous groups (such as CP) in order to identify unique vulnerabilities placing them at risk.

Qualitative Studies

Nine published qualitative studies reveal the complexity of abuse women with disabilities experience by exploring how abuse differs between women with and without disabilities. Studies also investigated issues making women with disabilities more vulnerable for abuse, the invalidation women felt because of their abuse, and reasons they

may not seek formal help when abuse occurs. Finally, the unique role of helping relationships in the abuse experience was also explored.

The complexity of abuse women with disabilities experience was revealed in a qualitative study of 31 women with functional impairments (Nosek, 1995). The study utilized open-ended interviewing techniques and was designed to explore the sexuality of women with disabilities. In addition to revealing many issues relating to their sexuality, the women revealed 55 separate experiences of abuse: 15 sexual, 17 physical, and 23 emotional. However, Nosek explored only sexual abuse experiences. She discovered, for some of the women, the abuse experiences were similar to abuse experienced by women in general, while others experienced abuse that was clearly disability-related. Disability-related factors increasing their vulnerability included architectural barriers to escape, reliance on caregivers to meet basic personal needs, inaccessible shelters, and social stereotypes (women with disabilities are asexual, dependent and passive). Even though the study is limited by the lack of information about data collection, it provides important information about the unique vulnerabilities women with disabilities have for abuse.

Nosek et al. (2001) also generated qualitative data in their quantitative survey of the sexuality of women with disabilities. Within the quantitative portion, 504 women with disabilities and 442 women without disabilities indicated whether or not they had been abused and whether or not they were willing to answer qualitative, open-ended questions about their abuse. In response, 181 women with disabilities reported emotional, physical, or sexual abuse. These women described abuse that could happen to women in general along with disability-related abuse. Disability-related vulnerabilities included a family's shame or anger because of the disability, reliance on family or caregivers to meet essential personal needs, and isolation within disability-related settings.

Gilson et al. (2001) expanded on the role disability-related vulnerabilities play in abuse. Sixteen participants, who either had a disability or an interest in women with disabilities, participated in a series of focus groups. The study participants revealed women with disabilities learn very early in their life that compliance behaviors are better received by caregivers than resistant behaviors. These compliance behaviors increase the risk for abuse by shrouding abuse in silence. Participants also revealed that impaired socialization caused them to be psychologically and emotionally defenseless against their abuser's expression of will and the demands made on them. Therefore, the authors believed that the conceptualization of abuse needs to be adapted to account for the particularly subtle and sinister abuse experienced by women with disabilities. They also observed that the "construct of limitation seems to be the major factor that transforms seemingly ordinary situations into harmful ones, placing disabled, abused women in cycles of poverty or isolation or both that then increase their vulnerability to even more abuse and limitations" (p. 232). As identified by Gilson et al. (2001), disability-related vulnerabilities, such as compliance behaviors or impaired socialization, interact with disability-related limitations to create environments that increase the risk for abuse.

Building upon previous research, Cramer, Gilson, and DePoy's (2003) conducted focus groups of 24 men and women (20 with disabilities and 18 who had experienced abuse). The two themes revealed in this study were vulnerable beginnings and complexity of abuse. Vulnerable beginnings referred to self-depreciation and self devaluation that correlated with having a disability. Low esteem and lack of worth interfered with subjects' ability to identify the potential for abuse or to employ self-protection techniques. The complexity of abuse included active abuse, described by one participant as "someone does something that takes advantage of my disability and makes

me more disabled than I have to be” (p. 192); abuse through image, which included society’s myths, stereotypes, ignorance, and negative attitudes; and abuse by social service and legislative systems, which included lack of access to resources or services that were unresponsive, discriminatory, and punitive. This was the first study to identify what could be termed the social construction of the vulnerability for abuse: socially created factors that devalue people with disabilities and contribute to their vulnerability for abuse.

Hassouneh-Phillips and McNeff (2004) suggested that differences in the nature of disability may also be a factor in rates of abuse and in the types of explanations women may make for the occurrence of abuse. Using purposive sampling of 13 women with spinal cord injuries, they found that women rated themselves as highly undesirable and often stayed with abusive partners, fearing if they left, they would never again have an intimate relationship. This dysfunctional belief system reflected the women’s internalization of the process of “invalidation,” a crippling psychological aspect of disability. When abuse and maltreatment are the norm—one woman described the situation where a caregiver left a bathroom door agape while performing bowel care on the disabled person (Hassouneh-Phillips & McNeff, 2004, p. 77)—it is likely that some of these embarrassing situations will turn inward, causing some disabled women to view themselves as devalued human beings. Although many findings were consistent with previous studies, this study revealed how society’s devaluation of women with disabilities increases their vulnerability to abuse.

The invalidation women with disabilities may encounter within the health care system as a result of their disability was the focus of another study by some of these same investigators (Hassouneh-Phillips, McNeff, Powers, & Curry, 2005). Their secondary

data analysis of data from three qualitative studies described other less obvious forms of control-taking, such as “manipulating the flow of information” and “restricting treatment options.” The manipulation of the flow of information is particularly insidious, because while the disabled woman is likely to be aware of medication or treatment being withheld by a caregiver (intimate or otherwise), she is not likely to know information is being kept from her unless she specifically asks for it. This extends beyond the bounds of caregiving and into areas of social networking and life issues. For example, a disabled woman who is kept largely sequestered may not have knowledge of the range of options for networking, exploring and receiving alternate treatments, or meeting new people; nor would she know to ask for that of which she has no knowledge. This study provides useful information about a subtle form of abuse adding to a woman’s vulnerability for other forms of abuse, when she internalizes a sense of worthlessness or is unaware of available services.

In another study, Hassouneh-Phillips and McNeff’s (2005) interviewed 37 women who were physically disabled and who identified themselves as having been abused. Results indicated a new aspect of the vulnerability of women with disabilities for abuse. Many of the interviewed women reported they felt undesirable, and these feelings were most pronounced among women with more visible or disabling conditions. Their feelings of undesirability stemmed from the social devaluation they felt and the negative stereotypes they often encountered. Many were inclined to remain with non-disabled, abusive partners, because they felt fortunate to have a partner without a disability and preferred any relationship to being alone. Finally, they perceived these partners as reinforcing their femininity and sexuality, even when the intimate relationships were abusive.

Milberger, Israel, LeRoy, and Martin (2003) explored reasons abused women with disabilities may not seek formal help. The first part of their study was a quantitative survey of 177 women with disabilities, 100 of whom indicated prior abuse. Eighty-five of the 100 participated in the second (qualitative) portion of the study. These women indicated they did not seek formal help following abuse because they didn't feel they needed help; they had informal help available; they were unaware of where to receive help; they felt guilty or embarrassed because of the abuse; they were afraid of the consequences; and finally, they didn't think shelters would be accessible. This study validated previous findings about the vulnerability for abuse and introduced new information about women's reasons for not seeking help after abuse.

Saxton et al. (2001) explored reasons for abuse of women with disabilities by personal care providers. Utilizing focus groups involving 72 women with disabilities, they found that boundary confusion and power dynamics between the care provider and the care recipient (who was also the employer) were central to care provider abuse. Other factors included difficulties differentiating between appropriate and inappropriate touching during intimate care, the complexity of using friends or family as paid care providers, and barriers to reporting abuse. The focus group participants took upon themselves much of the responsibility for preventing or stopping abuse and felt more thorough screening, better hiring practices, and backup care would help to prevent abuse.

These qualitative studies increase our knowledge and understanding of abuse of women with disabilities, and the heterogeneity of participants provides an understanding of abuse of women with disabilities in general. However, other than Hassouneh-Phillips and McNeff's (2004) study of women with spinal cord injuries, the variety of physical disabilities the participants have makes it impossible to determine whether a particular

type of disability puts one at greater risk for different types of abuse. The potential role a specific disability may play in abuse must be explored to allow for the development of interventions that specifically target the needs and abuse experiences of women with varying disabilities. This was clearly demonstrated in a pilot study that analyzed experiences of five women with CP who were abused (Hassouneh & Freeborn, 2006), wherein they described lifetime experiences that gave them feelings of inferiority and influenced their adult decision making capability.

Commonalities in the Literature

Taken as a whole, the literature, both quantitative and qualitative, weaves a beginning understanding of mistreatment of women with physical disabilities. While these women may be abused in the same way that any woman may be abused, disability-related abuse exists and occurs all too frequently. The social construction of abuse and disability, though not acknowledged, was clearly demonstrated in many studies. The descriptions include poor socialization that left women defenseless, vulnerable beginnings that made women feel devalued, and social prejudices and stereotypes that invalidated women's sense of self-worth and created the belief that she was undesirable to others. Society's devaluation of women with disabilities was described in family, social, and health-care settings. Even though most studies involved heterogeneous groups of women with disabilities, Diaz-Olavarrieta et al. (1999), Hassouneh-Phillips and McNeff (2004) and Hassouneh and Freeborn (2006) clearly demonstrated that particular disabilities may have unique vulnerabilities for abuse and that our understanding of abuse of women with disabilities must expand to include the exploration of specific disabilities. Utilizing the feminist biographical method to explore mistreatment experiences of

women with CP will provide greater understanding of this phenomenon as a lived experience and relative to gender, culture, social class and power.

Summary

This chapter explored research pertaining to feminist views of abuse and disability, CP and how it influences a woman's vulnerability to abuse, and abuse of women with physical disabilities. Important contributions previous studies have made to our understanding of mistreatment of women with disabilities were cited. The need to expand our knowledge by exploring the experience of mistreatment in women with CP is clear. Chapter Three describes the design of the present study, including participant selection, data generation, and data analysis. Steps to protect human subjects and ensure methodological rigor are presented as well.

CHAPTER THREE

Research Design and Methods

Methodology and Methods

This chapter includes a discussion of why the feminist biographical method was chosen for this study. Since the feminist biographical method is not usually associated with nursing research, a description of the method, its strengths and limitations are presented. The research design, study participants, procedures, data generation strategies, keys to methodological rigor, and protection of human subjects are also described.

Why the Feminist Biographical Method?

My interest in women with CP who have experienced mistreatment, and the meanings of these experiences in their lives—especially relative to gender, culture, social class, and power—contributed to my decision to conduct a qualitative study. While quantitative research provides important information and knowledge, its limited perspective would not allow me to explore the societal context and meaning of women's experiences (Denzin & Lincoln, 2000). However, there are numerous qualitative methods that provide rich, thick descriptions of the experiences, meanings, and context of participants' lives (Creswell, 1998; Erlandson, Harris, Skipper, & Allen, 1993; Sandelowski, 2004). The determination of an appropriate method for my aims led me to the feminist biographical method. I was drawn to the method because it emphasized breaking the silence about lives that are so often hidden and ignored (Denzin, 1989; Pirani, 1992), and because it is infused with the conviction that women's experiences are significant and there is great value in recording their lives (Broch-Due, 1992; Gluck & Patai, 1991). It also promotes the understanding of women's life histories and narratives within a societal context, providing a holistic view of the role gender, culture, and power

may play in their lives (Alpern et al., 1992; Gutierrez, 1992; Mahlstedt, 1999; Stewart, 1994; Waller, 2005). Therefore, the feminist biographical method offered the means whereby women with CP could share their life histories, which could be understood and interpreted not just on an individual basis but also within the context of being a member of society and a human being in the world (Nilsen, 1992; Smith, 1994). It was also important that this approach allowed me to include the autobiographical origins of my research, which is consistent with both the hermeneutical and feminist aspects of the feminist biographical method (Creswell, 1998; Mann, 1994; Reinhartz, 1992; Smith, 1994; Stanley, 1992; Thomas, 1999). By including the autobiographical origins of my research, I was able to document my assumptions, thereby affording the reader the opportunity to understand my position and critique my interpretations.

Feminist Biographical Method

This section describes the feminist biographical method as presented in the literature. It delineates the tenets of the biographical method and how feminists have embraced and developed the method into the feminist biographical method. In this section, I explain the use of the feminist biographical method in feminist research.

The biographical method uses a hermeneutical approach in investigating life-history narratives and written textual depictions (autobiographies, diaries, letters, and other personal documents) revealing the participant's personal character and relationship with social forces (Denzin, 1989; Erben, 1996). It focuses on exploring, understanding and interpreting the narratives or stories we tell about our lives. It is by telling stories that we share our lives with others; we make sense and meaning of our experiences, life events, thoughts, feelings, attitudes, beliefs, hopes, and dreams; and we understand how our lives interact with others (Smith, 1994; Tierney, 2000). As we listen to the narratives

of others, we learn not only their unique experiences but also the commonality of shared experiences (King et al., 2003). As we tell our own stories, our narratives become an active process in which we remake and reshape our past in relation to our present, through the perspective of time. Through this process we gain a greater understanding of ourselves (Dickinson, 1994).

Hermeneutic interpretation supports a holistic view of the phenomenon of interest by combining objectivist hermeneutics, in which interpretation goes between the whole and the part; and logical hermeneutics, in which interpretation goes between pre-understanding and understanding. This reconstruction of the hermeneutic process encourages the understanding and interpretation of individual narratives from a world view, the understanding and interpretation of our world from an individual view, and the deconstruction of our biases and prejudices in light of our newfound knowledge (Alvesson & Skoldberg, 2000). Understanding, therefore, is an interpretive process taking place as biases and prejudices are tested throughout encounters with new and previously unknown phenomena (Schwandt, 1994).

Focus on the social forces that influence our lives is consistent with the feminist concern with gender, culture, and power issues; thus, many feminists, such as Etter-Lewis (1991), Gluck and Patai (1991), and Minister (1991), have embraced the biographical method to illuminate the meaning of women's lives within societal, cultural, and historical contexts (Smith, 1994). Utilizing the biographical method with a feminist lens allows gender, culture, social class, and power to become a central part of the research inquiry and interpretation (Mahlstedt, 1999) and allows discovery of the stories of those who have been marginalized, silenced, or made invisible in society. Women with CP

represent a group about whom little documented research exists and whose voices are not heard by society (Denzin, 1989; Kibele & Llorens, 1989).

A basic principle of the feminist biographical method, supported by the hermeneutic interpretive process, is that interpretation and understanding are synonymous, and knowledge is gained by exploring the process by which we gain an understanding (Schwandt, 1994). The process of understanding is not isolated from our biases, prejudices, traditions, or culture but is actually influenced and shaped by them. Instead of bracketing or ignoring pre-assumptions, the researcher embraces his or her own beliefs, culture, relationships, and history (Erben, 1996; Popadiuk, 2004a; Schwandt, 1994). It is essential, therefore, that the researcher “bring himself or herself into the narrative and acknowledge his or her standpoint” (Creswell, 1998, p. 51); or, in other words, that the researcher explicitly acknowledge his or her standpoint.

While a biography is often considered a forum for examining the life of one, usually well-known individual, the examination of the lives of a group of women who share a specific phenomenon promotes the feminist view that the private is political (Gutierrez, 1992; Stanley, 1992) and advances our understanding of both the women and their shared phenomenon (Broch-Due, 1992). Using the biographical method’s diverse research strategies, which include interviewing participants, accessing participants’ written textual depictions such as letters and diaries, and analyzing other texts that may relate to the participants or the phenomenon of interest (Denzin, 1989; Smith, 1994), allows the researcher to explore participants’ life-course experiences with the phenomenon of interest. This life-course approach also gives participants an opportunity to reflect on their past, present, and even future lives, the experiences of their lives, and the meanings those experiences have had in their lives (Broch-Due, 1992).

Philosophical Approaches to Feminist Biographical Method

Understanding the feminist biographical method requires exploring how the philosophical underpinnings lead to the research design. What is the researcher/participant relationship? What is the role of the researcher? How are the biographies interpreted?

Researcher-Participant Relationship

The interaction that occurs between the researcher and the participant during an interview can incorporate many experiences, including power and emotions (Wengraf, 2001). The issue of power is of particular concern to feminist researchers, who have attempted to reduce the unequal power in the research relationship by encouraging the participant to take an active role in deciding what should be discussed or by establishing a reciprocal, friendship-type relationship (Acker, Barry, & Esseveld, 1991). However, Lyons and Chipperfield (2000) question the practice of establishing rapport through a friendship relationship, because participants in research usually understand the power differential of research and the purpose of the research interview. Therefore, they recommend the role of the interviewer be that of a friendly stranger. The researcher must also be aware of the tendency to develop a complex bond with participants, which further complicates the issue of power (Long, 1999). On the other hand, the power that exists within the researcher-participant relationship can be used responsibly if the researcher is aware of potential exploitation and maintains a respectful rapport with the participant (Acker et al., 1991; DeVault, 1999; Patai, 1991; Popadiuk, 2004a).

The Role of the Researcher

The role of the researcher in the feminist biographical method is that of biographer, author, researcher, and editor; thus, the participant may be viewed as subject,

informant, or character (Iles, 1992). With this multiplicity of roles, the researcher must explicitly acknowledge that he/she brings biases, agendas, and backgrounds to the data collection process (Personal Narratives Group, 1989). This acknowledgement allows the researcher to share in the process of understanding (Erben, 1996; Popadiuk, 2004a; Schwandt, 1994).

Documenting decision making enhances the trustworthiness of the research by providing an audit trail that includes contextual field notes, rationale for methodological decisions, analytic notes, and a reflexive journal (Rodgers & Cowles, 1993).

Documentation also makes the researcher conscious of his/her internal processes and how biases, agendas, and backgrounds may influence decision making and shape understanding (Erben, 1996; Popadiuk, 2004a; Stuart, 1992). The inclusion of the researcher's autobiographical data, which reflects her biases, agendas, and background, allows the reader to more holistically critique her interpretations (Stanley, 1992; Stuart, 1992).

Interpretation of Biographies

There are three interpretive formats that can be used in the biographical method (Denzin, 1989; Erben, 1996). The first involves narratives, edited but not interpreted by the researcher. The second uses autobiographies written by the participants with no editing or interpretation by the researcher. The third, which was used in this study, presents participants' narratives along with researcher's interpretations and allows for exploring social forces in the participants' lives (Denzin, 1989; Erben, 1996). A focus on social forces makes this format compatible with a feminist perspective and with the desire to highlight the lives of marginalized women while also examining issues of

gender, culture, social class, and power in their lives (Gutierrez, 1992; Popadiuk, 2004a; Reinharz, 1992; Smith, 1994; Wengraf, 2001).

Interpreting the lives of others in acquiring knowledge introduces the “crisis of representation” which is concerned with whether or not representations can truly reflect others’ lives. Denzin and Lincoln (2000) proposed that, while there is no unadulterated truth, the “crisis of representation,” should be addressed by each social scientist. The danger of misrepresenting others is increased if the historical, cultural, or political contexts of their lives are ignored (Nako, 2001). The feminist biographical method promotes contextualizing participants’ lives within their historical, cultural, political and social backgrounds. Atkinson (1998) asserts that interpreting the life stories of others does not mean judging their lives but, involves making connections and finding relevance in their narratives.

Representing the lives of others is complicated, since interpretation of the narrative may be different for the participant and the interviewer (Atkinson, 1998). Factors contributing to the meaningfulness of interpretation include establishing a trusting relationship with the participant, allowing adequate time for the interview so the participant doesn’t feel rushed, and acknowledging the interviewer’s own frame of reference (Atkinson, 1998; Finlay, 2002). This acknowledgement is enhanced by the interviewer’s reflexive evaluation of personal beliefs and experiences which can be documented in a reflexive journal (Finlay, 2002; Parsons, 1995). However, feminists expand reflexivity to include the researcher’s standpoint or position (Dowling, 2006). Feminists reject the concept that bias distorts findings, but instead, assert by acknowledging their position, reflexive researchers promote a greater understanding of their interpretations (Olesen, 2000).

The use of a reflexive journal throughout this study added to my personal understanding of my interpretation of participants' narratives. Entries in the journal were made after each contact with each participant. This has allowed me to reflect later on my thoughts and comments during the data analysis process. As categories, themes, and subthemes arose, I reviewed my journal to verify they were consistent with my initial interpretations. If subsequent data caused me to reevaluate previous interpretations, I recorded how and why changes were made.

Strengths and Limitations of the Feminist Biographical Method

The versatility of biographical research, which allows the researcher to match the method with the participants and the phenomenon, is one of its strengths (Erben, 1996). This versatility includes various data collection strategies, such as interviews, participants' writings, and diaries; written textual depictions by others concerned with the phenomenon; and the researcher's autobiographical data. The addition of the feminist lens further strengthens the method by revealing the connection between the participants, the researcher, and the larger culture or community. This relationship encourages the reader's connection to women and their lives (Iles, 1992; Stuart, 1992) and is consistent with the feminist ethic that research be collaborative, trusting, and non-oppressive (Fonow & Cook, 1991).

However, a limitation of the feminist biographical method is the potential for objectifying participants who may belong to a marginalized group. Therefore, according to Tierney (2000), biographical researchers must be aware of this potential problem. Their research must portray participants holistically as complex individuals and must take care not to promote oppression.

Research Design

The Participants

Women were invited to join the study through criterion sampling (Patton, 2002), and sampling continued until repeated patterning had been achieved (Leininger, 1994). Criterion sampling is a type of purposive sampling allowing for the inclusion of participants who meet a specific criterion; in this case, women with CP who have experienced mistreatment. A review of studies utilizing the biographical method revealed a range of 4 to 11 participants, with an average of 8 participants (Antikainen, Houtsonen, Huotelin, & Kauppila, 1995; Luk, 1995; Popadiuk, 2004b; Shu, 2006; Stewart, 2002; Ziehler, 1999). Therefore, a target range of 8 to 12 women was determined to be appropriate. Twelve potential participants responded to recruitment flyers. Inclusion and exclusion criteria were explained to potential participants who then decided if they met the criteria for participation. Allowing the women to determine their own eligibility was the first step in building and maintaining trust, which is an essential part of qualitative research (Lincoln & Guba, 1985). At the end of the screening process, eight women chose to participate in the study. Those who declined were not required to explain why, but two volunteered reasons. One stated she did not have a very interesting life and would not know what to tell me. The other, who had responded by email, stated that her speech was too difficult to understand. When asked if she could participate by writing, she stated that it was too hard for her to type more than a sentence or two at a time. Repeated patterning was clear before the inclusion of the last two participants.

Inclusion and exclusion criteria assured participation of women whose CP was significant in their lives but who did not have other conditions, such as mental retardation, uncontrolled epilepsy, or deafness, that may have altered their perceptions

and experiences of mistreatment. Inclusion criteria included women with CP over the age of 18, with no upper age limit, who had a communication skill level appropriate for conversation, the ability to provide consent, had used an assistive device such as a wheelchair, a walker, or crutches, and who had had an experience with mistreatment. A mistreatment experience could be emotional, physical, or sexual and did not have to be current or even recent. During the screening process, each woman was asked if she had ever been treated in a way that she considered inappropriate. Exclusion criteria included those with mild CP who did not require an assistive device, those with a severe expressive or receptive communication disorder, and women who had a legal guardian. After the inclusion and exclusion criteria were explained to the potential participant, she was asked if she qualified and if she still wanted to participate. At this point, three women declined to participate. A fourth woman stated she wanted to participate but declined before the first interview. Eight women chose to participate and completed both interviews.

Procedures

Participants were recruited through organizations such as United Cerebral Palsy, Centers for Independent Living, and the Brigham Young University Accessibility Center, which provide services to students with CP. These organizations gave potential participants an informational flyer (described in the Protection of Human Subjects section) that outlined the study and posted flyers in locations frequented by women with CP. Locations included, but were not limited to, community areas in the Centers for Independent Living and apartment complexes and group homes run by United Cerebral Palsy. The flyer included a phone number, address, and e-mail address for contacting the investigator so participants could select a safe contact method. Two participants

contacted the researcher by email, while the others telephoned. Participants were invited to give informational flyers to acquaintances they thought would meet the inclusion criteria.

When potential study participants made contact with the researcher by email, a convenient and safe time for telephone contact was determined. For participants who contacted the researcher by phone, a good time to discuss the research was determined. None of the participants chose to arrange another phone contact. At the time of the initial telephone contact, potential participants were given the following information: purpose of the study, how the results of the study would be used, amount of time required for the initial in-depth interview and follow-up contacts, and the inclusion and exclusion criteria.

When the applicant indicated she was willing to participate in the study and that she met the requirements, a convenient and safe interview location, such as her home or a friend's home, was determined. Informed consent was given and the consent form signed. Interviews began with introductory conversation that allowed the researcher and the participant to establish a rapport and create a trusting relationship. Before the end of the first interview, a time and place for the follow-up interview were established. Each interview lasted up to two hours. Each participant received a \$25 Target gift card at the conclusion of each interview.

Data Generation Strategies

Interviews

The interviewing process.

Data were generated through audio recorded unstructured, face-to-face interviews, consistent with the feminist biographical method, and the collection of demographic data (Fontana & Frey, 2000; Reinharz, 1992; Wengraf, 2001). Face-to-face

interviews were selected to enhance engagement with participants and allow for better communication when a woman's articulation, though understandable, was less than optimal. Feminist biographers utilize conversational interviews to facilitate the structure of the participant's own narrative with as little interruption as possible (Benner, 1994). Lincoln and Guba (1985) described the process of interviewing as starting with "grand tour" questions that allow the participant to get accustomed to talking with the interviewer. The "grand tour" question used at the beginning of the first interview was, "Tell me about your life and growing up with CP." As the first interview progressed, the interviewer allowed the participant to do most of the talking, because nothing is learned when the interviewer talks; but the interviewer occasionally helped the conversation advance by using routine conversational probes or clarifying questions (Atkinson, 1998; Benner, 1994; Denzin & Lincoln, 2000; Lincoln & Guba, 1985). Participants were informed that the interviewer would take notes for later use. The notes consisted of a sequential list of topics raised by the interviewee. In cases in which participants' articulation was difficult to understand, more detailed notes were taken to assist with the transcription process. When the interviewee finished her story, the second part of the first interview began. The interviewer then asked for more information about the topics in the same sequential order and language used by the interviewee. No questions were asked about topics not discussed in the first part of the interview (Wengraf, 2001). This process worked very well for all but one participant. Because of her difficulty talking, one participant was visibly exhausted by the time she finished her life story. The researcher determined it was not appropriate to extend the interview so, for this participant, the second part of the first interview actually took place at the beginning of the second interview, about one week later. For this participant, interviews lasted 45 minutes;

however, all other interviews lasted a minimum of one hour with the longest lasting two hours.

Interviews were used to elicit life stories which allowed the interviewer to listen not only to the participant's story but also to how the story was told. Emotion and humor often underscored the participants' words. As participants told their story, they revealed their understanding and interpretation of life events, and the importance of time (past, present, and future) and history in their life stories (Atkinson, 1998; Broch-Due, 1992; Denzin, 1989; Erben, 1996; Stanley, 1992; Wengraf, 2001). Minister (1991) emphasized the importance of women interviewing women so women's communication patterns are used and a gender-neutral atmosphere exists. This was particularly important when interviewing women with CP who may have their own communication patterns from the effects of CP. Establishing a disability-neutral attitude by listening intently, not interrupting or finishing their sentences, and encouraging the participant's level of comfort with regard to what was discussed (Kibele & Llorens, 1989) promoted mutually respectful communication between participant and interviewer.

The follow-up audio recorded interview was held after a preliminary analysis of the first interview (Wengraf, 2001), in most cases, 7 to 10 days after the first interview. The second interview was structured by the researcher, questions were asked that allowed the participant to clarify or elaborate on her previous narrative, then questions about new topics were also asked. The use of an interview guide in the second interview allowed the interviewer to use guiding questions and probes to assist the participant when there was need for clarification or to fill in missing details (Benner, 1994). While an interview guide was not used during the first interview, according to Wengraf (2001), it was appropriate for the follow-up interview. Examples of typical questions and probes are

shown in Table 1 in Appendix 1. After the second interview with the first participant, it became clear that the ordering of the question guide was awkward. Four guiding questions, with probes, were asked. However, the original order of the guiding questions went from a question about CP, then mistreatment, back to CP, and finally mistreatment. In order to improve the interview's flow, questions were reordered so questions about CP came before the mistreatment questions. All participants were asked the questions and probes listed in the interview guide.

The second interview gave the participant time to reflect on past experiences and generated new insights she wanted to share (Broch-Due, 1992). Additional advantages of multiple interviews cited by Reinharz (1992) include developing a stronger interviewer/interviewee bond, which promoted more diverse and more accurate interviews; a clearer understanding of the interviewee's personality, thought processes, and speech patterns; and the opportunity mutually to make meaning of the first interview.

Written documents.

The women were invited to provide written documentation that enhanced their personal narratives, including, but not limited to, diaries, stories, poems, and letters. While not all of the participants provided written documents, several shared poems, personal histories, and other personal writings. In addition to their own writings, participants were asked if they had read or seen any cultural texts, such as books, articles or films, that reflected their lives. Two women mentioned movies, one mentioned a television show, and none mentioned books.

Data Analysis

The data analysis followed several steps. First, each interview was transcribed verbatim by the researcher. The transcriptions were used in writing drafts of each

participant's biography and for thematic analysis. Each participant was provided with a copy of her biography at the beginning of the second interview and given time to read it and provide any comments. Each woman wanted to keep her copy of her biography. The second interview was also transcribed verbatim. Analysis of interviews was ongoing throughout and after the interviewing process. This analysis employed the hermeneutical procedure of comparing the part to the whole and the whole to the part. The process is also referred to as the hermeneutic spiral in which two levels of analyses occur: within-case analysis, in which new themes are identified and personal factors shaping themes and experiences are identified within each woman's narrative, and across-cases analysis, in which themes and relationships between themes are identified across all of the participants' narratives, and (Ayres, 2000; Ayres, Kavanaugh, & Knafl, 2003).

Utilizing an iterative process, narratives were coded to promote the emergence of themes (Benner, 1994). Initially, 26 themes were identified. As thematic categories were identified, exemplars of these categories were selected, which used the woman's own words to describe and elaborate on the meaning of the theme. During this process, themes were consolidated and divided into two major categories: living with CP, and mistreatment. Further theme analysis consolidated and expanded themes, until each category was supported by specific themes. Commonalities of living with CP emerged at four stages of development: childhood through adolescence, higher education years, young adulthood, and later adulthood. The meaning of mistreatment, with two subthemes, and outcomes of mistreatment, with three subthemes supported the category of mistreatment. Although particular attention was given to how participants' experiences related to gender, culture, social class and power, themes emerged from participants' narratives. Biographical data assisted in framing experiences within the participants'

personal and social histories. Written texts provided by the women and cultural texts (movies and television show) suggested by participants were interpreted through the identification of themes and exemplars. The hermeneutical process of examining the part to the whole and the whole to the part facilitated analysis of the women's stories, their written texts, and appropriate cultural texts (Curtin & Clarke, 2005; Erben, 1996; Popadiuk, 2004a).

Methodological Rigor

Unlike quantitative research, which is concerned with concepts such as generalizability and validity, qualitative research establishes methodological rigor through other standards, such as trustworthiness and the confirmability of knowledge gleaned from the participants (Atkinson, 1998; Benner, 1994; Erlandson et al., 1993; Lincoln & Guba, 1985; Sandelowski, 1986). Sandelowski (1993) questions much of the focus of trustworthiness in qualitative research and states that "rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work" (p. 2). In other words, the goal of the qualitative researcher should be to "practice good science" (Sandelowski, 1993). No specific standards for methodological rigor have been established for the feminist biographical method, but most researchers who have used the method utilize general qualitative research guidelines.

Nine specific criteria for ensuring methodological rigor in qualitative research were presented by McLeod (1994), and were appropriate for this study. First, he stated that the research procedures must be clearly and completely described, including the aims, methods, results, and conclusions of the study. Specific procedural details concerning participant selection and participation and data analysis assist the reader in evaluating the study. This criterion was followed carefully in the description of the aims

in Chapter One, in Methodology and Methods in the current chapter, and procedural details were summarized throughout the course of data collection and analysis as well.

Second, the study needs to be placed within an historical, social, and cultural context. The focus of the feminist biographical method on the societal and cultural context of women's lives and the use of external literature are consistent with this criterion. As each woman shared her own written texts or described cultural texts or media that reflected her life, this criterion was closely followed.

Third, the interpretive process should be clearly delineated and appropriate exemplars presented so the reader can follow the researcher's decision making. This criterion was strengthened by the use of a reflexive journal which documented decision making throughout the study and allowed the researcher to review previous decisions when needed.

Fourth, alternative interpretations should be considered when appropriate. While themes and exemplars may reflect commonalities across women's experiences, unique experiences were identified and presented as appropriate. Commonalities and differences were clearly addressed in the creation of the two paradigm biographies.

Fifth, since the main investigative tool in qualitative research is the researcher, he/she must show reflexivity throughout the research process, which makes keeping a reflexive journal during the research experience important. This reflexive journal expanded on my experiences throughout the research process, including initial contact with participants, interviews, follow-up contacts, and the analysis process.

Sixth, authenticity in describing and interpreting the phenomenon and analysis based on that description requires the researcher to accurately reflect the participants' experiences. Two members of the researcher's dissertation committee were included in

the analysis process and provided input regarding appropriate themes, exemplars, and interpretations.

Seventh, research data should be triangulated with other sources of information such as cultural texts and member checks. Only three participants suggested cultural texts they felt reflected their lives. These were accessed by the researcher who included them in the analysis process. Member checks were imbedded into the feminist biographical method during the second interview when each participant had the opportunity to review her own biography and further expand and clarify what she had revealed in the first interview.

Eighth, participants should be empowered by the research process. Follow-up contact with participants must determine how the study affected their lives. Follow-up contact has occurred with a few participants. They voiced their gratitude that they were included in the study. At the conclusion of the second interview with one participant, she refused the gift card and stated she should pay for the opportunity to have someone listen to her life story.

Ninth, while qualitative research is not designed to be replicated, it is important that the results not be idiosyncratic, but that they have relevance to other situations (McLeod, 1994). The relevance to health care practitioners will be discussed in Chapter Five. All criteria were followed throughout the research process. By adhering to the above guidelines, I strove to abide by Sandelowski's (1993) admonition to "practice good science."

Protection of Human Subjects

Permission to conduct the study was obtained from the Oregon Health & Science University and Brigham Young University Institutional Review Boards (IRB). Informed

consent was obtained prior to beginning an interview. Each participant was offered a copy of the consent form. To maintain confidentiality, audio recordings were coded by number and pseudonym, and only the researcher knew the true identity of the participants. Identifying data revealed during interviews were deleted. All sources of information were kept in a locked file cabinet with access restricted to the research team. The women were informed that they could withdraw at any time if they wished.

Flyers were distributed and posted at organizations that provided services for women with CP such as United Cerebral Palsy group homes and apartments, Centers for Independent Living, and the Accessibility Center at Brigham Young University. They invited women with CP who had experienced mistreatment to participate in a study. A phone number and email address were provided so potential participants could choose a convenient and safe way to contact the researcher.

Dealing with a vulnerable population such as women who have been mistreated or women with disabilities raised ethical concerns. While standard procedures of research were followed, it is crucial that issues specific to women who have been mistreated be considered (Lutz, 1999; Sullivan & Cain, 2004). The Nursing Research Consortium on Violence and Abuse guidelines for conducting research with women who have been abused were followed (Parker & Ulrich, 1990). These guidelines require participants to be informed that the topics discussed during the interviews may evoke feelings of hurt, anger, shame, or confusion. In order to end interviews on a positive note, women were encouraged to share positive experiences with the interviewer toward the end of the interview. Each woman was reminded of strengths and abilities she revealed during her interviews and told she may be helping other women by sharing her experiences.

Safety protocols adhered to for this study included: 1) Initial contact was made by the participant, 2) Safety of the woman was ascertained at the beginning of each contact, 3) Safety was a high priority when determining an interview location, 4) A cover story (determined by the participant and researcher) was in place if the interview was interrupted by a potential abuser, and 5) each participant was included in designing her own individual safety plan (Sullivan & Cain, 2004). Although safety was a crucial part of planning each interview, no situation arose in which either the cover story or safety plan was used.

The women were given the researcher's business card so they could contact the researcher if questions arose at a later date. A special email address was created specifically for the study to allow participants to access the researcher.

Utah has a mandatory reporting law for anyone who has reason to believe that a disabled adult is being abused, neglected, or exploited. This potential breach of confidentiality was explained in the informed consent and discussed when informed consent was obtained. Utah law does not define abuse, neglect, or exploitation, nor does it differentiate what is or is not reportable. This placed an additional burden on the researcher, who clearly explained her responsibility to each research participant at the time informed consent was obtained. No current abuse was revealed during any interviews. When past experiences with rape and abuse were revealed, they were explored by the researcher and determined that participants had received appropriate interventions. Information about disability and abuse resources was also provided.

Summary

This study of the experience of mistreatment of women with CP was based on the feminist biographical method. This chapter outlined the design of the study, including

participant selection, data generation, and data analysis. Steps to protect human subjects and ensure methodological rigor were also detailed. Chapter Four will present the results of the study.

CHAPTER FOUR

Results

This chapter presents the findings of the study. The aims of this study were to 1) describe the life experiences of women with CP who have experienced mistreatment, and 2) describe how these women understand the meaning of their disability and mistreatment experiences relative to gender, culture, social class, and power. During data analysis, two categories emerged: 1) mistreatment and 2) living with CP. These categories, while consistent with the study aims, presented themselves differently than expected. As participants described their life experiences, it became clear that understanding their lives mandated understanding their mistreatment experiences before being able to gain an appreciation and understanding of living with CP

This section presents the categories of mistreatment and living with CP, with supporting themes and exemplars. Exemplars, taken from the participants' narratives and presented in their own words, typify the participants' experiences and elucidate the themes and categories. Finally, exemplar biographies based on the participants' collective experiences will be presented. These contrasting biographies will exemplify how the categories and themes presented themselves differently in the lives of the participants.

During the first interview, each participant shared personal experiences of living and growing up with CP. Many of the participants lived in somewhat small communities and may have been the only person with CP in her community. In order to maintain confidentiality and prevent putting the participants at risk for further mistreatment, minimal demographic information will be presented.

To assure anonymity, the participants were identified by pseudonyms, and any identifiable data shared by the women were altered. The pseudonyms were, in most cases, chosen by the participants. The study participants included: Marie, a 22-year old with spastic diplegia; Jade, a 24-year old with spastic quadriplegia; Rachel, a 27-year old with spastic quadriplegia; Olivia, a 29-year old with spastic quadriplegia; Tink, a 40-year old with spastic quadriplegia; Becca, a 44-year old with spastic left hemiplegia; Pam, a 49-year old with athetoid CP; and Dorothy, a 55-year old with athetoid CP. Spastic CP is characterized by increased deep tendon reflexes, muscle weakness and spasticity, and may affect speech. Athetoid CP is characterized by jerky, involuntary movements of the arms, legs and trunk, awkward gait, and severe speech difficulties.

All participants, except one who was adopted at birth, were raised by their birth families. One participant's mother died at a young age, and she was raised by her birth father and stepmother. Participants' families included from two to nine children. All of the participants were involved in organized religion, with three different denominations represented, and they regularly attended Sunday services. All but one of the participants attended, or were currently attending college. One had an Associate's Degree, one had a Bachelor's Degree, and three had Master's Degrees.

Mistreatment

The first interview was designed to encourage each participant to tell her experiences, without prompts or questions, about growing up and living with CP. This permitted them to focus on experiences they felt were important and wanted to share. During the first interview, mistreatment clearly emerged as an integral part of their experiences during childhood, adolescence and adulthood. In fact, having CP and being mistreated were often simultaneously discussed. For example, when asked about the

meaning of CP in her life, Dorothy responded, “Sometimes I hate it. Sometimes I really hate it, having CP. Again, it’s the way other people treat me.” In other words, the significance of CP in her life did not center on the accompanying physical limitations but on how others treated her because of her CP. Because mistreatment was such a dominant theme in the interviews, this section presents a discussion of that theme and includes the meaning of mistreatment and outcomes of mistreatment in their lives.

The Meaning of Mistreatment

Participants reported their first significant experiences with mistreatment began in school, and were of either a harassing or discounting nature. Harassment experiences included 1) physical aggression, such as pushing and tripping, and 2) emotional antagonism, such as mimicking a participant’s awkward gait or speech, rejecting a participant’s work as not being her own, or treating a participant in a cruel or callous manner. The physical aggression against two participants adversely affected their school years. One woman cited the pushing, tripping, mimicking, and cruel taunts and heckling she endured as a child as the beginning of her depression. Another participant referred to her junior high school years as H-E-L-L because of being pushed, tripped, and ridiculed. A third participant was accused of cheating because her teacher was sure her aide had given her answers to a test.

Discounting experiences included 1) blatantly ignoring a participant’s presence, 2) denying appropriate accommodations, 3) excluding a participant from social activities, 4) making unfounded assumptions, and 5) failing to meet a participant’s educational needs. Being ignored included having people talk over them when they were in a wheelchair, or asking someone else for their order at a restaurant. Appropriate accommodations were denied by schools when they refused participants the opportunity

to go on field trips because of the lack of accessible buses, or when architectural barriers blocked their way. Many participants were never invited to peers' houses or school dances. All participants told of times others assumed they were cognitively impaired or unable to do something without being asked. Finally, participants were placed in classes with lowered expectations because schools did not assess participants' academic abilities.

Mistreatment experienced in adulthood included many of the same types experienced during childhood. However, harassment no longer included pushing or mimicking by peers but continued to include accusations of cheating and making rude and callous comments. Discounting experiences were similar to those in childhood; participants reported being ignored by waitresses in restaurants, denied accommodations in businesses, excluded from social activities, having unfounded assumptions made about them, and being prevented from pursuing their chosen majors in college. Additional types of mistreatment reported included 1) sexual abuse, which ranged from inappropriate touching during a physical examination to rape, and 2) job discrimination.

Each participant shared experiences of mistreatment that occurred in childhood, adolescence, and adulthood. Some experiences were shared in a matter-of-fact manner while others were accompanied by emotions of anger, frustration, or sadness. As participants shared their life stories, it became clear that mistreatment was a common experience both within an individual's life and across all participants' lives. The meaning of mistreatment in participants' lives was revealed in their definitions and explanations of mistreatment, which are described in this section.

Definition of mistreatment.

When asked, "How do you define mistreatment?" none of the participants described experiences of mistreatment. Instead, each woman paused for a moment and

then shared a definition of mistreatment that fell into one of three categories: showing disrespect, making unfounded judgments, or devaluing someone's abilities. Examples of disrespect included being called names, ignored, or ridiculed. Unfounded judgments included making assumptions about participants' limitations without talking with the participant and learning her strengths and weaknesses. Devaluing abilities, though similar to unfounded judgments, included refusing to acknowledge a participant's obvious qualifications, as demonstrated by job discrimination. Differentiating types and definitions of mistreatment allowed participants to explain not only what actions constituted mistreatment, but why they considered those actions mistreatment. Exploring the definitions of mistreatment revealed the meaning of mistreatment in the participants' lives.

Showing disrespect, making unfounded judgments, or devaluing someone's abilities have a common factor as explained by Olivia: "They're communicating that I'm lower than them or that I don't have the same kind of abilities, and that's where I'm just not as good. And they're assuming that I'm not capable in any way, shape, or form." In other words, mistreatment does not have to be a significant event but, as Olivia explained, "Sometimes it's just tone of voice or look. Other times it's something big like changing the qualifications for a job. But I don't think that happens nearly as often as the little things." When participants described mistreatment experiences such as being called names (showing disrespect), being accused of cheating because it was assumed they were incapable of producing the work themselves (making unfounded judgments), being denied a job in spite of being qualified (devaluing someone's abilities), they explained that it was not the action so much as the message that made them feel mistreated. For example, Tink told about going out with her aide and having people ignore her and only

talk with the aide. She explained that ignoring someone becomes mistreatment because she feels unimportant when “They act like I’m not there.”

Explanation for mistreatment.

As they defined mistreatment, six participants also provided explanations for mistreatment, which included ignorance and viewing others as inferior. For example, Marie, who was ridiculed, mimicked, and scorned by her school peers, explained the relationship between ignorance and mistreatment. She stated:

Anything that is foreign to you or isn’t what you normally experience tends to create fear. And what you fear, you don’t understand, and what you don’t understand, you can’t possibly love or give any kind of positive attention to.

While Marie’s explanation lacks the step from not giving “any kind of positive attention” to actually mistreating someone, three other participants described how ignorance leads to prejudice which leads to mistreatment. Each of these three participants compared their mistreatment to racial segregation, and explained the same type of prejudice that allowed others to justify their treatment of racial minorities also allows them to justify their mistreatment of those with physical disabilities. Pam used her grandfather, whom she considered a racist, as an example of someone who felt minorities were inferior to him and he was, therefore, justified in mistreating them. According to Pam, prejudice leads to mistreatment because viewing others as inferior justifies treating them in inferior ways.

Four participants explained how gender plays a role in mistreatment. For example, Marie stated:

Women have always been looked at as being “lessive” [lesser] beings than men are. And I know that there are some things about women and their personality and how they deal with things that make it easy for men to joke and to just treat

women more lightly. I think that definitely has a part to play in how any person is treated.

Marie's explanation reveals her belief that women are viewed as inferior and their inferior position promotes mistreatment.

All participants, even those who stated women were probably mistreated more than men, felt mistreatment of those with disabilities happened to both genders and that power played a more significant role in mistreatment than gender. As Jade stated, "I think people who are in positions of power probably think that they have... probably feel that they're above other people so they're probably in a greater position to extend mistreatment." Jade's description that people with power "feel that they're above other people" is consistent with Pam's and Marie's explanation that mistreatment occurs when people feel others are inferior.

Outcomes of Mistreatment

As participants described their mistreatment experiences, they also shared different ways mistreatment affected them. Emotional, social, and physical outcomes of mistreatment were often cited, and while most consequences were negative, some were positive. This section will discuss the emotional, social, and physical outcomes of mistreatment.

Emotional outcomes of mistreatment.

Six participants reported dealing with depression for much of their lives, and that they have received counseling or medication for the condition. Some women pinpointed when their depression started. For example, Marie stated, "So, that experience [when her school classmates treated her cruelly] had a very negative impact on me, those years in elementary school. I became very depressed." Even though she stated things got better

later, the depression has continued, just as it has for the other women. While most other women did not specifically reveal when their depression started, they agreed with Dorothy, who stated, “The root cause of my depression is how I’m treated by other people.” They agreed that their depression was directly related to CP and mistreatment.

Although participants shared ways in which mistreatment had negative emotional outcomes, five women shared positive outcomes. For example, Olivia explained mistreatment affected her “both positively and negatively. I think that in some ways it has made me speak up more, and in other ways, it has made me cower more.” When asked to clarify this statement, Olivia was unable to give specific examples but explained it depended on the situation. There were times when, in the face of mistreatment, she had the emotional strength to speak up and advocate for herself. Other times, however, she could not find that inner strength and withdrew from the situation. Other participants also described positive outcomes of mistreatment that they believe shaped their personalities. They cited being stronger, stretching emotionally, developing empathy for others who are mistreated, and learning to advocate or stand up for themselves.

Social outcomes of mistreatment.

As participants faced mistreatment from their peers and others, they described how it affected their social relationships. In one way or another, all the women described a mistrust of others. While four participants blatantly said they found it hard to trust others, the other four participants shared this outcome by explaining how CP helps them identify trustworthy people. For example, Olivia revealed her belief that some people are “fake” as she described one benefit of having CP. She stated:

I think that this is not always true, because there are people that sneak through and try to manipulate you because of your disability; but I think that, over all, it kind

of weeds out a lot of people from my life so that only quality people are left. I really appreciate that. It just gets the fake people out. It just siphons them out automatically.

Olivia described people she could not trust as sneaky or manipulative, and people she could trust as quality people.

Feeling socially isolated was identified by the participants as another outcome of mistreatment. This outcome could be inflicted by others, who excluded the women or failed to make accommodations that allowed them to participate, or it could be inflicted by the women themselves who purposely withdrew from social situations because of the pain involved. For example, due to self-imposed isolation, Jade revealed how she spent hours alone in her bedroom feeling withdrawn and alone. Others, however, who found themselves excluded from social situations, described how they filled their time with more meaningful solitary activities. These activities included school work, reading, and interacting with animals. Dorothy explained how she turned to dogs, instead of people, for social interaction. She stated:

And dogs were always my friends because, when I'm with a person, the person can see my handicap. They can't help but pass some kind of judgment based upon my handicap. But, to a dog, I'm not anymore handicapped than you are. So I just love dogs. They've always been my friends, you know. To this day, when I'm emotionally troubled, I go to my dog first. And I pet my dog, and I cry, and I use my dog's ears to wipe away my tears.

Even though Dorothy found solace in her dogs and the other participants found worthwhile activities, they often commented on how social isolation was the hardest part of having CP.

Physical outcomes of mistreatment.

Two participants related experiences of physical mistreatment that occurred during their childhood. These incidences included pushing and tripping resulting in falls, scrapes and bruises. Two different participants described sexual mistreatment occurring during adulthood. One incident involved a physician who touched the participant inappropriately during a physical exam. The other participant shared four incidences in which she was raped by four different male care providers. No participant revealed physical abuse during adulthood or sexual abuse during childhood.

Although only four participants recounted experiences with physical or sexual abuse the importance of this finding cannot be discounted. All participants cited ways mistreatment had physical outcomes. When asked how mistreatment affected them physically, the participants who were physically hurt as children did not describe their actual physical injuries, but just like the participants who were emotionally mistreated, they described how mistreatment affected their CP symptoms. For example, those with spastic CP explained how their spasticity or tightness became more pronounced, making activities even more difficult; those with athetoid CP described how mistreatment exacerbated physical awkwardness or speech difficulties. Five participants stated when their CP became more noticeable to people who were mistreating them, the mistreatment became worse.

Tink described social, emotional, and physical outcomes of mistreatment as inter-related. When she was raped, she reported that her first reaction was to blame herself. She said, "I thought it was my fault because they wanted to do sex and I didn't want to. So they did it to me." This guilt continued until she received counseling. Following this experience, Tink noted, "I shut everything out. I am a different person now. I'm quiet,

very quiet. I shut myself in my bedroom and didn't come out." Finally, Tink said the rapes affected her physically because of her CP: "I didn't trust some people to clean me. So I didn't get cleaned and taken care of like I should have." Tink was affected emotionally and blamed herself, she isolated herself from social situations, and she suffered physical consequences because she was afraid to allow others to care for her.

Living with Cerebral Palsy

Mistreatment was a common experience described by participants. However, as the women shared their experiences of growing up and living with CP, none of them focused on mistreatment as the only aspect of their lives. Although they shared experiences of childhood, adolescence, and adulthood that revealed mistreatment, they also shared happy, fulfilling experiences. This section will discuss how the participants described living with CP at four different stages of development: 1) childhood through adolescence, 2) higher education years, 3) young adulthood and, 4) later adulthood.

During childhood through adolescence, most participants described themselves as normal, intelligent young women who happened to have CP. During the higher education years most participants continued to depict themselves as intelligent and capable with a future full of possibilities. However, their experiences with job discrimination and an inability to work in their chosen career challenged their view of how they fit into society. After finishing college the women continued to describe themselves as normal, intelligent women, but began to relate experiences in which society treated them as neither normal nor intelligent. Finally, older participants over the age of 40 continued to describe themselves as normal and intelligent but conceded they often felt more disabled by the views and actions of others than by their physical limitations.

Each participant told how her family came to realize she had CP. Seven women shared examples of how their families reached out to health care professionals to provide their daughters with every opportunity available for children with CP and supported them physically, emotionally, and spiritually. Becca's experience, however, was different since her step-mother ignored her diagnosis and never provided her with physical therapy or other interventions. She struggled to come to terms with her physical limitations and continued to view her childhood with frustration and pain. The other participants, though, told of parents and families who accepted and supported them. For example, Olivia described a family that accepted her and included her in all of their activities. She shared an example of the kind of support she received from her siblings:

My one sister, who's 12 years older than me, she was always... she kind of tied feminism in with everything and told me, "Never be ashamed of who you are and what you need help with. Don't ever take any crap from anyone." And so she was always trying to empower me that way.

Supportive families helped participants accept themselves and played a major role in helping them keep CP in perspective. Consequently, Olivia and the others with supportive families began at an early age to develop a self concept that included, but was not dominated by, CP.

Throughout childhood, adolescence, and adulthood, each participant encountered experiences that either supported or challenged her view of who she was and how she fit into society. Jade described how her family treated her just like everyone else and always included her in all their activities. She recounted how she felt like a normal kid. Within her family, this was also true for Marie. She had to face her belief that she was just like everyone else, because as she stated, "I realized that I was really very different from

everyone else because I was always being made fun of in one way or another.”

Consequently, with every challenge, each participant had to decide how she viewed herself and how she fit into society. As participants shared their life experiences of growing up and living with CP, it became clear that how they viewed themselves and described fitting into society were different at different stages of life.

Childhood through Adolescence

Seven participants were diagnosed with CP early in life and reported their families rallied to meet their needs and provided them with all the love and care possible. Early childhood was described as a happy time filled with parents, siblings and extended family that interacted and played with them. While they might have used a wheelchair or walker, or had regular physical and occupational therapy sessions, they did not comprehend the significance of their physical disability during those early years. CP was just one, but not a particularly important aspect of their lives. For example, Rachel explained, “I just thought it was kind of like some people have brown hair and some people have red hair and I didn’t really see it as being different.” How CP was regarded by parents and family members had a profound influence on their acceptance and attitudes about themselves. For example, when 5 year old Rachel was not allowed to swim in a public pool because she needed a floatation device not permitted at the pool, she described rude behavior by a man who insisted that she and her father leave the pool. In talking about the experience Rachel stated:

I’m normal but I’m different and sometimes, you know, people might not like that. But then, you know, my parents just reassured me that it wasn’t my fault, you know, that it was just that man and his attitude, and I can still do stuff.

Rachel accepted her parents' explanation that the problem was the man's, and she felt confident she was not to blame and still could do many things.

When Rachel and the other participants entered school, they described CP as an insignificant part of their lives. For the first time in their lives, participants were exposed to large numbers of able-bodied peers. With the entrance of so many able-bodied peers into their lives, participants described watching and comparing their disabilities with their peers' abilities. For example, when Becca was asked when she realized she was different from other children, she stated, "When I was in grade school, I would see how people could do things on the playground, or I saw how they walked or they could get up from their desk and go sharpen their pencil." Each participant described watching her peers and becoming conscious others her age could do things that she could not do and could talk or walk without difficulty. The participants cited this time in their lives as when they began to understand they were physically different from other children their age. The participants, however, did not describe their physical difference as making them less than normal. For example, Olivia echoed the feelings of the other participants when she stated, "I do remember a time feeling that way, that I'm just a normal kid. It's just my body that is different." Therefore, during childhood, participants viewed themselves as normal but also began to realize they were different.

School was not only described as a new social experience for participants but also a time to learn and grow intellectually. They told, however, of roadblocks preventing them from achieving what they felt was their intellectual potential. In fact, upon entering school, five participants were placed in self-contained classrooms with other students with various types of disabilities. Even participants who were mainstreamed often faced

placement in remedial or special education classes. This placement was not based on any evaluation, as Pam explained:

In first grade, I participated half-time in a normal class and half-time in special ed. I did that for two years. In third grade, they tested me. And mentally I was fine, so I could be in a normal class all day.

Pam and others were placed in special education classes with no evaluation but had to be tested and evaluated before being reassigned to regular classes. Participants discussed how placement in self-contained classrooms, remedial classes, or special education classes caused them to struggle with feelings of inadequacy and doubt about their abilities to learn as well as their able-bodied peers.

Participants related that over time some teachers began to see their potential. In fact, six of the participants shared specific experiences where their attitudes about themselves and school changed because of a teacher's intervention. Dorothy related how significant her experience was to her, by stating:

I remember this teacher because he reached out to me and took me from where I was and helped me to dream of unreachable stars. I started thinking, "Hey, I'm not so dumb. I can even beat all of the smart kids if I want to." From then on, I started striving for "A's" because I started believing "A's" were possible for me to achieve.

The six participants who reported positive affirmations from a teacher described how they began to internalize the belief that they were intelligent and could be successful academically. For example, after her positive interaction with her teacher, Dorothy explained how at first she started thinking, "Hey, I'm not so dumb" and then began to strive for A's as she finally believed they were within her reach. Just as Dorothy

described the change in her attitude about herself because of feedback from her teacher, so did Rachel. She described how she was “at the peak of my learning” prior to the intervention of a supportive teacher, but then her attitude changed. She caught up with her peers, and she began to “thrive” academically.

By the end of adolescence, six participants described themselves as normal, intelligent young women who happened to have CP. On the other hand, the other two participants provided more negative descriptions of themselves. Becca, who had little or no family support, and Tink, who was denied a basic education because of the severity of her CP, described themselves as lonely, disabled and angry.

Higher Education Years

Seven of the eight participants attended college and described education as the key to their future. The eighth participant, while unable to attend college, explained how she was able to receive the education she had been denied and not only learned to read and write but also to enjoy writing poetry and short stories. According to these participants, the success accompanying college and learning contributed to their sense of being capable, intelligent women.

Five participants completed their college education: Three have Master’s Degrees, one has a Bachelor’s Degree, and one has an Associate’s Degree. For the most part, college was described as a rewarding experience; however three participants were prevented from pursuing the education major they initially wanted. One was advised teaching would be too strenuous, so she voluntarily changed her major. When the other two participants applied to the Education Department, they were denied admission and given only vague explanations. Each woman told how she was initially disappointed but

then evaluated the situation and chose a different major which was enjoyable and would lead to success.

While college was described as a rewarding experience, participants also mentioned several challenges. Challenges included the size of the campus, distances between classes, the need to arrange for personal care assistants during school and other activities, and the expectations of some faculty that the women with disabilities were not capable of college-level work. On the other hand, participants also described college as a time to become more independent and participate in scholarly conversations and pursuits. The importance of attending college and obtaining a degree was explained by Olivia. She stated that when others seemed to question her abilities or were talking about their educational accomplishments, she would simply say, “Oh yeah, I went to the university.” If the others had a college degree, they were now academic peers and her CP was relegated to the background. If the others did not have a college degree, Olivia was now academically superior. In either case, having a college degree was described as validating participants’ self-concept as intelligent, accomplished women.

Two participants are still in the higher education years, and their life is focused on the excitement of college life and hopes for the future. Marie, who is attending college and enjoying social life, is typical of other participants’ experiences during this stage of life. She described herself as intelligent and capable with a future full of possibilities and agreed with Olivia’s mother who stated, “You’ll never be a world class dancer but, if you are educated, then you can do x, y, and z.” Although Marie initially wanted to major in education, she was encouraged to change majors, which she did. She told of thoroughly enjoying her new major and how it would prepare her for a career after graduation. She expressed optimism about her future.

Although Jade's childhood through adolescence was just as optimistic as Marie's, she described the higher education years as stressful. After being successful at her local community college, she transferred to the university, stating her belief that education was the key to a successful future. Jade sadly described how her physical limitations proved too difficult to manage at the university, which was a considerable distance from her family and support system. She explained the role good grades and academic achievements played in how she felt about herself. She stated:

I had a nickname that sort of stuck with me in high school. And it was fun for a while until I realized... they used to call me Miss 4.0 and that was because everybody knew that I was a very nervous person when it came to school projects and stuff. I would put 110% into grades or into things like that. And I think that maybe I... that became so important that's the one way negatively in which maybe I wrapped my identity a little too much into that.

Because of her ability to not just participate but to compete academically with other high school students, Jade did not view CP as significant in her life. She explained:

As long as I could feel like I was doing what most of my peers were doing, that was normal to me. Now I don't give much thought to my physical limitations, but I am doing more with the emotional aspects because, like it or not, and I hope this doesn't sound wrong, but it would have been a lot easier for me to pursue a college degree or, you know, handle college if it weren't for the physical aspects of CP.

Even as Jade stated that she does not give much thought to her physical limitations, she acknowledged that they have affected her adjustment to college, and expressed concern that it would "sound wrong" to blame her disability. Jade described herself as normal and

intelligent, with a focus on her religious beliefs in the attempt to create meaning for her life. She stated, “God has a purpose for my having CP.” She continued to search for a way to pursue a university education.

Both Marie and Jade viewed themselves as normal and intelligent young women. Because of her educational goals, Marie was optimistic about her future. Jade had the same optimism for the future when she attended her local community college and then transferred to a university. Her CP, however, proved too difficult to deal with so far away from her family and support system. This difficulty caused Jade not only to re-evaluate her future but to actually fear it. She stated, “I’m fearful in the sense that I wonder how my adulthood is going to be when my support system is not there.” She, like Marie, described herself as normal and intelligent. However, Marie was optimistic for the future; Jade was fearful.

Young Adulthood

After obtaining their degrees, the college graduates expressed optimism about their futures. They anticipated getting a job in the career for which they were educated, getting married, and starting a family. Rachel described her hopes for the future:

I want to get married, and have a job, and have kids, and have a house, and all those things that I think most people would want in their life. But when I stop—ideally, that’s what I want, but the reality of the situation is that those things, as far as marriage and the children, may not come to me in this lifetime. It’s the same—if I wasn’t disabled, that they would or wouldn’t come.

As time passed and her hopes remained unfulfilled, Rachel faced “the reality of the situation” and tempered it with the understanding that even some people without disabilities do not fulfill all of their dreams. On the other hand, she and Olivia, who were

at this same stage of development, were not ready to give up on their hopes and dreams. Both described their beliefs that they will reach their goals at some point in their lives. This was clearly expressed by Rachel, who stated, “When I stop and think about it, I think I’ll probably get what everyone else has but just not in the same time or in the same way.”

Participants who graduated from college obtained an education they believed prepared them not just for a job but also for a career. They expressed their belief that they were well prepared to work in their chosen field. However, three participants described experiences they believed were job discrimination and prevented them from getting their desired jobs. Rachel’s description of her experience was representative of the other participants. She applied for a job for which she explained she was well qualified, had the appropriate degree, and had worked in the specific area during her graduate school practicum. When she spoke with the supervisor on the phone, she stated he was “really excited, really enthusiastic,” and she was told to get her papers in by a specific date, which she did. However, when she went for the face-to-face interview, and the interviewer saw she was in a wheelchair, “The people that interviewed me were very condescending.” Later, she found out that not only did she not get the job, but “They hired someone with no experience, who hasn’t even done the job,” and actually submitted her papers after the deadline. Rachel went on to say, “I can never know for sure, you know, if I was truly discriminated against or not. But I felt like I was.” Job discrimination as a crucial experience was explained by Olivia, who stated:

I’ve had a hard time getting a job. I’ve had a really hard time with that. So it’s brought a whole new element to my life because I think up to that point in my life I’ve felt pretty fairly treated. Of course, there are always stupid people and

there are always going to be situations. I have felt pretty consistently like I'm hitting a wall when I look for job.

Olivia expressed a positive, optimistic view of life prior to her experiences with job discrimination. She did not deny facing mistreatment but explained how she dealt with earlier experiences by stating, "There are always stupid people and there are always going to be situations." In other words, as hard as earlier situations may have been, she was able to explain them away as relatively unimportant. She described job discrimination, however, as "hitting a wall" and bringing a new element to her life.

By this phase of the participants' lives, they began to lose some of their optimism. Just as Jade, as a young adult, had to face that her CP prevented her from attending the university, these new college graduates faced the realization that they might not attain their goals. However, they were not ready to blame their difficulties on their disability. They expressed the desire to be positive and did not want negative experiences to dominate their lives. As Olivia stated, "I don't want to come off as bitter and like I hate the world." Or as she explained further, "I learned a long time ago that feeling bad for yourself isn't going to change the situation." While participants in the young adult phase of life continued to describe themselves as normal, intelligent women, they began to temper this view with the realization that it was not shared by society.

Later Adulthood

Four participants were over 40 years of age. Of these four, two were married with children and one had a successful full-time career. Two others conveyed their satisfaction with part-time employment. Dorothy, who would like full-time employment in her chosen field, continued to describe job discrimination as an active aspect of her life. Since she was unable to achieve her goal of full-time employment, Dorothy accepted

part-time jobs when available. She left one position because she felt mistreated by the staff, but described her current position as very fulfilling as well as satisfying. Pam, who has a full-time job, believed she was accepted in her position because she did not work with the public. She stated, "I'm behind the scenes. I think if I worked with the [public] that would be a different story."

Pam would still like to have a relationship and marriage, but decided it probably would not happen for her. In order to not spend her life alone, she adopted a little girl from another country. Pam reported being much less lonely since becoming a mother and less concerned about marriage. As participants in later adulthood faced barriers, they described how they altered their goals in order to fit into a society that often did not accept or accommodate them, thereby finding satisfaction with their lives.

Becca, who struggled all through childhood and adulthood with a belief others did not care about her, continued in later adulthood to feel alone in dealing with her disability. She stated, "The world doesn't make things accessible. You're trying to fit and you're trying to live your life but they don't let you." Unlike the other women at this stage of life, she described herself as different and often mentioned that the world did not accept her.

Participants in later adulthood described successes and failures that have influenced how they describe themselves. When asked about the best parts of having CP, all the women in their twenties effortlessly shared good aspects, while older participants immediately questioned, "Are there any?" The optimism expressed so often by younger participants was not shared as often by those over the age of forty. An essay written by Pam when she was 18 years old demonstrated that at one time, older participants also viewed life with optimism. In her essay entitled "A Handicapped Optimist," Pam wrote:

I have observed many handicapped people and have found that most of them face life with an optimistic view. Few are bitter about their handicaps or ashamed of them. They find out what they can do well and what they cannot do. When asked if, thirty years later, she still felt the same way, Pam replied, "I'm not as optimistic." Although Pam stated she is basically an optimistic person, she conceded, "the older I get, the harder it is to bounce back. Things are more personal, or maybe I take it more personally." Indeed, Pam and the other older participants often struggled to maintain their positive views.

Dorothy, the oldest participant at 55 years of age, also struggled to maintain a positive view but explained her negative views were not of herself. She stated:

There were times when the brick walls seemed too well constructed to dent even a little, and I still had my doubts. The doubts I had, though, were not in myself but in others. I wondered whether I could help them to see and teach them to feel. I questioned whether I could reach them. But with all my being, I always came through silently yet unwaveringly with a more positive, invincible belief in myself.

Dorothy and the other participants over the age of 40 continued to view themselves as normal, intelligent women. They conceded, however, that society and the world do not view them as such and have built "brick walls" that have magnified their disability.

While not as optimistic as they once were, these women came to accept themselves. They differentiated between the limitations placed on them by their disabilities and the limitations placed on them by others. As Dorothy explained, "There have been many times when I was more handicapped by the opinions of people and their prejudices than by the handicap itself." All acknowledged the difficulties they have faced and shared

Dorothy's view when she stated, "It has been an uphill battle most of the way." Although the later adulthood view of self continued to be that of normal, intelligent women, participants described themselves as being disabled by society and others.

Exemplar Biographies

Participants shared their experiences of growing up and living with CP in biographical format. Most of the women started with narratives about their birth stories and progressed through childhood, adolescence, and adulthood. As experiences were shared, it became clear that there were many commonalities and differences among the women's lives. Two exemplar biographies, based on the collective experiences of the participants, are presented to elucidate the experience of living with CP. The first biography (Liz) represents experiences typical of most of the participants. The second biography (Debbie) represents atypical experiences of primarily two participants. How each biography relates to the categories and themes will also be discussed.

Liz

Liz was born after a normal pregnancy but a very difficult labor and delivery. She initially had difficulty breathing but was soon stabilized, and after a short stay in the neonatal intensive care unit was able to go home. When Liz was just a few months old, her mother realized she was pregnant again and would have her second child when Liz was about one year old. By her first birthday, Liz was not crawling or reaching other developmental milestones. Liz's doctor noticed her delays at her well child checks, but did not want to increase her mother's stress during a rather difficult pregnancy. It wasn't until Liz was about 14 months old that the family doctor suggested they take Liz to specialists in another city. After the assessment by the specialists, her parents were informed that Liz had spastic quadriplegia and were told that she would not walk or talk

or ever think for herself. One of the specialists suggested to her parents that the care and resources needed to raise Liz would be overwhelming and would negatively affect their other child, so they should institutionalize Liz. Her parents were devastated. They struggled to know what to do. Years later, her mother told her they never considered institutionalizing her, but felt overwhelmed with the situation. A close family friend became aware of their dilemma and offered her advice. She said, “Your job is to be her mom and take her and raise her and give her the best quality of life. And do the best you can do.”

Liz’s parents began doing research on CP and interventions that were available for her. Since they lived in a small, remote town, they located a therapy facility that would provide intensive physical therapy and teach Liz’s parents how to continue the therapy after returning home. Leaving her sister and father at home, Liz and her mother traveled to another state, where Liz received intensive physical and occupational therapy. After two months they returned home, and Liz’s mother taught her father what she had learned. They continued to provide therapy in their home. Liz described specific memories of her father lifting up her legs and having her “walk” on her hands. Her parents also became interesting in patterning, in which five helpers moved her arms, legs, and head in the same manner that a child moves when crawling. Family members, neighbors, and friends volunteered to help and many hours a day were spent patterning Liz for crawling.

Therapy proved to be very beneficial and Liz began to progress physically. As Liz’s sister, Mary, began to roll over, Liz tried to roll over. When Mary started to crawl, Liz started to crawl. When Mary sat in her highchair feeding herself, Liz wanted to sit in her highchair and feed herself. As Liz progressed, the spasticity in her legs caused them

to scissor which interfered with her movement and prevented her from standing. Another trip to the specialists determined she would benefit from tendon lengthening surgeries. At this time, Liz's parents decided to move closer to a metropolitan area where Liz could receive the proper care and therapy, and they would be closer to grandparents and extended family who could assist with both Liz and Mary.

Over the years, Liz had several surgeries. She remembers telling people before one of her surgeries, "They're going to cut off my legs and sew them back on and everything is going to be fine." Apparently, for several years Liz thought that she would stop having CP. Before her 12th birthday, she wrote in her journal, "When I'm 12 I'll be cured and. . ." Liz was sure that no one in her family ever made her think she had something that could be cured, or even that she had something that needed to be cured. She remembers her family as being extremely supportive and including her in all of their activities.

Being included in family activities often required her parents to carry her. Liz remembered that her parents had a special backpack she sat in so she could be carried on their backs. She described how she felt very special in her family and never questioned that she was an important family member. When she was four years old, Liz tried to manipulate a doll from Mary by saying she was special because she was in a wheelchair. Her father, who overheard the exchange, immediately intervened and explained to Liz that she was special, but so was Mary. He also explained that she was to never use being in a wheelchair as a reason to be selfish or to gain an unfair advantage.

Liz was excited when it was time for her to attend school. She and Mary often played school and Liz was learning to read simple books. Since Liz needed help with toileting and eating, she was placed in a self-contained classroom with several aides who

were available to help. The students in her class had a variety of physical, emotional, and educational disabilities. Academically, Liz progressed quickly. Except for math, she had no trouble grasping concepts. By the time Liz was in third grade, she was no longer enjoying school. The same concepts were taught over and over, and she didn't feel challenged to learn new things. Her parents began to worry and decided it was time to transition Liz to the local neighborhood school where she would be in a regular class.

When it was time for her parents to sign papers reenrolling Liz in special education for the new school year, they refused and informed the school district they wanted Liz in a regular class. The school district fought their decision and required IQ testing before they would discuss the transfer. Even when the IQ test was completed (Liz never knew what the results were), it wasn't until disability rights lawyers became involved that the district relented and allowed Liz to be placed in her neighborhood school. Liz's placement in a regular fourth grade class was provisional. If she couldn't keep up with the other students, she would be returned to the self-contained class. When Liz started fourth grade, it was clear she was far behind her peers both academically and socially. Luckily, her teacher attributed Liz's academic difficulties to her lack of preparation in the self-contained classroom and spent extra time after school tutoring her. It wasn't long before Liz made academic strides. She again loved learning and felt good about herself because her teacher was always praising her for on her work.

Socially, Liz reported that she continued to have some difficulties. Not all of the students were accepting of her differences. Liz talked about how much she wanted to be like the other students. For the first time in her life, she realized that she was physically very different from her peers. She was always aware she had some differences; however, in her family her CP was accepted as just a normal part of life. Watching her peers do

things she could not do made Liz realize she was more different than she thought. She also realized her CP made her more of an observer of activities than a participant.

Liz made one very good friend in her new class. At first, her new friend seemed oblivious to Liz's disability, and Liz was very happy. While other students were playing games on the playground, she and her friend would share secrets and laugh and giggle. Unfortunately, other students teased Liz and her new friend until her new friend stopped being her friend. Liz was devastated. She remembers crying for what seemed like days. She was miserable. Liz had always been able to talk with her parents about anything, but this time she didn't. She is not sure why; maybe because her parents had always told her she was special and important and this time she didn't feel special and important. She felt different and didn't want to cry when her parents told her she wasn't different. So she kept it to herself.

Liz's brother, who at the time was about 16 years old, knew something was bothering her. He tried to get her to tell him, but she refused. Finally, he went into her room, sat on her bed and refused to leave until she told him. She cried and cried as she talked about losing the only friend she had. He listened and waited until she calmed down and then said:

You know, Liz, the world is made up of two kinds of people. There are big people and little people. The little people are those who get up in the morning, get dressed, go to school or to work, come home, eat dinner, watch TV and go to bed. They don't care about the world. They don't mean anything to the world and the world doesn't mean anything to them. You don't need to worry about them. It's the big people you need to worry about. They do more than the little people. They care about the world, and make decisions to try to make it a better

place to live. They are successful in living and not just making a living. But you don't even need to worry about them because if they are truly big people they will have big enough hearts to love you and accept you as you are.

Her brother's words helped her begin to heal from her trauma. She would think back to that day many times as she grew up, and even as an adult found comfort in what he said.

Without a friend, Liz didn't know what to do during recess, so she started going to the school library. The librarian took a special interest in Liz. In addition to spending time reading, Liz would help the librarian do simple tasks. This was the beginning of Liz's lifetime love of books and libraries. The sadness she felt from being socially excluded did not feel as acute when she filled her spare time with books. However, Liz found she had a more difficult time trusting people and was careful to not become too attached to one person. She didn't want to be hurt again.

As Liz progressed through school, the attention of her fourth grade teacher and his faith in her abilities stayed with her. She worked hard at achieving good grades and often found herself on the honor roll and realized she didn't feel as different as she had back in fourth grade. Her ability to do above-average school work did, however, cause Liz some problems in high school. Since she was unable to write well enough for others to read her writing, or quickly enough to keep up in class, Liz had an aide to whom she dictated her work. On more than one occasion, her teachers questioned that her work was actually hers. Liz felt they looked at her physical disability and assumed she must be cognitively affected. As Liz reflected back on the first time she was accused of cheating, she remembered how difficult it had been for her to answer her teacher's questions. She felt her body stiffen and she struggled to calm down but could hear increased spasticity in her voice. Although she told her teacher she had not cheated, she felt extremely humiliated,

deeply hurt, and terribly misjudged. Talking to her parents helped her cope with her feelings. The discussion with her parents made them all wonder if the stress of school was causing Liz to become depressed. They all decided it was time to discuss their concerns with the family doctor who agreed it was time to address her depression. This proved to be very advantageous to Liz, who felt more in control of her emotions. Liz soon found herself more determined than ever to prove she was just as smart as anyone else.

By the end of high school, Liz was determined to go to college and earn a degree. Her mother always told her, with an education, she could do just about anything she wanted to do. At first, she decided to be a teacher so she could help other students like her fourth grade teacher had helped her. Liz was accepted to college but, unfortunately, the Education Department determined she could not major in education and refused to let her apply. Again, Liz was devastated. She struggled with what to do until she remembered how much she had enjoyed books and how nice the librarian had been to her. Majoring in library science, Liz found she loved college.

Liz found she was included in social activities during college, due to the maturity of college students. This was a new experience and she enjoyed it tremendously. She even found herself trusting others and realized, for the most part, her disability kept shallow people away from her and there were many quality people who accepted her for who she was. The future seemed bright, and Liz made plans to work after graduation and then return to college for graduate school.

With her degree firmly in hand, Liz applied for several jobs, knowing she was well qualified for the positions. She approached her first interview with confidence and was disappointed when she didn't get the job. Undaunted, she interviewed again and

again, with no success. Not wanting to sound bitter, as if she were blaming her disability, Liz kept much of her disappointment to herself, but admitted the experience felt like discrimination. In an attempt to secure employment, she even applied for a job for which she was over-qualified. When the interviewer explained they had a new qualification Liz didn't have, Liz was convinced they had changed the qualifications to exclude her. She was hurt and angry, and didn't know what to do. Her mother tried to be supportive, but Liz got angry with her. She just didn't understand how people couldn't see that she was capable of doing the job.

Liz decided it was time to return to college; after all, if she couldn't get a job she needed to do something. When one of her friends asked her how she was able to keep going on in the face of adversity, Liz replied, "What choice do I have? Just sit in a chair and watch TV all day?" So, Liz embarked on a graduate degree in library science. As part of her education, she worked in the university library, which proved advantageous, since after graduation she was offered a full-time librarian position. When she had not been able to get a job before her master's program, she thought all she needed was the opportunity to show she was a capable employee. She felt validated when she realized those who saw her in her internship recognized her abilities.

Although she finally had a full-time job in her chosen area, Liz was lonely in her personal life. She dated a few times, but nothing ever developed. It seemed the only men who would ask her out were men with some type of disability. Dating a man with a disability didn't bother Liz except she felt she didn't have anything in common with them except for the disability. When in her 40's, Liz met a man with CP, but she hesitated to let their relationship grow. However, after a lengthy courtship, he proposed, and she decided to say yes. They aren't married yet, but Liz admits being engaged makes her feel

like other women. Nevertheless, Liz is concerned about the future, knowing it is difficult to fit into society as a single woman with a disability and wondering how they will fit in as a couple. She finds the older she gets, the harder it is to go into situations where she anticipates the stares and even rude comments of others. She realizes she takes things more personally. She tries to always be optimistic but admits it can be difficult to maintain a positive attitude.

Liz represents participants who had supportive families and who generally faced life with optimism. Supportive families helped participants (as represented by Liz) put their CP in perspective and find ways to cope with challenges. They also explored appropriate treatment options, such as physical and occupation therapy and surgery. The lives of participants represented by Liz, though basically optimistic, included experiences of mistreatment by school administration, peers, teachers, potential employers, and strangers. Throughout their lives, these participants have been supported by parents, siblings, and extended family members. The next exemplar biography (Debbie) contrasts the lives of participants represented by Liz and presents atypical experiences of individual participants.

Debbie

Debbie was born prematurely at 32 weeks gestation. Her mother was advised not to have children after the birth of Debbie's brother, who is three years older than Debbie. Her mother had type I diabetes and was not in good health. After her birth, Debbie was in the neonatal intensive care unit for several weeks. When she was taken home, her mother was too sick to take care of her. Debbie's mother died when Debbie was about 10 months old. When all of her extended family came for the funeral, several older cousins were put in charge of Debbie. They played with her as if she were a doll and dropped her

on her head, resulting in a severe head injury requiring hospitalization. When Debbie was four years old, her father and step-mother took her to the circus. Sitting on her step-mother's lap on the drive home, Debbie was thrown through the front windshield when the car was hit by a drunk driver, again resulting in a severe head injury.

Debbie was slow meeting appropriate developmental milestones. While her right side was well developed, her left side, both arm and leg, were always smaller and didn't work properly. She remembers being very clumsy, having difficulty walking and falling a lot. She never remembers her father or her step-mother taking her to be evaluated. She does remember, however, her parents always telling her to be less clumsy. They told her she needed to try harder to keep her balance and to take smaller steps when she walked. Debbie often had pain in her left leg, but her complaints were brushed aside as simple growing pains.

On many occasions, when Debbie needed help doing something at home, her step-mother asked, "How long have you tried?" If she hadn't tried long enough, her step-mother said, say "Try harder." Debbie resented her step-mother's attitude and noticed she willingly helped her older brother whenever he asked.

In school, Debbie felt different from the other children. She hated recess because she couldn't run or jump rope or do any of the things other girls did. When teams were chosen for games, Debbie was never picked until the teacher interceded. In spite of her physical awkwardness, Debbie dreamed of being a ballerina. It was a dream she never told anyone. She knew her step-mother would laugh at her. She remembered overhearing her step-mother talking with her aunt about how immature and clumsy Debbie was and wondering what in the world Debbie would ever do when she grew up. At that time, Debbie knew she could never share her dreams with her parents.

In the classroom, Debbie struggled to understand what was being taught. She had particular difficulty with math and could never get better than a “C.” As an adult, she wondered why no teacher ever approached her parents about her physical or academic difficulties. She decided no one cared.

Debbie was lonely all through childhood. She watched her brother develop into the “life of the party,” while she preferred being alone in her room. She was never invited to parties and decided she was better off alone. When she found herself in social situations, she felt as if she didn’t know what to say. The older she got, the more time she spent by herself. Her memory of her childhood is of being lonely and without any friends.

As she matured, Debbie realized there must be a reason she had so many physical difficulties. Walking became so difficult she started using a wheelchair when she had to travel distances. She also searched out doctors who could help her. The first doctor thought she had fibromyalgia but sent her to a neurologist for further testing when none of his interventions proved effective. The neurologist was amazed no one had diagnosed her CP. He said she had the classic signs of hemiplegia and any pediatrician should have picked it up when she was a young child.

Debbie approached her father and step-mother about the diagnosis. Her step-mother became very defensive and said she told them the doctor had diagnosed CP when Debbie was very young. Her father just held his head in his hands saying, “I didn’t know. You didn’t tell me. I would have remembered that.” Debbie again felt no one really cared about her.

Since she struggled so much in school, Debbie didn’t think she could go to college but knew she needed some type of job training, so she attended a local junior college. There she met her husband. Not long after their marriage, they had their first son,

followed by two more sons in rapid succession. Although Debbie enjoyed her family, she found it difficult to do everything expected of her. She found walking harder and harder and began using her power wheelchair as much as possible. This proved to be problematic for three reasons: 1) the school where she was working as a clerical aide wouldn't accommodate the wheelchair, 2) she found it awkward to work in the kitchen from the wheelchair, and 3) her husband didn't like it when she used the wheelchair and was always discouraging its use. Feeling others didn't really care about her needs, Debbie often found it impossible to insist on using her wheelchair.

The wheelchair, however, allowed Debbie to get around so much easier, and she wasn't exhausted and in pain by the end of the day. Debbie also noticed other people were nicer to her when she was in her wheelchair. When walking, she often struggled to open heavy doors, but in her chair, people would speak nicely to her as they helped with doors. She also noticed, though, while people were nicer, they seemed to talk louder and slower when she was in her wheelchair, as if she weren't smart. She wondered why things had to be so difficult, why people couldn't be nice all the time, and why no one seemed to really care about her, whether or not she was in her wheelchair.

Her sense no one cared enough to accommodate her needs intensified as she watched school officials accommodate the needs of a young boy with muscular dystrophy who used a wheelchair. The boy's restroom was actually remodeled for the wheelchair but the ladies' restroom Debbie used had a very narrow door. She had to find a place to park the chair and walk to the restroom. This was a problem, since the school principal told her she couldn't leave her chair in the hallway. The walk from her office to the restroom was a long enough distance to cause Debbie fatigue and pain.

As her pain and spasms worsened, the neurologist suggested she was a good candidate for a baclofen pump, a system that includes a reservoir and tube which is surgically implanted and allows medication to be directly released into the spinal fluid. The medication, baclofen, is an antispasmodic agent that reduces spasticity caused by spastic CP. The pump was very helpful for the bladder spasms Debbie had since childhood as well as for mobility difficulties. Ironically, as Debbie felt physically better, she began to focus on all the years no one had helped her with her CP. She resented her step-mother who apparently ignored her diagnosis. She wondered why her teachers, pediatrician, and others never reached out to her. She even questioned why the world, or society, not only doesn't care about those with disabilities but actually seems to make things more difficult for them.

Once she knew her diagnosis, Debbie researched CP and appropriate interventions. As she learned about physical and occupational therapy she speculated her physical difficulties would have been minimized if she had been provided with therapy. She also wondered if she could have overcome some of her learning difficulties if her visual tracking problem had been identified when she was younger. Knowing of missed opportunities, she became frustrated and angry about her childhood.

Debbie is now in her late forties. She quit her job because her employer refused to accommodate her physical needs, and she has been unable to find another job. She talks often about job discrimination, societal discrimination, lack of accommodations, and the failure of disability organizations and the government to meet the needs of those with disabilities. She is angry, sad, and very pessimistic about her future.

Debbie's biography represents experiences not typical of most of the participants. While several atypical experiences were shared by participants, the most important was

the lack of supportive parents or other adults in her lives. Other participants learned they were important and special, but the participants represented by Debbie learned they were not important and no one really cared for them. As they internalized negative feelings through their lives, these participants saw the negative aspects of their experiences. Their parents' failure to support or accept her with their disability as children was repeated throughout their lives by her teachers, employers, husband, and children.

Summary

Each participant shared experiences about growing up and living with CP. While each woman's story is unique and special in its own right, there were commonalities across all of the narratives. The women cited difficulties with mistreatment that began in childhood and continued through adulthood. They shared difficulties and benefits that came from living everyday with a physical disability. As demonstrated by the exemplar biographies of Liz and Debbie, the participants led complex lives. While the categories and themes reveal essential elements of their lives, the biographies depict the wholeness of their lives and reveal some of the complexities of living with CP. Chapter 5 will present meanings and implications of findings relative to health care providers and future research. Researcher assumptions and study limitations will also be discussed.

CHAPTER FIVE

Discussion

The purpose of this study was twofold: 1) to describe the life experiences of women with CP who have experienced mistreatment and, 2) to describe how these women understand the meaning of their disability and mistreatment experiences relative to gender, culture, social class, and power. Using the feminist biographical method allowed the eight participants to share experiences during the first interview without prompts or guides by the interviewer. The first interview, therefore, encouraged participants to describe life experiences they deemed important. The second interview was designed to allow the interviewer the opportunity to ask questions about the first interview and also about the aims of the study. By listening to participants' individual stories, reading their personal written texts, and reading and watching their suggested cultural texts and movies, a deeper appreciation of the complexity of their lives emerged. The feminist biographical method enabled the researcher to gain a deeper understanding of growing up and living with CP by both listening to the voices of the women and exploring the aims of the study. This chapter will discuss researcher assumptions, study findings, implications for professionals, and recommendations for further research.

Researcher Assumptions

The feminist biographical method allowed me to present the personal origins of my research and identify assumptions I brought to this research (Mann, 1994; Reinharz, 1992; Thomas, 1999). During the first interview, I listened as participants told their life stories; I did not ask questions that may have guided their narratives. This process allowed me to set aside my assumptions and gain a holistic understanding of participants'

lives. Through this understanding, I have come to realize that, while some of my assumptions were confirmed, others were not.

Based on my assumptions and life experiences with a child who has cerebral palsy, I expected participants' mistreatment experiences to include discrimination, emotional, physical, and sexual abuse, and that gender and disability would be the major factors in their mistreatment experiences. I also assumed childhood experiences, whether positive or negative, would prepare participants for adulthood in such a way that mistreatment and disability would play less important roles in their adult lives. While some of my assumptions were validated by my research, others were not.

Discrimination as Mistreatment

Although I assumed participants would describe experiences of discrimination, they only used the term in relation to job discrimination. This is not surprising, since the Americans with Disabilities Act (ADA) defines discrimination on a societal level addressing barriers to employment, transportation, public accommodations, public services, and telecommunications (Jones, 2003); in other words, legal discrimination is the denial of that to which one is legally entitled. Green, Davis, Karshmer, Marsh, and Straight (2005) described legal discrimination that includes individual and societal acts. They wrote, "Discrimination...interferes with an individual's ability to participate fully in the social and economic life of her/his community" (p. 198) which would be a form of moral discrimination. This broader definition of moral discrimination was seen when participants described experiences where they were not allowed to participate in activities and/or felt excluded, devalued, or discounted, such as 1) blatantly ignoring a participant's presence, 2) denying appropriate accommodations, 3) excluding a participant from social activities, 4) making unfounded assumptions, 5) failing to meet a participant's

educational needs, 6) denying a participant from pursuing her educational goals, and 7) denying a participant a job for which she was qualified. Participants believed these discounting experiences had long-term consequences, such as social isolation and depression. However, many of these experiences were not identified as discrimination by participants but rather shared as examples of mistreatment experiences.

Other Types of Mistreatment

Experiences more easily identified as abusive were harassment experiences. These experiences included 1) physical aggression, such as pushing and tripping, inappropriate touching, and rape, and 2) emotional antagonism, such as mimicking a participant's awkward gait or speech, rejecting a participant's work as not being her own, or treating a participant in a cruel or callous manner. These experiences also contributed to participants' sense of social isolation and depression.

Gender and Mistreatment

I also assumed gender and disability would play major roles in participants' mistreatment experiences. Although participants cited disability, ignorance, and power as the most important causes of their mistreatment, only four participants mentioned the relationship between gender and mistreatment. They explained gender increases a woman's risk for mistreatment because women are viewed as being inferior to men, and it is this inferior status that is the basis for mistreatment.

Mistreatment and Disability Over Time

My assumption about adult women with CP was that they would have learned to deal with mistreatment and CP as children and adolescents, and by adulthood would describe them as inconsequential in their lives. I was wrong. This assumption was based on ignorance, since prior to this study I never met a woman over the age of thirty with

CP. The feminist biographical method allowed participants to tell their life stories in a chronological fashion, thus putting mistreatment experiences into a lifetime perspective, rather than an experiential perspective. This perspective highlighted how mistreatment experiences evolved over the women's lives. For instance, younger women faced repeated and consistent physical aggression during elementary, middle, and high school years. Physical aggression in adulthood occurred less frequently but included particularly harmful experiences of rape and inappropriate sexual touching. Older women also faced repeated and consistent social exclusion, which was often described as the most difficult aspect of living with CP. In fact, the four study participants over the age of 40 described the major role CP played in most aspects of their lives. Compared to younger participants, older participants were less able to separate mistreatment experiences from their disability, were more likely to describe their disability in relationship to their mistreatment experiences, and exhibited more psychological distress. I realize now, as a health care provider and mother of an adult with CP, I need to acknowledge that mistreatment will continue to occur and not assume its consequences will diminish over time.

Discussion of Findings

This section presents a discussion of study findings, living with cerebral palsy and mistreatment, and the significance of the findings relative to current literature. There is a paucity of research about women with CP who have experienced mistreatment. Previous research focused on physical and sexual abuse of women with disabilities. While mistreatment and abuse can be synonymous terms, the term mistreatment is not as value laden and thus allows for the inclusion of experiences that participants may hesitate to label as abusive. This study adds to our understanding of the mistreatment and/or abuse

experiences of disabled women, and advances the belief that specific disabilities may be a variable in abuse (Hassouneh-Phillips & McNeff, 2004).

Two categories, consistent with the study aims, were supported by the data: 1) living with CP, and 2) mistreatment. Participants articulated detailed information regarding their experiences with mistreatment and living with CP. They shared their personal written texts and cultural texts they believed reflected their lives. The category, living with CP, revealed similarities and differences that occurred at four stages of development: 1) childhood through adolescence, 2) higher education years, 3) young adulthood, and 4) later adulthood. Themes discussed under the category of mistreatment included: 1) the meaning of mistreatment as revealed by participants' definitions and explanations of mistreatment, and 2) emotional, social, and physical outcomes of mistreatment. The importance of understanding these categories and themes for health care providers and others who interact with girls and women with CP and how these categories fulfill the aims of the study will be discussed in this chapter.

Living with Cerebral Palsy

The first aim of the study was to describe the life experiences of women with CP who experienced mistreatment. During each stage (childhood through adolescence, higher education years, young adulthood, and later adulthood) of development, participants described themselves as normal and intelligent. Participants' views of themselves and their lives at various stages of development revealed the changing nature of living with CP (Harrison, 2003). Without denying or ignoring their disabilities, participants at all stages of development represented themselves as having the same hopes, dreams, and aspirations as other girls and women. During childhood through adolescence, participants accepted their disabilities as part of who they were but

considered it a small, almost minor, part. The higher education years encouraged participants, who believed education was the key to success, to look toward a future full of possibilities. However, after college, participants faced unrelenting job discrimination. As young adults they began to question how, or even if, they would be allowed to fit into society. While maintaining their view of themselves as normal, intelligent women, their experiences as young adults led them to acknowledge that society treated them as neither normal nor intelligent. Finally, in later adulthood, participants viewed society as imposing limitations on them that were often more disabling than CP.

Ewing's (2002) reevaluation of Goffman's (1963) landmark study on stigma in her essay on stigma and its influence on the lives of women with disabilities seems to capture the essence of this finding:

Young women with disabilities today want to believe that if they try hard enough and are patient, they can have all the good things life has to offer. Only as they have practical life experiences with discrimination and marginality will they question the assumptions of equal opportunity. (p. 74)

Just as Ewing predicted, participants in later adulthood, whose lives were filled with discrimination and marginality, questioned the assumptions of equal opportunity. They acknowledged working hard and being patient did not guarantee getting everything they wanted. In spite of not getting all the good things they wanted, and while acknowledging that living with CP means facing many challenges and difficulties, they described how their challenges and difficulties made them stronger women who developed empathy for others and learned to advocate or stand up for themselves.

Exemplar Biographies

During data analysis, categories, themes, and subthemes emerged, which underscored areas of importance in participants' lives. In order to exemplify how the categories, themes, and subthemes presented themselves differently in the lives of participants, two types of biographies were constructed: one typical biography with many commonalities across participants, and one biography that included atypical experiences primarily from two participants. The creation of the paradigm biographies contributed to the fulfillment of the first aim of the study: to describe the life experiences of women with CP who have experienced mistreatment. It was important that two biographies representing typical and atypical experiences be presented. This will enable readers to view women with CP holistically and gain a better understanding of the experience of growing up and living with CP (Curtin & Clarke, 2005; Gutierrez, 1992; Popadiuk, 2004a).

The typical biographies, common to six participants, were filled with stories of supportive parents and families who offered appropriate help throughout their lives. Two participants, however, consistently related different stories. In order to more fully understand the typical (Liz) and atypical (Debbie) biographies, two exemplar biographies were created and presented in Chapter Four. During the analysis process, when categories, themes, and subthemes were emerging, the lives of participants became fragmented. The creation of the exemplar biographies not only allowed the researcher to reconstruct participants' lives, but it was instrumental in gaining a deeper understanding of contrasting experiences and their outcomes. Both biographies were filled with positive and negative experiences. However, Liz's biography was generally positive while Debbie's was generally negative. Liz's biography of an educated woman, while typical

for study participants, may not be typical of other women with CP. For instance, four participants had bachelor's or master's degrees which is much higher than the United States average of 26% of women over the age of 25 with bachelor's or master's degrees ("Educational attainment," 2008). On the other hand, Debbie's biography represented participants with less education, one with an associate's degree and one who did not graduate from high school.

Protective Factors

The major difference between the two biographies was the consistent presence or absence of a supportive family and the occasional presence or absence of an encouraging teacher. Support systems have been demonstrated to be important in the lives of both adolescents with and without disabilities. Adolescents without disabilities who identified the presence of supportive families, friends, teachers, or others in their lives demonstrated higher levels of healthy behaviors, self-efficacy and self-care (Callaghan, 2006). The protective nature of a strong support system was identified in King's et al. (2003) study of protective factors in the lives of people with chronic disabilities. They identified protective processes that assist people with disabilities to find sense and meaning in their lives. They also identified support from family, friends, and community members as an extremely important protective factor. As demonstrated by Liz's biography, participants with supportive family members and teachers perceived their lives as more fulfilling. In their analysis of models of resilience O'Leary and Bhaju (2006) explained the presence of protective factors do not negate negative factors but interact "with a risk factor to reduce the probability of a negative outcome" (p. 159). It is also important health care providers and parents understand that even though studies of women with disabilities have found "the social environment in which women with disabilities live is primarily a

hostile one” (Nosek, Hughes, Swedlund, Taylor, & Swank, 2003), there are protective factors promoting resilience and life satisfaction (King, Cathers, Brown, Specht et al., 2003).

Each participant cited ignorance as a basic cause of many of their experiences with mistreatment. If ignorance can cause mistreatment, participants predicted an awareness and understanding of the abilities and needs of girls and women with CP would prevent mistreatment. Understanding both typical and atypical life experiences of participants, and how these experiences have different meanings over time, is the first step in gaining the awareness and understanding participants described as necessary for health care providers, educators, and parents to address the needs of girls and women with CP.

The Meaning of Disability and Mistreatment

The second aim of the study was to describe how participants understood the meaning of their disability and mistreatment experiences relative to gender, culture, social class, and power. Gender referred to societal expectations of male and female roles, activities, attributes, and expectations. Culture included participants’ self-views including ethnicity, religion, and backgrounds. Social class included social status or economic situation. Power encompassed role distinctions based on authority, control, or influence. How participants discussed these topics provided an understanding of their perceptions. For example, as participants shared their life experiences, it became apparent mistreatment was an important part of their lives that coexisted with their disability. Although the link between CP and mistreatment was revealed by some participants as they talked about CP, at other times it was revealed when they talked about mistreatment. All participants described experiences with disability-related mistreatment. However,

younger participants expressed concerns that they would sound bitter or wrong if they acknowledged having a disability means being mistreated.

Gender, Power, and Mistreatment

By explaining their experiences with mistreatment, participants revealed the relationship between gender and power. All participants stated mistreatment occurs when there is a difference in power between people. Four participants explained that gender allows men to view women as inferior, which can result in mistreatment. Participants saw culture and social class as unimportant relative to mistreatment, except with reference to cultural norms of gender and expectations of appropriate female roles.

Not all participants believed gender played a role in either their disability or mistreatment. The four who did explained that in addition to being viewed as inferior because of their CP, they were also viewed as inferior because of their gender. This belief was consistent with feminist Gerschick (2000) whose essay promotes a theory of disability and gender.

All participants acknowledged the power differential between those with and without disabilities and believed the misuse of that power was an integral part of mistreatment. Research exploring power and abuse often focuses on the powerlessness of the victims, instead of the power of the perpetrators (Nahmiash, 2002). Only one participant cited her own powerlessness as the cause of her mistreatment, whereas other participants focused on the power of others. These participants described mistreatment experiences as fitting into one of four power differentials: the power of the able-bodied, the power of adults over children, the power of men over women, and the power of authority figures. These power differentials are consistent with Neath's (1997) feminist essay which discussed two types of power differentials: power with and power over.

Power associated with the able-bodied and authority figures is supported by societal norms. On the other hand, the power of adults and men over children and women results from society's hierarchical relationships.

Participants confronted power issues at many stages of their lives. When they were young, their parents or siblings explained the problem was not theirs, but the other person's. As adults, however, participants described feelings of powerlessness in situations of job discrimination, social rejection, and their struggle to reject negative self-views. They described times when they refused to accept society's stereotypes and other times when they felt discouraged and accepted them because they did not have the energy to refute them. In a book on disability, oppression, and empowerment, Charlton (2000) described how the internalization of misconceptions and negative stereotypes is devastating to people with disabilities. It also seems appropriate to quote here:

Most people with disabilities actually come to believe they are less normal, less capable than others. Self-pity, self-hate, shame, and other manifestations of this process are devastating for they prevent people with disabilities from knowing their real selves, their real needs, and their real capabilities and from recognizing the options they in fact have. (p. 27)

Just as Charlton described the effects of internalizing negative stereotypes, participants explained how they confronted feelings of powerlessness and inadequacy. The ability to confront the negative aspects of disability was also explored in an essay by feminists Collins and Valentine (2003). They explained how understanding the lives of women with CP and interacting with them in a supportive manner can actually give them a greater sense of power: "Understanding and acknowledging the discrimination and stereotyping that women with disabilities experience daily can be a very empowering and

healing practice strategy” (p. 39). In other words, just as participants acknowledged negative stereotypes and worked to counteract their affects, health care providers and parents can empower women with disabilities by also acknowledging the discrimination and stereotyping that occur in their lives.

Disability, Ignorance, and Mistreatment

The association between disability and mistreatment emerged as participants explained their perceptions of the role ignorance plays in mistreatment. Ignorance was described as a lack of understanding about CP in general, and more specifically, of the abilities and qualities of people with CP. The participants further explained that ignorance allowed able-bodied people to view those with CP as inferior, which is consistent with findings of previous studies (Deal, 2003; Goffman, 1963; Gordon et al., 1990; Green, 2003; Green et al., 2005; Thomas, 2000). Unlike other studies this study demonstrated participants’ beliefs that ignorance was the reason they were viewed as inferior, and therefore the cause of their mistreatment.

Outcomes of Mistreatment

Further consequences of mistreatment in the lives of participants were revealed as they described outcomes of mistreatment, which has been shown to negatively affect women’s health and well-being (Barrier, 1998; Campbell et al., 2002; Coker et al., 2002; Wathen & MacMillian, 2003). Initially, participants described only emotional or social outcomes of mistreatment, with depression and social isolation being the most common. When questioned physical outcomes were also revealed. Interestingly, the physical outcomes were more disability- related than other outcomes. For example, participants described how physical manifestations of CP, such as spasticity, gait difficulties, or speech inarticulation, increased under the stress of mistreatment. The increased physical

manifestations of CP are an example of disability-specific implications of mistreatment or abuse (Hassouneh-Phillips & McNeff, 2004). Participants who experienced physical or sexual abuse also talked about how their fear of letting care attendants provide basic health needs resulted in poor hygiene.

Physical and Sexual Abuse

Four women in this study reported experiences of physical and sexual abuse. This is lower than reported in the literature (Powers et al., 2002; Young et al., 1997). Since the study's informed consent clearly delineated the need to report current or ongoing abuse if either were revealed in the interview, perhaps some women may not have reported experiences with abuse. However, the examples of physical abuse were from peers during childhood, and the examples of sexual abuse occurred during adulthood (one involved inappropriate touching during a doctor's examination). This is consistent with findings that women with disabilities are more likely abused by health care providers than women without disabilities (Young et al., 1997).

Another participant reported being raped by four different personal care attendants. This participant relied on personal care assistants to provide personal care, transfer her from bed to her power wheelchair, and assist with feeding. This reliance is consistent with studies that found a link between decreased mobility and/or reliance on personal care attendants and an increased incidence of abuse (Nosek, 1995; Nosek, Foley et al., 2001; Nosek et al., 2006; Powers et al., 2002; Young et al., 1997).

This study is important because it allowed participants to focus on experiences which were not discussed in earlier studies. For instance, several participants used the common experience of being ignored by waitresses in restaurants as an example of mistreatment. They each acknowledged they may not have considered being ignored

mistreatment if it did not occur on a frequent and consistent basis. In addition, many participants acknowledged they were teased as children at school, and the teasing was over long periods of time. Disability-related abuse may differ, not only in its incidence and nature as cited by several researchers (Nosek, 1995; Nosek, Foley et al., 2001; Powers et al., 2002; Saxton et al., 2001), but also in its persistence, consistent nature, and definitions.

This study is also important because it used a broad definition of mistreatment. Although the terms mistreatment and abuse are interchangeable, abuse is more value laden. Emphasizing the term mistreatment minimized the possibility that participants would consider abuse to be only physical or sexual and therefore exclude themselves from the study or discount mistreatment experiences. Participants in this study, therefore, may have shared experiences missed in other studies.

Study Limitations

There are three limitations to this study: 1) small sample size, 2) non-verbal women were excluded, and 3) the challenge of representation. Each limitation will be discussed in this section.

Study participants were selected using criterion sampling; only women with CP who had experienced mistreatment participated (Patton, 2002). Based on previous studies which used the feminist biographical method, a target range of 8 to 12 participants was determined to be appropriate (Antikainen et al., 1995; Luk, 1995; Popadiuk, 2004b; Shu, 2006; Stewart, 2002; Ziehler, 1999). Although 12 women responded to recruitment flyers, only eight agreed to participate. Women who did not participate were not required to give a reason, although two did volunteer explanations. One stated she did not have a very interesting life and would not know what to tell me. The other, who

responded by email, stated that her speech was too difficult to understand. When I asked if she could participate in writing, she stated that it was too hard for her to type more than a sentence or two at a time. Although eight is a small sample size, each participant took part in two in-depth interviews, and repeat patterning of themes was evident before the final three participants were enrolled.

Small Sample Size

The small sample size and qualitative method preclude generalizability of findings to other people and situations; however that was not the purpose of this research. The choice of using the feminist biographical method permitted an in-depth exploration of participants' lives, yielding a deep understanding of their perceptions of growing up and living with CP. Therefore, the small sample size allowed a thorough and detailed examination of participants' lives. In spite of the small sample size, the depth of the interviews and the richness of the data divulged categories, themes, and paradigm biographies whose interpretation and usefulness becomes the responsibility of the reader to interpret (Reinharz, 1992).

Exclusion of Non-verbal Women

The exclusion of nonverbal women from the study is another limitation. Although only one potential participant declined because of impaired speech, other potential participants may not have been given the recruitment flyer because of their non-verbal status. The difficulty of interviewing women with incomprehensible speech is obvious. However, the need to gain a fuller understanding of the experience of living and growing up with CP mandates their stories be uncovered. Of the eight study participants, four had speech affected by CP, with two having almost incomprehensible speech. The time required to listen to these participants, learn their speech patterns, and record their stories

was well worth the effort. I would have been willing to meet with the woman who declined participation because of her communication difficulty and try to find a way to hear her story, but it was her choice to decline.

Challenge of Representation

The challenge of representation was discussed in Chapter Three. This challenge refers to the problem of whether or not researchers can accurately capture the life experiences of participants. This research does not claim to find the truth of participants' lives, but to reflect their lives in a manner that allows readers to gain a holistic understanding of the experience of living and growing up with CP.

Implications for Professionals

This study provides health care providers, educators, and other professionals the opportunity of gaining a deeper understanding of the lives of women with CP. This understanding can lead to improved interactions with women with CP which can better address their needs. This section explores implications this study has for professionals who work with girls and women with CP.

This study highlights the importance of health care providers having a holistic view of the lives of women and children with CP. This means appreciating the whole lives of those with CP, and within those lives, understanding the roles disability and mistreatment play. Interactions with health care providers were mentioned in only a limited fashion during the interviews. Many participants told how their parents were given very grim prognoses at the time of their diagnosis. Only one participant shared an experience in which a health care provider provided helpful advice and one participant described an experience of sexual abuse by a health care provider. Hassouneh-Phillips et al. (2005) described the invalidation of women with disabilities by health care providers.

This invalidation is consistent with participants' descriptions of ignorance as the basic cause for the inappropriate ways they were treated. Addressing both invalidation and ignorance in the lives of their patients with CP should be a goal of health care providers. Therefore, taking time to listen to girls and women with CP explain their needs and concerns will assist health care providers in providing appropriate health care.

Other implications for health care providers include understanding the importance of supportive families in the lives of girls with CP. Knowing the support of families can have positive lifelong ramifications will help health care providers address not only the needs of the child, but family needs that will assist them to provide support for their daughter. For example, one participant never received appropriate early interventions. She believed her pediatrician diagnosed her condition, but her step-mother ignored the diagnosis. Without interviewing the step-mother, who is now deceased, it is impossible to know what truly happened. However, it is possible the stepmother was either overwhelmed by the diagnosis or did not understand what it meant. Regardless, she was unable to provide her step-daughter with the support she needed. Consequently, health care providers need to realize able-bodied parents do not instinctively understand the physical, emotional, or social needs of a child with a disability. Indeed, providing parental assistance and support becomes a crucial part of providing appropriate health care for the family and child with a disability.

As participants talked about growing up and living with CP, they identified how the meaning of their disability changed over time. Understanding these developmental differences highlights the importance of encouraging girls and women with CP to identify the meaning of their disability at their present stage of life. Pediatricians, school based nurses, and family health practitioners should address age-specific needs and concerns of

their clients with CP and be aware of transitions that occur throughout the life span. For instance, older women with CP may have more psychological distress related to their disability than children or younger women. Given the high proportion of participants who reported depression, all women with CP should be screened for depression. Finally, study participants demonstrated high academic attainment in spite of severe physical impairments. Health care providers should, therefore, inquire about patients' interests and strengths (academic and otherwise) in order to more holistically address their needs.

Health care providers must understand disability-related mistreatment and abuse is different than other types of mistreatment and abuse. Screening for physical and sexual abuse is important but screening should also focus on emotional and social mistreatment. Asking questions about friends, social activities, interactions with teachers, and academic achievements may assist the health care provider identify needs to address. The need to screen for mistreatment experiences was validated by Curry et al. (2003) whose refined screening tool for abuse of women with disabilities included five disability-specific items, including being yelled at or feeling put down. This refinement is a positive step in identifying both harassment and discounting types of mistreatment.

Health care providers should encourage girls and women with CP to pursue their educational goals. Participants in this study were better educated than most able-bodied women. Their educational attainment was not limited by the severity of their CP. Three participants required considerable physical assistance and two required moderate assistance. Of these five participants, one did not graduate from high school, two are pursuing higher education, one has a bachelor's degree, and one has a master's degree. The other two participants with master's degrees have significant speech difficulties. Although CP may make attending college difficult, as was often discussed by

participants, it did not make it impossible. Only one participant has interrupted her college studies because of the difficulty her physical needs entail, but she is actively searching for ways to achieve her educational goals.

Finally, participants described both positive and negative educational experiences. The importance of supportive teachers in participants' lives was addressed by most participants. Study participants achieved a high level of educational attainment, often attributed to teachers who not only took an interest in a participant, but instilled in the participant a belief that she could learn and be a successful student. Educators, therefore, need to identify the abilities and talents of their students with disabilities and encourage a love for learning.

Recommendations for Further Research

This is the first study to explore the mistreatment of women with a specific disability. As indicated by Hassouneh-Phillips and McNeff (2004), specific disabilities and abuse may have unique interactions. It is important, therefore, to expand the exploration of mistreatment and abuse to women with other specific disabilities. Special focus should be placed on women whose stories may be difficult to uncover. For example, women with CP who are non-verbal may be particularly at risk for mistreatment and abuse. Designing a methodology and procedures allowing non-verbal women with CP to share their stories should be a focus of future research. Some non-verbal women utilize communication boards or computers. Although interviews focusing on verbal communication may not be possible, interviews using communication boards or computers may allow some women to share experiences. This will provide a broader and deeper understanding of the problem of abuse of women with disabilities and direction for appropriate interventions.

An interesting finding in this study was the report of depression by six participants. Future research should therefore explore depression in the lives of women with CP and its relation to disability. As revealed by this study, women with CP experience mistreatment over their lifetime. More research also is needed to better understand how this may contribute to depression.

In addition, the protective factor of supportive families emerged as important to participants who, in the face of multiple challenges, found positive aspects of life. Since protective factors were not a focus of this study, it is unclear if other factors also contributed to the positive life experiences of six participants. A few studies have explored protective factors in the lives of people with chronic disabilities and found that protective factors, such as social support, improve self-esteem and offset negative experiences (King, Cathers, Brown, & MacKinnon, 2003; King, Cathers, Brown, Specht et al., 2003). Consequently, protective factors and experiences of mistreatment should be the focus of future studies.

The role of supportive parents emerged as important in the lives of participants. Only one participant related advice from a pediatrician being helpful to her mother, who learned to accept and support her as a young child. The role health care providers play in supporting parents with children with CP and what is and is not perceived as supportive by parents could also be the focus of future research.

Study participants have lived with CP their entire lives. Experiences with mistreatment began in childhood and continued throughout adulthood. No studies have investigated how the persistent and continual nature of mistreatment may affect those with a life-time disability, such as CP. Unlike those with acquired disabilities, women with CP have never experienced life without a disability and, as revealed in this study,

without mistreatment. The implications of persistent and unrelenting mistreatment over a lifetime should be the focus of future studies.

Summary

This study increases our understanding of the life experiences of women with CP who have experienced mistreatment. It also describes how these women understand the meaning of their disability and mistreatment experiences relative to gender, culture, social class, and power. The use of the feminist lens, in general, and the feminist biographical method, specifically, promoted a better understanding of disability and mistreatment relative to gender, class, culture, and power. Mistreatment was clearly part of these women's lives, and has emotional, social, and physical outcomes. Having an understanding of the difficulty of growing up and living with CP may be helpful for health care providers and others who interact with girls and women with CP. My hope is that this research will encourage others to listen to the voices women with CP, replace ignorance with understanding, and promote a holistic approach to meeting their emotional, social, and physical needs.

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Appendix A

Consent Forms



Oregon Health & Science University
Consent Form

IRB#: 3313

Protocol Approval Date: 6/25/2007

OREGON HEALTH & SCIENCE UNIVERSITY
Consent and Authorization Form

TITLE: The Life Experience of Women with Cerebral Palsy who have Experienced
Mistreatment

PRINCIPAL INVESTIGATOR: Kathleen Knafl, PhD (503) 494-4288

CO-INVESTIGATOR: Donna Freeborn, MSN, FNP, CNM (801) 422-3507

SUPPORTED BY: Brigham Young University College of Nursing provides financial support for this study

PURPOSE:

The purpose of the study is to understand women's experience of having cerebral palsy. We will also ask about any experiences you have had that you felt were hurtful. These experiences may include mistreatment or other situations important to you. You have been invited to be in this research study because you have cerebral palsy and have indicated you have had experiences that may be considered mistreatment. 8 to 12 women will take part in the study.

PROCEDURES:

This study requires at least two interviews that will last up to 2 hours each. Follow-up contact by phone, email or in-person may also be arranged. You will be interviewed twice by Donna Freeborn, the doctoral student who is doing this study. The interviews will be tape-recorded and will take up to 2 hours. We will meet in a place you choose that is convenient and safe for you.

In the first interview, you will be asked questions about having cerebral palsy as well as any experiences you consider inappropriate or troublesome to you. In this first interview you also will be asked to talk about other things you think are important about having cerebral palsy. All information that you provide will remain confidential. All interview tapes will be destroyed when the study is over, and your name and other identifying information will be kept private.

You will also be invited to give the interviewer a copy of any poems, stories, diaries or other materials you have written that you feel tells more about your life experiences. If you allow Ms. Freeborn to borrow some of your personal materials, you will be asked to sign a separate consent form.

After this first interview, Ms. Freeborn will write a brief biography of your life based on what you have told her about yourself. You will be asked to review your biography at the beginning of the second interview to see if it gives a true description of your life. During the second interview, Ms. Freeborn will ask you additional questions about your life, including questions about times you experienced inappropriate treatment. Ms. Freeborn will give you a copy of the biography she has written if you would like one to keep.

RISKS AND DISCOMFORTS:

Possible risks include loss of privacy, being embarrassed, and feeling discomfort or emotionally upset as you share your story. You are free not to discuss those things that you believe are too private to share with a researcher. If you become uncomfortable or upset during the interview, you can ask to stop at any time.

BENEFITS:

You will not benefit from being in this study. However, understanding your experiences may help health care professionals understand and care for women with cerebral palsy in the future.

ALTERNATIVES:

You may choose not to be in this study.

CONFIDENTIALITY:

We will not use your name or your identity for publication or publicity purposes.

Since all data will be collected in Utah, it is necessary to obey Utah laws. Under Utah Law, suspected abuse, neglect, or exploitation of a disabled adult that is currently ongoing **must** be reported to appropriate authorities. If current abuse, neglect, or exploitation is disclosed during the interviews, you will be reminded that it needs to be reported. You will be invited to participate in the reporting process. Past mistreatment experiences do not need to be reported under Utah law.

The information that you give in the study will be handled confidentially. You will be identified by a made-up name that the researcher will assign to you. Every written record will have only the made-up name on it. The tape recordings will be destroyed after they have been transcribed. Any information given during the interview that may identify you will not be included in the written record. This would include names of other people or names of places.

The persons who are authorized to use and disclose any information about you are the two investigators listed on page one of this consent form and the OHSU Institutional Review Board.

The persons authorized to receive this information are those at BYU, and the Office for Human Research Protection. However, as described in the preceding paragraph, your name and all identifying information will be removed from your interview data and the biography Ms. Freeborn writes.

You have the right to revoke this consent and you can withdraw your permission for use of your information for this research by sending a written request to Ms. Freeborn, 457 SWKT, Brigham Young University, Provo, UT 84601. If you do send a letter withdrawing your consent to be in the study, the use of your information will stop as of the date Ms. Freeborn receives your request. However, Ms. Freeborn is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives.

This study has applied for a Certificate of Confidentiality from the federal government, which will help us protect the privacy of our research subjects. The Certificate protects against the involuntary release of information about subjects collected during the course of our covered studies. The investigators involved in the studies cannot be forced to disclose the identity or any information collected in the study in any legal proceedings at the federal, state, or local level, regardless of whether they are criminal, administrative, or legislative proceedings. You or the investigator may choose to voluntarily disclose the protected information under certain circumstances. For example, if you request the release of information in writing, the Certificate does not protect against that voluntary disclosure. Furthermore, federal agencies may review our records under limited circumstances, such as a Department of Health and Human Services (DHHS), or an Office for Human Research Protection (OHRP) request for information for an audit or program evaluation or a US Food and Drug Administration (FDA) request under the Food, Drug and Cosmetics Act.

COSTS:

It will not cost you any money to participate in this study. You will receive a \$25 Target gift certificate at the completion of each interview.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Donna Freeborn 801-422-3507.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions regarding this study now or in the future, contact Donna Freeborn (801) 422-3507. If you have any questions regarding your rights as a research

subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

If you request it, a summary of the findings will be sent to you.

If you choose not to participate in an interview, you will not receive a \$25 Target gift card.

We will give you a copy of this form. If you do not want to keep it, you may return it to the researcher.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

<p>OREGON HEALTH & SCIENCE UNIVERSITY</p> <p>INSTITUTIONAL REVIEW BOARD</p> <p>PHONE NUMBER (503) 494-7887</p> <p>CONSENT/AUTHORIZATION FORM APPROVAL DATE</p> <p style="text-align: center;">Jun. 25, 2007</p> <p>Do not sign this form after the Expiration date of: <u>6/24/2008</u></p>

Subject signature

Date

Signature of person obtaining consent

Date



**Oregon Health & Science University
Consent Form**

IRB#: 3313

Study Approval Date: 6/25/2007

**OREGON HEALTH & SCIENCE UNIVERSITY
SECONDARY CONSENT**

TITLE: The Life Experience of Women with Cerebral Palsy who have Experienced Abuse

PRINCIPAL INVESTIGATOR: Kathleen Knafel, PhD (503) 494-4288

CO-INVESTIGATOR: Donna Freeborn, MSN, FNP, CNM (801) 422-3507

SPONSOR: Brigham Young University College of Nursing provides financial support for this study

PURPOSE:

You have already consented to participate in a research study because you have cerebral palsy. During this research project you will be invited to share personal writings such as poems, stories, or diaries with the investigator.

PROCEDURES:

If you choose to share your personal writings, you will make these available to the interviewer at the first interview. She will make copies of your writings and return the originals to you at the second interview.

RISKS AND DISCOMFORTS:

Sharing of your personal writings is voluntary and is not required in order to take part in this research. If you choose to share such items, you may feel a loss of privacy or embarrassment.

BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit others with cerebral palsy in the future.

CONFIDENTIALITY:

The copies of your writings will be secured in a locked file cabinet. They will be shared only with the research team and will be identified by your pseudonym. They will be destroyed at the end of the research project.

LIABILITY:

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from the use of your writings through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at 503-494-7887.

PARTICIPATION:

Kathleen Knafel (503) 494-4288 has offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

We will give you a copy of this form. If you do not want to keep it, you may return it to the researcher.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to permit this use of your personal writings.

<p>OREGON HEALTH & SCIENCE UNIVERSITY</p> <p>INSTITUTIONAL REVIEW BOARD</p> <p>PHONE NUMBER (503) 494-7887</p> <p>CONSENT/AUTHORIZATION FORM APPROVAL DATE</p> <div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 10px auto;"> <p style="text-align: center;">Jun. 25, 2007</p> </div> <p>Do not sign this form after the Expiration date of: 6/24/2008</p>

Subject signature

Date

Signature of person obtaining consent

Date

Appendix B

Safety Protocol

APPROVED: Jun. 25, 2007

Safety Protocol

Women who are currently in an abusive situation are excluded from the study. The following safety protocol will, however, assure the safety of both the researcher and the interviewees. To further protect study participants, a Certificate of Confidentiality will be obtained.

- 1) Participation in the study is voluntary. No woman will be coerced or pressured into participation. Initial contact will be made by the participant.
- 2) Interviews will be private and confidential. Women will be identified by a pseudonym with their true identity known only to the interviewer. Identifying information revealed during the interviews will be altered or eliminated as appropriate.
- 3) If at any time during an interview, the interviewer feels unsafe (due to information shared by the woman, the surroundings of the interview or other individuals in the vicinity) or the woman expresses concerns about her immediate safety, the interview will be terminated and safety will be determined.

Appendix C

Interview Guides

APPROVED: Jun. 25, 2007

Interview Questions and Probes for First Interview

The first interview is designed to be unstructured to allow the participant to tell her story in her own words. To initiate this interview, each participant will be asked, “Tell me about your life and growing up with cerebral palsy.”

In the first part of the first interview, the interviewee is told that she won’t be interrupted unless clarification is needed or the participant asks a question; also that the interviewer will take notes for later use. The notes consist of a sequential list of the topics raised by the interviewee. When the interviewee finishes her story, the second part of the interview begins. Here the interviewer asks for more information about the topics raised by the participant in the same sequential order and language used during the interview. No questions are asked about topics that were not discussed in the first part of the interview.

APPROVED: Jun. 25, 2007

Interview Questions and Probes for Second Interview

Many of the following questions and probes may have been covered adequately during the first interview. The interview guide for the second interview is designed to elicit elaboration of data from the first interview, if needed, and to explore topics not covered in the first interview.

Guiding Question	Probes
<p>In our first interview, you told me about growing up with cerebral palsy. I would like to ask a few questions about your experiences to make sure that I understand what you said.</p>	<p>When did you first realize you were different from other children?</p> <p>How did cerebral palsy influence your childhood? school? activities?</p> <p>What were the hardest parts about having cerebral palsy?</p> <p>What were the best parts about having cerebral palsy?</p>
<p>What meaning has cerebral palsy had in your life?</p>	<p>How has it affected who you are today?</p> <p>Has gender played a role in your disability?</p> <p>How does culture or society affect disability?</p> <p>How is disability affected by power issues?</p>
<p>When we first talked you said you had been treated inappropriately when you (mention experience she described). I would like to know more about that (those)</p>	<p>What were your thoughts or feelings at that time?</p> <p>Did you tell anyone?</p> <p>How was the mistreatment related to your</p>

<p>experiences.</p>	<p>having cerebral palsy?</p> <p>How did the experience(s) affect you emotionally, socially, and physically?</p> <p>What could be done by others (health care providers, parents, teachers) to prevent these things from happening to other girls/women with cerebral palsy?</p> <p>What can be done to prevent other girls/women from being mistreated?</p>
<p>What meaning has mistreatment had in your life?</p>	<p>How do you define mistreatment?</p> <p>How has it affected who you are today?</p> <p>How does gender play a role in mistreatment?</p> <p>How does culture or society affect mistreatment?</p> <p>What role does power play in mistreatment?</p>

Appendix D

IRB Approval Communication

OREGON HEALTH & SCIENCE UNIVERSITY

Research Integrity Office, L106-RI
 2525 SW First Avenue, Portland, OR 97201
 Phone: (503) 494-7887

MEMO

Date: 6/13/2007

To: Kathleen Knafl, MA ,PHD
 Susan B. Bankowski, MS, JD, Chair, Institutional Review Board, L106-RI
 Gary T. Chiodo, DMD, FACD, Director, OHSU Research Integrity Office, L106-RI

From: Charlotte Shupert, Ph.D., Associate Director, Research Integrity Office, L106-RI
 Kara Manning Drolet, Ph.D., IRB Co-Chair, Institutional Review Board, L106-RI
 Susan Hickman, Ph.D., IRB Co-Chair, Institutional Review Board, L106-RI
 Katie McClure, M.D., IRB Co-Chair, Institutional Review Board, L106-RI

Subject: IRB00003313, Life experiences of women with cerebral palsy who have experienced mistreatment

<p>Initial Study Review Protocol/Consent Form Approval</p>

This memo also serves as confirmation that the OHSU IRB (FWA00000161) is in compliance with ICH-GCP codes 3.1-3.4 which outline: Responsibilities, Composition, Functions, and Operations, Procedures, and Records of the IRB.

This study is approved for 20 subjects.

Your protocol is approved for one year effective 6/25/2007.

Your combined consent/authorization form is approved by the IRB effective 6/25/2007.

You may use only copies of the approved consent/authorization form for the informed consent process.

Your secondary consent form is approved by the IRB effective 6/25/2007.

You may use only copies of the approved consent form for the informed consent process.

The approved consent form can be found by logging on to the eIRB system and going to your study. Next, click on the Study Documents tab and locate your approved consent form under the Approved Documents heading.

Other items reviewed and administratively approved by the IRB include:

- Advertisement Flyer
- First Interview Guide
- Interview Guide

- Lay Protocol Summary
- Safety Protocol

Other items reviewed and noted by the IRB include:

- BYU memo

This study met the criteria for EXPEDITED IRB review based on Category # 7, where the study employs interview methodologies.

The requirement to obtain informed consent and HIPAA authorization has been waived or its elements have been altered in accordance with 45CFR46.116(d)(1-4) and 45CFR164.512(i)(1)(i). This memo confirms:

- That the research involves no more than minimal risk to the subjects;
- That the waiver will not adversely affect the rights and welfare of the subjects;
- That the research could not practicably be conducted without the waiver;
- That the research could not practicably be conducted without access to and use of the PHI;
- That the use or disclosure of the PHI involves no more than minimal risk to the privacy of the subjects as a result of:
 - An adequate plan to protect the PHI from improper use and disclosure;
 - An adequate plan to destroy any identifiers contained in the PHI at the earliest opportunity consistent with the research;
 - Adequate written assurances that the PHI will not be reused or re-disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted; and
 - Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

This waiver of consent and authorization applies only to the PHI for which use or access has been requested and described in the attached request for waiver.

Accounting for disclosures is not needed because the information will not be disclosed outside of OHSU or BYU.

Not needed because the information is defined as a Limited Data Set.

Required following the instructions for 50 or more records (please contact acctdisc@ohsu.edu to obtain a user account and instructions.)

Required following the standard instructions for PHI (please contact acctdisc@ohsu.edu to obtain a user account and instructions.)

A Data Use Agreement is required (please complete and submit the form available at www.ohsu.edu/cc/hipaa/forms.shtml).

This approval may be revoked if the investigators fail to conduct the research in accordance with

the guidelines found in the Roles and Responsibilities document (<http://www.ohsu.edu/research/rda/rgc/randr.pdf>). Please note that any proposed changes in key personnel must be submitted to the IRB via a Modification Request and approved prior to initiating the change. If you plan to discontinue your role as PI on this study or leave OHSU, you must arrange either (a) to terminate the study by so notifying the IRB and your department head, or (b) propose to transfer the responsibility of the PI to a new faculty member using a Modification Request.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinical medical record (if applicable).