The Problem With Prevention: The Case of Spina Bifida

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In this paper, I present a viewpoint about prevention and spina bifida that is not usually expressed within the occupational therapy literature. Using an autoethnographic account, I convey my experiences as a person with impairments from spina bifida in order to problematize current preventive efforts undertaken to eradicate this birth defect. This self-reflexive account connects my personal experiences to historical and medical views about spina bifida. The messages inherent in preventive efforts are discussed from a disability rights perspective. Occupational therapists are challenged to examine their attitudes toward disability, act as advocates in their practice, and, in a more informed manner, support or contest policy initiatives.


Still leaning against the incubators he gave them, while the pencils scurried illegibly across the pages, a brief description of the modern fertilizing process . . . actually showed them how this liquor was drawn off from the test-tubes; how it was let out drop by drop onto the specially warmed slides of the microscopes; how the eggs which it contained were inspected for abnormalities, counted and transferred to a porous receptacle. (p. 5)

—Excerpted from Brave New World by Aldous Huxley, 1932

Luckily, queer ones like her don’t happen often. We know how to nip most of them in the bud, early. (p. 60)

—Excerpted from Fahrenheit 451 by Ray Bradbury, 1950

There were only two occasions of release which were not punishment. Release of the elderly, which was a time of celebration for a life well and fully lived; and release of a newchild, which always brought a sense of what-could-we-have-done. This was especially troubling for the Nurturers, like Father, who felt they had failed somehow. (p. 7)

—Excerpted from The Giver by Lois Lowry, 1993

The above quotes from futuristic tales depict life-and-death choices made at both ends of the life cycle. Today, these choices are no longer limited to the realm of science fiction. For example, preimplantation genetic diagnosis or PGD (Harper, 2001), the latest technique for detecting certain genetic diseases, allows parents to select a “healthy” embryo for implantation. Preventing the birth of an infant with a disability would appear to be a good thing not only for the child and parents, but, considering the costs related to health care, a good thing for society. My paper provides a different way of framing prevention. Using autoethnography (Ellis & Bochner, 2000), I will convey my experiences as a person with impairments from spina bifida in order to problematize preventive efforts undertaken to eradicate this birth defect.

Autoethnography refers to both a research method and the self-reflexive texts that link ethnography with autobiography. Autoethnography is all at once about...
For me, as a researcher studying adults with spina bifida, a group of which I am a member, autoethnography provides a means for me to connect my self-as-researcher and self-as-research participant. In previous articles, I have used my personal experiences of living with spina bifida to question the dominant discourses about pain (Neville-Jan, 2003) and about sexuality (Neville-Jan, 2004). Autoethnography as a means to understand the lived experience of disability fits within Kielhofner’s (2004, 2005) recommendations for research in occupational therapy that incorporates disability studies. Autoethnography contributes a perspective beyond the personal disability experience to the social and political contexts in which disability occurs.

For the past 3 years, I have been a coinvestigator on two ethnographic studies funded through a disability supplement from the National Institutes of Health (National Institute of Child Health and Human Development, National Center for Medical Rehabilitation Research, #RO1 HD 3887801A1S). The project that my research supplements is an ongoing ethnographic and longitudinal study of 30 black families who have a child with a disability (#RO1 HD 3887801A1). For this project, I have been a participant observer during clinical encounters, interviewed family members and practitioners, and recruited participant families, 4 of whom have a child with spina bifida. The second project used narrative, ethnographic, and longitudinal methods to study 14 adults with spina bifida. I am one of the 14 participants as well as one of the researchers. Through such intense involvement with children and adults who have spina bifida, I have realized the importance of narrating parts of my story as reflexive texts to the ethnographies described above.

For me, the topic of this paper is profoundly disturbing. What if prenatal testing were available when I was conceived? Would I exist today? Is there value to having spindle parents about particular disorders, families and individuals and outpatient centers. Whereas genetics specialists counsel specialty spina bifida clinics, school-based practice arenas, families in a variety of settings, including neonatal units, specialty spina bifida clinics, school-based practice arenas, and outpatient centers. Whereas genetics specialists counsel parents about particular disorders, families and individuals with particular impairments frequently direct their questions to frontline professionals such as occupational therapists who engage with them in day-to-day activities. In their everyday practices occupational therapists champion the rights of persons with disabilities through empowerment and advocacy activities. On an individual level these efforts are notable. Yet, how can occupational therapists become more involved in the political and economic barriers that restrict participation in occupation?

In order to apply the perspective of autoethnography to the discussion about spina bifida, I begin by relating selected experiences of growing up with spina bifida and layer them within their medical and historical contexts. I will go back and forth between my experiences (represented in italics) and the literature. A discussion follows with implications for occupational therapy.

1950

I came into the world on December 13th at around 8:30 a.m. I weighed 7 lbs 2 oz and was the third child born into a family that would include one more sibling. My mother described her experience of being told that her newborn infant had spina bifida. She said:

They told me you had spina bifida. I had never heard those words before. They said that some infants are born with their spine exposed, but yours was closed and you had a hair spot. No one in the family had seen anything like that before. I was very upset and they gave me a sedative to calm me down. The obstetrician said you probably wouldn’t walk and that we should watch your head because it might get big. He said that you could be mentally retarded.

My mother further told me that she didn’t know why it happened but she did recall that her father, my grandfather (born in Sicily), had a brother who had a ‘tail on his back.’ His brother never came to America, so we don’t know what happened to him.

The worst case scenario presented to my parents was not realized. I walked at 18 months, although my gait was different. Both feet pointed to the right when I walked, and my right leg was less muscular, slightly shorter, and a little contracted at the knee, resulting in a limp when I walked. My right foot had no sensation. My mother said that after I was born, she had no idea what to expect. She recalled:

I would put you in an infant seat in the yard and you’d jump up and down. I thought that was part of the spina bifida, but they said you were supposed to do that. After you began walking, I took you to the pediatrician who was present at your birth and showed him how your foot pointed inward. He said: “That’s not a problem. We never thought she’d walk!”

Because 90% of infants born with spina bifida develop hydrocephalus, my parents were advised to monitor the size of my head. Looking back, I feel lucky that I did not develop hydrocephalus. The shunt now typically used to drain the cerebrospinal fluid that accumulated on the brain was not developed until 1952.
What Is Spina Bifida?

Spina bifida occurs during the very early weeks of pregnancy when the neural tube fails to close properly. The type and severity of impairments result from the extent and location of the spinal cord lesion and can therefore be highly variable (Feuchtbaum et al., 1999; Hunt & Poulton, 1995; Mazur, Shurtleff, Menelaus, & Colliver, 1989; Swank & Dias, 1992). Smith (2001), in a historical account, found evidence of spina bifida in skeletal remains dating as far back as 10,000 B.C. Few reports of the long-term consequences of spina bifida existed until 1652, when Professor Nicholas Tulp, a Dutch anatomist, gave spina bifida its name and described the consequences more fully (Smith).

Today, the estimated incidence of spina bifida occurring within the United States ranges from approximately .5 to .8 per 1,000 live births (Lary & Edmonds, 1996; Singh, 2003). Surveillance data (1983–1990) of prevalence rates at birth in the United States (16 states participated) report significant variations by state, ethnicity (Hispanics rate highest, followed by whites, blacks, and Asians), and gender (rates higher for females) (Lary & Edmonds). Trends suggest a decrease in the incidence of spina bifida since the implementation of prenatal screening, followed by abortion, and folic acid supplementation programs (Davidoff, Petrini, Damus, Russell, & Mattison, 2002; Rekate, 1991).

Of those born with spina bifida, rates of survival into adulthood have steadily increased, from 60% in 1963 to an estimated 90% in 1990 (Lary & Edmonds, 1996; Singh, 2003). Smith (2001), in a historical account, found evidence of spina bifida in skeletal remains dating as far back as 10,000 B.C. Few reports of the long-term consequences of spina bifida existed until 1652, when Professor Nicholas Tulp, a Dutch anatomist, gave spina bifida its name and described the consequences more fully (Smith).

To date, only a few studies have been conducted with adults who have spina bifida. These studies have focused on young adults and medical outcomes related to problems such as hydrocephalus, tethered cord, or incontinence (Andren & Grimby, 2000; Dunne et al., 1986; Mazur et al., 1989; Query, Reichelt, & Christoferson, 1990). Researchers have not explored the everyday life experiences of adults with spina bifida, their experiences growing up, and their concerns for the future. Our current research efforts intend to fill this gap in the literature.

1960–1970s

I wasn’t aware that I walked differently until one day, as I was crossing the street with my best girlfriend Julie— I think I was about 11 years old— she asked me, “Do you ever notice how people stare at the way you walk?” From that point on, I noticed all of the time. Some people would even turn around after I passed them to continue staring. I was different and I didn’t want to be. I wanted to be “normal” like my friends. In an effort to achieve this, my mother and I saw an orthopedic surgeon, referred by our general practitioner. He slated me for a “makeover.” First, he recommended orthopedic surgery to correct my right foot that turned inward. Second, I was referred to a plastic surgeon to remove the hairy nevus, the technical name for the hair spot on my back. It was a large rectangular patch of hair about 4 inches by 6 inches. If someone happened to see it, they’d say, “What’s that on your back?” Attempts by my mother to shave it never worked. There was one happened to see it, they’d say, “What’s that on your back?”

Surveys of children and adolescents report a concern for the future as a prominent theme (Appleton et al., 1994; Holmbeck & Faier-Routman, 1995). Specifically, when asked about their future, children and adolescents with spina bifida have described feelings of apprehension in regard to establishing friendships, finding a life partner, holding a job, and sexuality (Lollar, 1994a).

Rose, my mother’s best friend, had polio. One day Rose’s mother and my mother shared stories while shopping at the grocery store. She told my mother, “Make sure your daughter gets as much education as she can.” I heard that comment many times growing up and I guess it made a difference because I did just that. Other than going to school, I was not expected to marry or have children. Although when I was a child I had fantasies about getting married and keeping my incontinence a secret, when I found out about sex, I figured getting married was not a possibility. There were no adult role models for me, either, probably because not many infants born before me survived into adulthood.

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Of those born with spina bifida, rates of survival into adulthood have steadily increased, from 60% in 1963 to an almost 90% survival rate in the 1990s (Kinsman & Doehring, 1996). The Spina Bifida Association of America (SBAA) estimates that today there are 70,000 Americans living with spina bifida (Spina Bifida Association of America, n.d.) Secondary conditions associated with spina bifida can include physical impairments such as pain, bowel and bladder incontinence, pressure sores, scoliosis, orthopedic malformations, and short stature (Farley, Vines, McCluer, Stephens, & Hunter, 1994; Lollar, 1994b). In addition, psychological impairments such as depression, anxiety, impaired body image, and learning difficulties have been documented (Dennis & Barnes, 2002; Dennis, Fletcher, Rogers, Heretherington, & Francis, 2002; Dennis, Rogers, & Barnes, 2001; Lollar, 1994a; Marge, 1994). These secondary conditions, some of which can occur at any time throughout a person’s life, can impact activity and participation in education, employment, community living, and health care (Dunne, Gingerh, Olsen, & Shurtleff, 1986; Hunt, 1990; Peterson, Rauen, Brown, & Cole, 1994). It has been suggested that the aging process compounds these secondary conditions (Bergman, 1994; Turk, 1994).
had four surgical procedures (three on my foot and one on my back). I was very disappointed in the results. I really thought my body would be made to look "normal."

Treating orthopedic and urinary problems resulting from spina bifida has benefited from several technological advancements. New plastic materials introduced in the '70s improved the splints and braces that assisted children in attempting to walk. Today, children who walk primarily with extensive bracing, once in school, move toward a wheelchair that provides more ability to participate in social activities. Urological procedures followed a similar path. During the 16th and 17th centuries, nonmetallic catheters were first used to drain urine. The results were poor due to infection, smell, and social stigma. Techniques developed in the late 19th century provided an alternative to catheterization through the use of various methods to divert the urine. Transplanting the ureters to a loop of ileum became the recommended method to treat urinary incontinence in the early 20th century. Today, there has been a return to catheterization along with surgically augmenting the bladder with artificial sphincters and increasing the bladder capacity. New “odorless” pads and catheterization provide a more socially acceptable and natural means to manage this problem (Smith, 2001).

In 1961, spina bifida clinics, composed of multidisciplinary teams, were established in several major cities across the United States in an effort to coordinate the many complex secondary conditions related to spina bifida. The largest clinic was located in Sheffield, England, and was directed by neurosurgeon John Lorber. In a highly controversial study of 524 infants born with spina bifida between 1959 and 1969, Lorber (1971) developed prognostic criteria to decide which infants should be treated (closing the spina cord) at birth. Those infants thought to be too severely handicapped were not treated but provided analgesics and normal nursing care. They were left to die.

Bladder incontinence became the most stigmatizing impairment for me. In 1970, I had a surgical procedure called an ileal conduit, which diverted urine from my bladder to an outside appliance on my abdomen. After the surgery I finally achieved independence. The following year, I left home, bound for New York City to study occupational therapy. I had experienced physical therapy (specifically, whirlpool for infections and muscle testing) during my hospital admissions but never occupational therapy. I learned about occupational therapy from a book my sister received at a career fair. I remember that the brochure described occupational therapy as a health profession that brought science together with art. This seemed perfect for me and my interests. I majored in biology in college and seemed to have an artistic flair noted by my high school art teacher. I volunteered in an occupational therapy department at Johns Hopkins Hospital during my last year in college and decided this was what I wanted to do.

While living in New York, I continued my quest to be "normal." For me, this meant doing everything an adult developmentally accomplishes—having a career, getting married, and having children. I read about these goals in my developmental theory books in occupational therapy school. Periodically, I was confronted with the fact that having spina bifida meant that I was not "normal." For example, one of my professors, after reviewing a paper I wrote about growing up, said: “You should read other students’ papers to learn what it’s like to grow up normally.” Another encounter occurred during a week-long fieldwork experience. I had requested a placement in a spina bifida clinic to observe the role of occupational therapy in this area. My supervisor was not happy with having me there. I became acutely aware of this after I attended a conference at which the clinic team was discussing an option of institutionalization with a family whose child had spina bifida. After the meeting, the therapist said to me, “I was really nervous about having you witness this meeting. I thought you might overidentify with the plight of the child and it would upset you.” Again, I was confronted with someone else’s expectation based on my diagnosis. This was the decade of Lorber’s selection criteria, which may have added to her worry about my presence in the clinic. At the time, I wasn’t aware that selective treatment occurred.

1980s

The Maternal Alpha Fetal Protein (MAFP) blood test became available in the early 1980s. The test, performed between the 15th and 17th weeks of pregnancy, measured the amount of alpha fetal protein secreted from the fetus into the mother’s blood stream. An elevated MAFP meant that there was an increased risk for a neural tube defect. A repeat test, ultrasound, and amniocentesis might then be offered to parents for more definitive results (Powell, 2000).

It was February 1982, I was in my bedroom reading. The television was on in the background. I was drawn away from my book when I heard the opening statement on a news show called “The Terrible Choice.” The journalist said:

Imagine this. You are pregnant, or your wife is. The fetus is 4 months old, and you are able to look inside the womb and see your baby. And what you see is deformed, crippled, and will be for life. What would you do? (Utley, 1982)

I was glued to the TV set for the rest of the segment. The show was about the newly developed maternal alpha fetal protein blood test that, according to the news report, “Can now determine within almost 100% accuracy, whether a baby will be born with this fatal or crippling defect.” After a positive test, an ultrasound scan was typically recommended to determine if the fetal spine showed “evidence of a defect in its formation.” Here’s how the announcer described spina bifida:
What it usually means is paralysis below the waist. No control over bladder or bowel functions, and often mental retardation. Joan [not her real name] is lucky. She did not suffer brain damage. But every 3 hours, her mother, who adopted her, must insert a tube to drain her urine. That is Joan’s life, and this is why. Look through an electron microscope at the fetus of any creature with a backbone, and this is what you will see. First, a tiny plate appears, and begins to curl upward. This is the neural tube, which will form the brain and the spinal cord. By the 30th day of pregnancy, before the mother even knows she is pregnant, the tube must seal itself perfectly from top to bottom. Usually it does. But once or twice in every thousand babies, it doesn’t. There is a gap, a neural tube defect. If it is at the top of the tube, the brain will never develop, the baby will almost certainly die soon after birth. If the defect is near the bottom of the neural tube, the baby can survive, but it will face a life which at very best will be severely handicapped. It will have spina bifida. (Utley, 1982)

After reviewing the program again on a rerun and subsequently purchasing a copy of the tape, I found only one sentence devoted to the possibility of a positive outcome or that it might not be a tragedy. “Spina bifida children can and do triumph over their condition; with specialized training and surgery, many become strong, productive adults” (Utley, 1982). However, this was followed by, “For each child, the cost can run to thousands of dollars a year—financed sometimes by a family’s private insurance, sometimes by the taxpayer, through Medicaid” (Utley). The announcer interviewed parents who opted for abortion after finding out their growing fetus had spina bifida. It was stated that most of the doctors consulted for the new segment agreed with the parents’ decision to not have a child with spina bifida. In fact, one of the physicians interviewed stated that over 90% of parents decide to terminate a pregnancy when their child is diagnosed with spina bifida.

At first, I remembered feeling shocked. They were talking about me. Although I had spina bifida, I did not see myself as “severely handicapped” or “crippled,” as described on the show. I had a career. I was “normal,” or at least I was trying to be. I had never written a letter in response to an issue in the news. My friends (they had a color TV; I didn’t), I waited. Finally the producer gave me my letter (see above) with several sentences underlined. She told me just to read it. The camera rolled continuously. She asked me questions and commented on my mood to get me into the frame of mind with which I wrote the letter. She said, “Aren’t you angry about this?” After a few more “takes,” she said, “I think we have it.” We went into a video room to look at the tape and she seemed pleased. All week I worried about how my comments would be placed. On the Friday evening, as I sat with friends (they had a color TV; I didn’t), I waited. Finally the anchor said:

Time now for your comments. Last week, I did a report we called “Terrible Choice.” It was about a new medical technology that can tell whether a fetus inside the womb has a defect known as spina bifida, or open spine. And we reported that when faced with the knowledge that their child will be crippled, over 90% of the parents are choosing to have an abortion. (Utley, 1982)

Then came the viewers' responses. The first comment was from a parent who indicated that his 10-year-old son watched
hormones as well as alpha fetal protein and had a better development in diagnosis and treatment (Graves, 2000). A newer blood test, called a triple screen (Graves, 2000), can be performed at an earlier stage of pregnancy. It is based on the critical period when there is the highest risk of congenital anomalies (Powell, n.d.).

Research continues to pursue less invasive testing that can be performed at an earlier stage of pregnancy. According to the International Federation for Spina Bifida and Hydrocephalus (IFsbh) policy statement, an estimated 90% of women in Western countries interrupted a pregnancy after a positive screening for spina bifida (IFsbh, n.d.). For those who continue a pregnancy after a diagnosis of spina bifida, there are benefits to screening. For example, transfer to a tertiary neonatal unit may be indicated as these facilities are more capable of managing high-risk pregnancies and increase the chance of survival for the newborn.

In the 1980s and 1990s, prenatal testing became more efficient and less risky with the introduction of chorionic villus sampling and enhanced ultrasonography (Powell, 2000). A newer blood test, called a triple screen (Graves, Miller, & Sellers, 2002), measures two other enzymes or hormones along with alpha fetal protein. The triple screen calculation also included a woman's age, weight, race, and whether she was diabetic.

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Also, knowing ahead of time that a child will have a particular birth defect allows parents time to prepare physically and emotionally for the child's birth (Merkens, 1997).

I married at age 34. My very first pregnancy lasted 5 months. Although my AFP test was negative, it was recommended that I have an amniocentesis due to my age and my history of spina bifida. I had a 2–3% risk of having a child with spina bifida and an even higher risk of having a child with Down syndrome. Two weeks after the amniocentesis, I developed an infection that resulted in losing our child. She did not have spina bifida but I later learned that because I had an ostomy, the bacteria present on my abdomen could not be removed by simply scrubbing with betadine. Putting the needle into my abdomen most likely introduced bacteria into the fallopian tubes.
clinical trial funded by the National Institutes of Health. In the United States, there are four centers that are currently participating in the study. So far, the surgery has decreased the need for a shunt at birth (Bruner et al., 1999).

Looking back on my TV appearance 23 years ago, I realized this was my first experience as a disability activist. At the time, it was not a conscious effort at taking a political stand, but a natural one, moved by my personal experience. Today, I am more firmly against selective abortion but consider myself pro-choice. Reading the disability literature and attending a seminar led by disability activist and political scientist Harlan Hahn has strongly influenced my thinking and awareness. This happened not just by reading the disability literature, some of which I had previously read; it was hearing Professor Hahn's vivid personal stories that moved me to refine my viewpoint and self-image. The seminar was a transformative experience through which I began to view myself as disabled, rather than a person with spina bifida striving to be "normal." I realized I also had stories to tell and began to do so in my writing. For example, in a recent article in the American Journal of Occupational Therapy (Neville-Jan 2003), I challenged several widely accepted views about chronic pain. In another paper, published in Disability & Society (Neville-Jan, 2004), I used autoethnography to connect the personal experience of pain more directly with political action.

Being a relative newcomer to the field of disability studies, I naively thought I could write this paper from an apolitical stance. However, to truly "get" disability studies is to realize that "an apolitical disability stance" is an oxymoron. Disability studies by its nature is political. bell hooks (1989), a radical feminist writer, provided a cogent way to understand the process involved in realizing the true meaning of the statement "the personal is political." She states:

"Politization of the self can have its starting point in an exploration of the personal wherein what is first revolutionized is the way we think about the self. To begin revisioning, we must acknowledge the need to examine the self from a new, critical standpoint. Such a perspective, while it would insist on the self as a site for politicization, would equally insist that simply describing one's experience of exploitation or oppression is not to become politicized. It is not sufficient to know the personal but to know—to speak it in a different way. Knowing the personal might mean naming spaces of ignorance, gaps in knowledge, ones that render us unable to link the personal with the political." (p. 107)

In the discussion that follows, I will problematize prevention and spina bifida and speak of prevention in a different manner.

Discussion

Prevention

Typically we think about prevention as a good thing. In fact, much government spending in the United States targets prevention programs. For example, research results coupled with educational campaigns alert us that attention to diet, weight, and physical activity level can potentially reduce our risks for cardiovascular disease, diabetes, and stroke (U.S. Department of Health and Human Services, n.d.). According to the U.S. Preventative Services Task Forces’ Guide to Clinical Preventive Services (1996) these examples represent primary prevention activities that “… refer(s) to the complete prevention of disease, often through methods that inhibit exposure to risk factors” (p. 1). Primary prevention aims to completely eradicate disease. Because a heavy economic and social burden results from diseases such as cancer and cardiovascular disease, programs focused on primary prevention incur the least cost to society. The list of primary preventive actions that are recommended by government and health officials are innumerable and constantly changing, based on biomedical and genetic research into the causes of disease. Several emerging areas of occupational therapy practice have addressed primary prevention, such as assessments and interventions for preventing school violence and workplace injury (Malugani, 2004). The “Well Elderly” program has received wide acclaim and given birth to a variety of targeted applications of the prevention-oriented lifestyle redesign genre of intervention (Clark et al., 1997).

Secondary prevention aims to detect the early onset of disease and limit disease effects (U.S. Preventative Services Task Force). Screening tests done on persons who are at risk for or who exhibit initial symptoms of a disease can potentially alter the course of a disease such as breast cancer or diabetes. Occupational therapists are increasingly involved in promoting healthy lifestyles in people screened for or who are already diagnosed with diabetes, arthritis, and heart disease.

Tertiary prevention involves treatment and rehabilitative activities in order to prevent further impairment. The goal is to restore a higher level of functioning in someone already with a diagnosis (U.S. Preventative Services Task Force, 1996). This level of prevention is the most costly to society, as it takes place after a person has already acquired some degree of impairment. Tertiary prevention continues to be a major practice component of occupational therapy within the rehabilitation paradigm.

Prevention and Spina Bifida

Medical technological advances have greatly aided primary and secondary prevention of spina bifida. Primary prevention actions are those timed prior to conception and include recommendations for women of child-bearing years to supplement their diet with folic acid (Geisel, 2003). In fact, folic acid campaigns are ubiquitous. The Centers for Disease Control and Prevention (CDC), the March of
Spina bifida is a severe and devastating birth defect.

Although it cannot be disputed that folic acid campaigns have been successful in reducing the number of infants born with neural tube defects (CDC, 2002), as a person with spina bifida, I find descriptions of spina bifida in the medical literature that are associated with these campaigns to be overwhelmingly negative. For example, the CDC, a major national promoter of folic acid, provides an educational booklet for “campaign partners” (CDC, 2001). The booklet profiles a family that has two children born with spina bifida. One child has “…a severe form of spina bifida” and the other child “…a milder form of spina bifida.” More alarming to me than the words are the pictures that accompany the text. The first picture depicts the infant’s back with the unaltered sac prior to surgery. Next are photographs that show the scars left from surgery. More photos illustrate gastrostomy tubes, a breathing apparatus, splints, crutches, and a wheelchair. Both children are pictured smiling, but the text describes a negative perspective that “…most affected children have some learning disability. Many of these children have problems with bowel and bladder control, a source of major concern and embarrassment to them” (p. 8). Although the information presented is accurate, it is overwhelmingly negative. It reminds me of the news program in the ’80s, “The Terrible Choice” (Utley, 1982).

Bannister (2000) presented arguments for and against intrauterine surgery for spina bifida. At the end of the article, he stated:

It cannot be contested that spina bifida aperta is anything other than a major disaster affecting the whole of the central nervous system, and minor improvements in the neurological status do not make the outcome significantly better. (p. 112)

I disagree. For me, spina bifida has not been a “major disaster.” Peter Singer (2002), a controversial bioethicist recently appointed to Princeton University as a Professor of Bioethics at the Center for Human Values, describes spina bifida. He states:

. . . the infant is born with its spinal cord exposed. Three out of every thousand babies have this condition, which adds up to a large number of babies. Although treatment is possible, with the more severe cases even immediate surgery and vigorous treatment will not result in successful rehabilitation. The children will grow up severely handicapped, both mentally and physically and they will probably die in their teens. (p. 226)

After further descriptions of a child with spina bifida as incontinent, paralyzed, blind, retarded, spastic, and with
hydrocephalus so severe as not to be able to hold his or her head up, Singer stated that “the obvious alternative” to bringing up such a child, namely “a swift, painless death for the infant,” is against the law. Although his perspective does not represent all bioethicists, Singer’s status and position give him a powerful voice in this debate. Not Dead Yet (www.notdeadyet.org), a disability activist organization, has challenged mercy killing and views it as the ultimate means of discrimination.

Spina bifida negatively impacts the quality of life of a child and his or her family.

As presented earlier, Lorber (1971) justified the nontreatment of infants with spina bifida based on several prognostic criteria. Infants not treated and left to die (actually, some infants took 9 months to die) were those who possessed severe handicaps. Treatment was withheld based on the imagined future quality of life for these infants. Shaw (1977), a pediatric surgeon, provided a “rule of thumb” for determining quality of life in these life and death situations: QL = NE x (H + S). This means that quality of life results from the interaction of the infant’s natural endowment and contributions of home and society. Hahn (2002) is highly critical of this formula, stating that according to this calculation, “...non-disabled rich people enjoy a higher ‘quality of life’ than persons who are poor and disabled” (p. 174). Quality of life arguments for withholding treatment have been criticized as being too vague and unclear about who is being served. Are decisions made about the well-being of the infant or about the family and society? Also, and most importantly, where do you draw the line in determining whose quality of life is unacceptable? Disability studies writers (Kittay & Kittay, 2000; Mostert, 2002) refer to the “slippery slope” related to these arguments. The genocide in Nazi Germany began with exterminating those who were deemed “defective.” Will selective termination and prenatal testing result in attempts to get rid of all people society labels as “undesirable”? How often is treatment withheld in the neonatal intensive care unit today? Singer (2002) reports of a “recent investigation” in the nursery at Yale-New Haven. He states:

... over a 2 1/2-year period, 43 deaths, or 14 percent of all deaths in the nursery, were related to withholding treatment. The decision to withhold treatment at this nursery was in each case made by parents and physicians together on the basis that there was little or no chance for a meaningful life for the infant. (p. 225)

Singer (2002) contends that needless suffering occurs because society fails to see that “...the case of a dying horse is really quite parallel to the case of a dying infant” (p. 225). Would we let a horse die in agony rather than kill it? Then why do we do that with infants who will probably die? Further, he states, “The burden on the family can easily be imagined, and it is doubtful if the child’s life is a benefit for him.” (p. 226)

The social and economic burden of spina bifida is substantial.

The SBAA (n.d.) describes the economic costs to society of spina bifida to exceed $200 million per year. As Kielhofner stated in his opening paper (2005), rehabilitation was driven by the need to reduce the economic burden to society of persons with disabilities. Today, economists calculate the cost of a disability. Medical researchers use this information as a rationale for support or contest policy decisions. The economic consequences for an individual parent raising a child with an impairment are also considered in the decision to terminate a pregnancy.

Singer proposed “active euthanasia” as a “rationale basis” for managing the resource allocation problem in health care. Similar views are expressed by Buchanan, Brock, Daniels, and Wikler (2000). They focus primarily on prenatal testing and reproductive freedom and believe that a fetus is not self-conscious and therefore not a person. In response to critiques from the disability community that their views devalue persons with disabilities, they state:

Advocating the fourth model of intervention (selective abortion) is tantamount to saying that people like you (who have disabilities) have no right to exist only on the highly controversial assumption that fetuses are persons. (p. 280)

Buchanan et al. (2000) further assert that the disability rights critique is the “familiar objection to the age-old practice of abortion” (p. 280). However, many in the disability community are pro-choice but against selective abortion (Paren & Asch, 2000).

The disability rights movement has been very vocal in the worry that the new genetics will become the new eugenics. Bioethicists such as Peter Singer at Princeton University and Dan Brock at Brown University have prominent positions through which to transmit their views. People in the disability community feel that their unique perspective about their own quality of life is mostly disregarded by the medical community, including genetics counselors, genetics researchers, and bioethicists (Anstey, 2003; Wertz, 2000).

Summary

Many myths and negative conceptions exist in society about persons with impairments. These preconceptions direct many decisions both at the beginning and end of life, and reflect a lack of exposure to the viewpoints and lived experiences of persons with impairments. Each situation is
different, highly complex, and poses its own moral dilemmas. Parens & Asch (2000) present an excellent discussion of the disability rights critique.

**Implications for Occupational Therapy**

Disability studies calls for dismantling the stereotypical thinking that exists in society about disability. However, in many occupational therapy academic programs, disability studies is only beginning to become an integral part of the curriculum. Wright (2004) proposed that occupational therapy programs include disability studies through the incorporation of the World Health Organization's *International Classification of Functioning, Disability and Health (ICF)* (WHO, 2001). The ICF aims to incorporate both a medical model and social model of disability. Occupational therapists need to gain an increased awareness of the multiple perspectives that exist within the community of persons with impairments. Occupational therapy researchers need to add to the literature with both qualitative and quantitative research, allowing the voices of study participants with impairments to be heard and their lived experiences to be explored and understood. Occupational therapists need to become aware of the current status of topics such as euthanasia. For example, according to an Associated Press report (2004, November 30), a study by Dutch physicians found that, since 1997, 22 newborns with severe spina bifida were killed. In the Netherlands, euthanasia is legal for adults. However, it is illegal to euthanize persons who are unable to make informed decisions such as terminally ill infants and persons in a coma. The report stated that one hospital has already developed a protocol for infant euthanasia and applied it to euthanize four newborn infants. The guidelines suggest that the medical team, including independent physicians and parents, make the decision based on amount of unrelied pain and lack of future improvement. The report pointed out that this practice goes largely unreported and is hidden in medical practice. The Groningen Protocol, named after the hospital where this practice takes place, reminds me of Lorber's criteria used in the '70s to determine which infants with spina bifida should live (Lorber, 1971).

Harlan Hahn (personal communication, March 2004) has suggested that parents who are predicted to give birth to a child with a disability be offered the opportunity to meet a person with the same disability so they can see for themselves the reality of their lives. Carla Verpoorten (2000), in an overview of the international literature about termination of pregnancy in the case of spina bifida, states: “The pessimistic public opinion has to be changed before we can assure prospective parents that they and their future child will be welcomed whether or not the child has a disability” (p. 3). Only then can truly informed choices be made. Disability studies provides a way to reframe thinking about persons with impairments. Armed with this information, occupational therapists can act as advocates, and, in a more informed manner, support or contest policy initiatives.

**Conclusion**

IFsbh hosted its 12th conference in 2000 in Toulouse, France. The conference produced “Resolution Toulouse 2000” concerning the theme, “The Right to be Different.” The following statements summarize the resolution and were endorsed by adults and parents of children with spina bifida:

- People with spina bifida and hydrocephalus live a full life with equal value to that of any other citizen
- Adults with spina bifida stated very clearly that their quality of life is not a reason for abortion
- Parents and adults state that the impairment is not the burden. The burden is the constant struggle against inaccessible environments and inadequate systems, which should be allies and should be supportive of them http://www.ifglobal.org/pregnancy.asp?lang=1&main=8&sub=3

This resolution provides an alternate view of spina bifida, not as the disaster and tragedy presented in the medical literature, but as a positive experience for the person and their family.

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**Endnote**

1In this paper, I prefer to use person-first language and use the term “impairment” rather than “disability.” For example, I say “women with physical impairments” rather than “disabled women” or “women with a
disability.” Those in the disability movement have recommended using disability-first language as a means of resistance to and rejection of the dominance of nondisability in society. Activists in the disability movement felt that the term “impairment” tended to focus on “cure” and directed money towards medicine “. . . rather than on barriers which make it possible to participate in the dominant culture with an impairment” (Russell, 1998, p. 16). This so-called social model of disability has achieved some success in challenging “. . . disabilism, oppression and exclusion in society” (Hughes & Paterson, 1997, p. 325). However, several writers (Hughes & Paterson; Stineman, 2001) have called for a recognition of the embodied nature of disability and thus more attention be devoted to impairment. My language preference reflects this embodied perspective of disability. I feel my language choice does not detract from my message that is equally about medicine and attitudinal barriers in society.

References


The purpose of the department, headed by Gary Kielhofner, is to discuss and exemplify better approaches to generating and disseminating evidence for practice. While there is substantial literature on the importance of rigorous research and evidence-based practice, the problem of how research translates to practice innovation and change is less understood. This department seeks articles that discuss: (1) challenges faced by practitioners in using research evidence, (2) research methods and strategies which produce more practice-relevant findings, (3) successful strategies for translating research findings into practice. Please submit manuscripts for review to:

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