Narratives of Disability


Disability and Quality of life


This paper builds on the work of Sol Levine to examine a disability paradox: Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence? The paper uses a qualitative approach to develop an explanation of this paradox using semi-structured interviews with 153 persons with disabilities. 54.3% of the respondents with moderate to serious disabilities reported having an excellent or good quality of life confirming the existence of the disability paradox. Analysis of the interviews reveals that for both those who report that they have a good and those who say they have a poor quality of life, quality of life is dependent upon finding a balance between body, mind and spirit in the self and on establishing and maintaining an harmonious set of relationships within the person's social context and external environment. A theoretical framework is developed to express these relationships. The findings are discussed for those with and without disabilities and directions are given for future research.


This study evaluates the effect of complete traumatic tetraplegia on the life satisfaction and well-being of 87 individuals, 42 of whom are ventilator supported, 2 years or more postinjury. Standard psychosocial instruments were used. The relative distress comparing ventilator dependence with loss of extremity function was also evaluated. The ventilator assisted individuals with tetraplegia (VAITs) were significantly more satisfied with their housing, family life, and employment when applicable, than were the autonomously breathing individuals with tetraplegia (ABITs). The VAITs' life satisfaction and other well-being and quality of life indicators were generally positive, and were significantly underestimated by a control group of health care professionals. Only 23.8% of the VAITs expressed general dissatisfaction with their lives compared with 35.6% of the ABITs. The ABITs and the control group significantly overestimated the distress which the VAITs associated with ventilator use by comparison with loss of upper extremity function. We conclude that long-term life satisfaction and well-being are considered to be positive by the majority of both ABITs and VAITs, are at least as high in the latter as in the former, correlate best with family and social interaction, and are severely underestimated for both ABITs and VAITs by health care professionals.


We examined the literature on ethical decisions regarding neonates, to assess whether personal beliefs and prejudices influence end-of-life decisions taken by caregivers. Studies show that religion and familiarity with disability influence caregivers' decisions, whereas the influx of already being a parent, age, sex and professional experience is controversial. Caregivers' attitudes towards end-of-life decisions are also affected by personal concerns about litigation, prejudices and their view of disability. The concept of 'poor quality of life' is widely used as a reference in end-of-life decisions, but this can be interpreted differently, leaving room for a wide range of personal viewpoints. In most cases, parents' opinions are considered important and are sometimes the main determinant in decision making. However, it is unclear whether parents' decisions are based on their own wishes or on the best interests of the newborn. Conclusion: In neonatal end-of-life decisions, patients may not receive cures based only on their best interests.


Down syndrome is a genetic disorder that can be identified prior to birth. The syndrome is the result of a chromosome abnormality, and features of the syndrome include moderate to severe mental retardation with distinct physical characteristics, such as short stature. Although Down syndrome can be predicted, the condition is permanent and there is no treatment. To investigate the reaction of parents and medical professionals concerning Down syndrome, an 18-minute film entitled 'Down Syndrome - A Parental Perspective' was shown to 36 mothers, 29 genetic counselors, and 32 nurses. The three groups contained individuals of similar age, educational backgrounds, and socioeconomic levels. The film consisted of videotaped discussions of parents of Down syndrome children, and was designed to introduce pertinent issues
and stimulate further discussion. An evaluation was completed by the subjects after viewing the film, and some statistically significant trends emerged. When questioned on the accuracy of the film in portraying the attitudes of parents, 89 percent of the mothers responded that the film was accurate, but only 14 percent of the genetic counselors and 40 percent of the nurses believed the film was accurate in this respect. Ninety-four percent of the mothers and 83 percent of the nurses believed that the benefits of having a Down syndrome child outweigh the problems; 48 percent of the genetic counselors felt similarly. Most of the genetic counselors (56 percent) believed that parents would choose to abort a Down syndrome fetus, but only 8 percent of the mothers and 10 percent of the nurses felt that most parents would choose abortion. These results indicate that there is a gap between what parental attitudes towards Down syndrome children actually are, and what genetic counselors perceive them to be. Because the medical professionals that counsel parents on the results of genetic tests often have little or no contact with Down syndrome children and their parents, their knowledge of how families are affected by this condition must be increased in order to provide effective counseling.


Until recently, the sequelae of aging with a spinal cord injury (SCI) have not been examined comprehensively by the scientific community. Due to medical advances resulting in extended life expectancies for those with SCI, several investigations have been undertaken. Reviewed in the article are the results of available studies designed to evaluate the quality of life of aging SCI persons and the importance of quality of life to the evaluation of rehabilitation and the importance of quality of life to the evaluation of rehabilitation outcomes. Data indicate that the quality of life enjoyed by those with SCI, young and old, is relatively good and, in the case of older SCI veterans, is actually better than similarly aged able-bodied males.


**STUDY OBJECTIVES:** To measure emergency care providers' attitudes toward quality of life after spinal cord injury (SCI) and to determine if their perceptions influence the care they provide. **DESIGN:** A closed-ended questionnaire. **SETTING AND PARTICIPANTS:** Two hundred thirty-three emergency nurses, emergency medicine technicians, emergency medicine residents, and attending physicians at three level I trauma centers were surveyed. Their responses were compared with previously reported quality-of-life ratings of a group of 128 high-level SCI survivors. **MEASUREMENTS AND RESULTS:** One hundred fifty-three emergency care providers completed the survey (response rate, 63%). Forty-one percent believed that resuscitation efforts after severe SCI are too aggressive, and 28% believed that future quality of life should be a factor in determining the interventions that should be provided. If they sustained severe SCIs themselves, 22% of providers would want nothing done to ensure their survival, and 23% would want pain relief only. Only 18% imagined they would be glad to be alive with a severe SCI, compared with 92% of a true SCI comparison group. Seventeen percent of providers anticipated an average or better quality of life compared with 86% of the actual SCI comparison group. **CONCLUSION:** The quality of life, self-esteem, and outcomes that emergency health care providers imagine after SCI are considerably more negative than those reported by SCI survivors. Because providers' knowledge and attitudes may affect the care they provide and may influence patients and families struggling with critical treatment decisions, emergency care providers must be aware of outcomes, well-being, and life satisfaction following severe SCI.


Fibrous dysplasia of bone (FD) is a congenital, non-heritable skeletal disorder that is associated with multiple skeletal complications, including repeated fractures, limb length discrepancy, and bone pain. The disease-specific impact of FD on quality of life outcomes is unknown. We sought to understand the impact of the scope and extent of the skeletal disease on quality of life in adults and children with FD. The health-related quality of life was quantified in a population of adults (n = 56) and children (n = 22) with FD using validated health assessment questionnaires, the Medical Outcomes Study 36 Item Short-Form Health Survey, volume 2 (SF36) (adults) and the Child Health Questionnaire Parent Form 50 (CHQ-PF50) (children). Clinical demographic data and skeletal disease burden scores (SDBS, amount of skeleton involved with FD) were measured, and correlations with health-related quality of life were sought. The SF36 and CHQ-PF50 revealed lower Physical Function Summary scores in FD patients compared to the U.S. population norms (adult 41 vs. 50, Z score < -5.0, pediatric 39 vs. 50, Z score < -5.0). However, the SF36 and CHQ-PF50 Mental/Psychological summary scores
were not different from those of U.S. population norms (adult 50 vs. 50, Z score = 0, pediatric 48 vs. 50 Z score = -0.9). The score on the Physical Function Domain of both tools was strongly negatively associated with the SDBS (adult Spearman rho = -0.43, P = 0.009, pediatric Spearman rho = -0.72, P = 0.005). The groups of adult and pediatric patients with SDBS > 30 had decreased Physical Function Domain scores when compared to those with scores < 30 (adult 35 vs. 45, P = 0.002, pediatric 57 vs. 78, P = 0.04, respectively). One of the largest effects was seen in the parents of children with FD, who had significantly lower Parental Emotional scores than those of the parents of healthy norms (54 vs. 88, Z score < -5.0), suggesting a high degree of emotional morbidity in the parents of children with FD. Despite measurable functional limitations in adults and children, and significant parental emotional impairment, patients with FD achieve a high level of social and emotional function. These data are important for prognosis and parental reassurance.


The locked-in syndrome (LIS) describes patients who are awake and conscious but severely deafferented leaving the patient in a state of almost complete immobility and loss of verbal communication. The etiology ranges from acute (e.g., brainstem stroke, which is the most frequent cause of LIS) to chronic causes (e.g., amyotrophic lateral sclerosis; ALS). In this article we review and present new data on the psychosocial adjustment to LIS. We refer to quality of life (QoL) and the degree of depressive symptoms as a measure of psychosocial adjustment. Various studies suggest that despite their extreme motor impairment, a significant number of LIS patients maintain a good QoL that seems unrelated to their state of physical functioning. Likewise, depression is not predicted by the physical state of the patients. A successful psychological adjustment to the disease was shown to be related to problem-oriented coping strategies, like seeking for information, and emotional coping strategies like denial—the latter may, nevertheless, vary with disease stage. Perceived social support seems to be the strongest predictor of psychosocial adjustment. QoL in LIS patients is often in the same range as in age-matched healthy individuals. Interestingly, there is evidence that significant others, like primary caregivers or spouses, rate LIS patients' QoL significantly lower than the patients themselves. With regard to depressed mood, ALS patients without symptoms focus significantly more often on internal factors that can be retained in the course of the disease contrary to patients with depressive symptoms who preferably name external factors as very important, such as health, which will degrade in the course of the disease. Typically, ALS patients with a higher degree of depressive symptoms experience significantly less "very pleasant" situations. The herein presented data strongly question the assumption among doctors, health-care workers, lay persons, and politicians that severe motor disability necessarily is intolerable and leads to end-of-life decisions or euthanasia. Existing evidence supports that biased clinicians provide less-aggressive medical treatment in LIS patients. Thus, psychological treatment for depression, effective strategies for coping with the disease, and support concerning the maintenance of the social network are needed to cope with the disease. Novel communication devices and assistive technology now offers an increasing number of LIS patients to resume a meaningful life and an active role in society.


Paraplegia can lead to social stigmatisation, sexual difficulties, and emotional maladjustment. The specific nature of problems experienced in these areas were investigated in an interview study of 22 male and female paraplegics. These interviews were followed up by a postal questionnaire and both qualitative and quantitative data are presented in this report. Effective counselling can only be offered on the basis of an understanding of problems as they are subjectively experienced, and with an acknowledgement of the wide differences that exist between individuals in the way that they view and react to their situation.


OBJECTIVES: To estimate and to compare the self-assessed health status and health-related quality of life of extremely low-birth-weight (ELBW) and control infants during adolescence. DESIGN: Prospective, observational study of an inception cohort with a concurrent control group. SETTING: Geographically defined region in central-west Ontario. PARTICIPANTS: We interviewed 141 (83 percent) of 169 ELBW survivors born between 1977 and 1982 and 124 (86 percent) of 145 controls aged between 12 and 16 years. In addition, proxy responses obtained from parents were used for 9 severely impaired teenagers. MAIN OUTCOME MEASURES: Assessments of health status (6 attributes), measured with the Health Utilities Index Mark 2 classification system, and health-related quality of life (utilities), quantified with 2
preference measurement techniques, were used to quantify each participants self-reported, subjectively defined health state and 4 preselected hypothetical health states. RESULTS: Adolescents who were ELBW infants reported a higher number of attributes affected, as well as more complex and severe limitations in cognition, sensation, self-care, and pain, compared with controls. Statistically significant differences for the teenagers' health-related quality of life were noted between ELBW and control teenagers in the mean utility scores (0.87 +/- 0.26 vs 0.93 +/- 0.11; P=.02 on a conventional scale where O=dead and 1.00=perfect health). However, a similar percentage of ELBW and control teenagers (71 percent vs 73 percent) gave utility ratings of more than 0.95 for their health status. CONCLUSIONS: Direct measures of self-reported health status and utility scores indicated that, as a cohort, adolescents who were ELBW infants suffer from a greater burden of morbidity and rate their health-related quality of life as significantly lower than control teenagers. Nevertheless, the vast majority of ELBW respondents view their health-related quality of life as quite satisfactory and are difficult to distinguish from controls.


Much research is still needed on the effectiveness of neonatal intensive care for extremely low-birth-weight babies. A 1996 study that followed a group of low-birth-weight babies until they were teenagers found that many of the teens scored equally well on measures of quality of life as teens who had a normal birth weight. However, this does not prove that intensive care is effective, since it was not commonly used at the time they were born. In addition, the results of the study may not be applicable to other groups of premature infants.


There is often a discrepancy between quality of life estimates from patients and the general public. These discrepancies are of concern to the disability community, who worry that the public does not understand how valuable life can be for people with disabilities; policy planners, who must decide whose quality of life estimates to use in economic analysis; and practitioners and patients facing difficult medical decisions, who may have to worry that people have difficulty imagining unfamiliar health states. We outline several factors that may contribute to these discrepancies. Discrepancies might occur because patients and the public interpret health state descriptions differently – for example, making different assumptions about the recency of onset of the health state, or about the presence of comorbidities. Discrepancies might also arise if patients adapt to illness and the public does not predict this adaptation; because of response shift in how people use quality of life scales; because of a focusing illusion whereby people forget to consider obvious aspects of unfamiliar health states; because of contrast effects, whereby negative life events make people less bothered by less severe negative life events; and because of different vantage points, with patients viewing their illness in terms of the benefits that would result from regaining health, while the public views the illness in terms of the costs associated with losing good health.

Decisions about whose values to measure for the purposes of economic analyses, and how to measure discrepancies, should take these potential contributing factors into account.


Three hundred randomly selected members of the American Academy of Pediatrics were surveyed to determine their perceptions of mildly, moderately, and severely mentally retarded individuals. For each of the three categories of mental retardation, pediatricians completed the Prognostic Beliefs Scale which consisted of 27 functional capabilities and choices of residential and vocational placement. Of the 169 (56%) questionnaires returned, 142 (47%) were available for analysis. The pediatricians' perceptions were different for mildly, moderately, and severely retarded individuals. Most pediatricians believed mildly retarded individuals could do all but tasks requiring judgment, could function in unskilled competitive employment, and were likely to live in their own apartments. They believed that those with moderate retardation were limited in their capacity to simple and supervised tasks, could function in sheltered workshops, and were likely to live in group-home settings. They believed that severely retarded individuals were restricted to simple feeding tasks and following one-stage commands, were not capable of any productive employment, and would most likely live in institutions. Pediatric expectations and prognostications for placements were significantly lower than those of other professionals caring for mentally retarded individuals.
Disability in Palliative & End-of-Life Care


The neuromuscular diseases, such as infantile spinal muscular atrophy, Duchenne's muscular dystrophy, and amyotrophic lateral sclerosis, are widely considered to be terminal illnesses. However, as with many neuromuscular and neurologic diseases, morbidity and mortality are caused by dysfunction of inspiratory, expiratory, and bulbar musculature. This article will discuss how inspiratory and expiratory musculature can be supported by simple, noninvasive means that are rarely considered when, as with the general population, individuals with disabilities are counseled about advance directives. Failure to use noninvasive aids almost invariably results in respiratory failure, intubation, and tracheostomy or death. When noninvasive aids are available, invasive measures referred to in advance directives (eg, intubation) are often needed only temporarily. Yet, ill-informed patients are often advised to refuse intubation and die or to be intubated and left to decide whether to undergo tracheostomy for long-term ventilatory support. Further, despite severe disability, ventilator users with neuromuscular disease report normal life satisfaction. Health care professionals, on the other hand, tend to ignore the patient's life satisfaction and consider quality of life measures not designed for the disabled to justify withholding life-saving interventions. Advance directives, although sometimes appropriate for patients with irretractable pain and advanced cancer, are inappropriate for patients with severe disability because of muscle weakness, and virtually no patients are appropriately counseled about all therapeutic options.


This article presents the methods, findings, and implications of a participatory action research project that attempted to shed additional light on the debate over death with dignity (DWD) or physician-assisted suicide (PAS) legislation. In-depth, qualitative interviews with forty-five physically disabled residents of the San Francisco Bay Area, conducted by others with disabilities, revealed a wide breadth of opinions about and attitudes toward such legislation. For close to half of the participants, the desire for autonomy in making end-of-life decisions was a primary concern, yet fear that PAS legislation could violate this autonomy in various ways was a deep concern as well. Also reported were widespread accounts of disability-based discrimination and frequent expressions of fear about openly discussing positions that diverge from the official, publicly held opinions of disability leaders who oppose such legislation. The findings support those of a recent Harris poll demonstrating considerable diversity of opinion about PAS legislation among people with disabilities. The findings further suggest the need for additional research on the apparent disjunction between the diversity of attitudes held by those interviewed and the more unified position taken by many disability activists. Use of the study findings to promote greater dialogue within the community and to better position people with disabilities to take their place at the policy table also is discussed. In addition, the findings are seen as reinforcing the need for the public health community to become more engaged in this central ethical debate.


The author argues that Terri Schiavo was a “person with a disability” who faced disability discrimination, a view that is consistent with national disability rights groups. The author notes that Schiavo was not “terminally ill” and that feeding tubes should not be considered “medical equipment.” The belief that people with severe disabilities want to die is questioned, since many people who acquire severe disabilities change their minds about suicide, and implications for advance directives are explored. Finally, the author notes that although Terri Schiavo was a disabled woman, women's groups did not take up her cause.


The social, legal, and political discussion about the decision to stop feeding and hydration for Terri Schiavo lacked a medical ethics assessment. The authors used the principles of medical indications, quality of life, patient preference, and contextual features as a guide to medical decision-making in this case. Their conclusions include the following: (a) the use
of a feeding tube inserted directly into the stomach constituted artificial treatment; (b) the treatment prolonged biological life but did not lead to a cure and did not restore health; (c) quality of life was absent for the patient, with no sensation and no motor or cognitive functioning; and (d) by preponderance of medical opinion, she would have chosen not to live in a persistent vegetative state. The authors find the withdrawal of treatment was permissible and correct. It was not a choice between living and dying, but a decision of when to allow dying consistent with the patient's choice.


One of the most rewarding tasks a nurse can ever perform is to support someone at the end of their life, and appropriate care and support at this time should be available to all who need this regardless of personal circumstances. However, it is becoming increasingly evident that personal factors (i.e. where you live, poverty, social class, gender, sexuality, age, ethnicity, religion and disability) can all affect the nature and quality of the palliative care received, and certain marginalized populations are likely to be perceived as 'disadvantaged dying'. People with intellectual disabilities are often regarded as a marginalized group, and never more so as when they are diagnosed with a life-limiting condition and as the end of life draws imminently closer. This article introduces the challenges faced by nurses caring for people with intellectual disabilities diagnosed with a life-limiting condition. The overall aim is to identify the inherent challenges involved so that they can be addressed from a practical perspective.


Good end-of-life care requires that clinicians, families, and ethicists be aware of biases that influence patient cases, particularly in the acute care setting where the aim is primarily cure and return to optimal functional level. Persons with disabilities may pose unique challenges; their potential for quality of life is viewed through the lens of highly functional clinicians who might have a biased view of the disabled person's quality of life. The authors aim to present three categories of disability that do not claim to be absolute but rather offer clinicians and ethicists a lens through which to reflect on bias that unconsciously may influence their approach to the patient who is seriously ill and may be nearing the end of life. The categories include (a) a person who has lived with a disability from birth or early life, due to trauma or disease, and is now faced with a serious illness that requires that life-sustaining treatment; (b) the otherwise healthy person who acquires a disability through an acute event of disease or trauma and whose condition requires that life-sustaining treatment decisions be made; and (c) the person who has lived with a progressive chronic illness, such as lung or heart disease or amyotrophic lateral sclerosis, and may have gradually adjusted to disabilities imposed by the condition and now is faced with lifesustaining treatment decisions. The concept of inherent dignity (Pellegrino 2005) is suggested as a filtering lens in case consideration.


Both older persons and those who have disabilities can encounter discrimination when they seek medical care. Just as ageism and stereotypes about older persons may inappropriately limit medical care for the elderly, limits may be placed on medical care for those who are disabled simply because of the presence of a disability. At the same time death is the natural end of the lifespan for all individuals and there are situations when aggressive medical care is not indicated. It is not right to always insist on "doing everything" for a person even if that person may be at risk otherwise for discrimination. Using the example of the elderly, this paper examines the risks of discrimination and the dangers of overtreatment in caring for older persons and suggests parallels in the appropriate care of those who have disabilities.

**Disability, bioethics & humanities**


The nursing profession's emphasis on empathy as essential to nursing care may undermine nurses' power as a collective and detract from perceptions of nurses' analytical skills and expertise. The practice of empathy may also obscure and even compound patients' suffering when it does not fully account for their subjectivity. This essay examines the relation of empathy to women's agency and explores the role empathy plays in obscuring rather than empowering the suffering other,
particularly people who are disabled, through a close reading of Edith Wharton's 1907 novel, The Fruit of the Tree, and through discussions of empathy and sympathy from literary and disability studies.


Autobiographical narratives of illness and disability are influential in popular and medical discourses of illness and disability, in part because these narratives represent illness and disability within a sociocultural context, intersecting with other categories of difference. Clinicians can benefit patients through a critical understanding of the formal and social conventions that shape illness and disability narratives and the effect these conventions can have on the lived experience of illness and disability. I analyze the 2003 edition of Lucy Grealy's *Autobiography of a Face* to illustrate these socio-narrative conventions, especially in light of an afterword that significantly revises the ending to Grealy's narrative. I explore the parallels between narrative conventions-such as the "recovery narrative"-and caregivers' expectations that shape the role of the "good patient," as well as the resistance to conventions of closure, represented by the "renegotiated ending."


The recent case of Ashley X has sparked much recent public debate and controversy, and raises critical questions for physiatrists and rehabilitation professionals. The case came to light when Gunther and Diekema published an article in the October 2006 issue of Archives of Pediatric and Adolescent Medicine describing a novel growth attenuation treatment for Ashley X, a 6-yr-old girl with developmental disabilities. Her parents also published a blog about Ashley, with detailed explanations for their rationale in choosing this treatment on behalf of Ashley which involved beliefs about her future and quality of life. Ashley's parents refer to the series of interventions as the Ashley Treatment in their blog, and this phrase has also been adopted by the popular press and others who have commented on the case. In this article we present an analysis of the Ashley X treatment and use a disability ethics approach to examine the perspectives of various stakeholders involved, including Ashley and other girls with extensive disabilities, parents, physicians, and bioethics committees. We conclude with critical questions for physiatrists and other disability specialists who are in a unique position to examine medical controversies involving people with disabilities.


Bioethics, and indeed much ethical writing generally, makes its point through narratives. The religious parable no less than the medical teaching case uses a simple story to describe appropriate action or the application of a critical principle. While powerful, the telling story has limits. In this paper the authors describe a simple teaching case on "end-of-life" decision making that was ill received by its audience. The authors' ill-received example, involving the disconnection of ventilation in a patient with ALS (Lou Gherig's Disease) was critiqued by audience members with long-term experience as ventilation users. In this case, the supposedly simple narrative of the presenters conflicted with the life histories of the audience. The lessons of this story, and the conflict that resulted, speak critically to the limits of simple teaching cases as well as the strengths of narrative analysis as a tool for the exploration of bioethical case histories.


Contemporary bioethics has been somewhat skewed by its focus on high-tech medicine and the resulting development of ethical frameworks based on an acute-care model of healthcare. Research and scholarship in bioethics have paid only cursory attention to ethical issues related to disability. I argue that bioethics should concern itself with the full range of theoretical and practical issues related to disability. This encounter with the disability community will enrich bioethics and, potentially, society as well. I suggest a number of items that the bioethics agenda should include, such as the development of a casuistry of the right to healthcare and to community integration and an advocacy role in fostering an understanding among the public and policy makers of the need to reform research and treatment related to disability.

In the bioethics, medical, and disability studies literature, ethical issues in the rehabilitation care of adult patients have received sporadic interest over the last 20 years. This overview of the literature focuses on the cornerstone of contemporary bioethics—the doctrine of informed consent. Problems in applying this doctrine to patients whose values and personal identity may be challenged by disease or injury, as well as radically altered life options, are addressed. Practical guidance regarding informed consent and decision-making capacity in the clinical setting is offered, highlighting the issues raised by evolving reimbursement structures, as well as the ethical issues involved in the quest for objective measures of quality of life.


In the bioethics, medical, and disability studies literature, ethical issues in the rehabilitation care of adult patients have received sporadic interest over the last 20 years. This overview of the literature focuses on the cornerstone of contemporary bioethics—the doctrine of informed consent. Problems in applying this doctrine to patients whose values and personal identity may be challenged by disease or injury, as well as radically altered life options, are addressed. Practical guidance regarding informed consent and decision-making capacity in the clinical setting is offered, highlighting the issues raised by evolving reimbursement structures, as well as the ethical issues involved in the quest for objective measures of quality of life.


Disagreement about the proper attitude toward disability proliferates. Yet little attention has been paid to an important meta-question, namely, whether “disability” is an essentially contested concept. If so, recent debates between bioethicists and the disability movement leadership cannot be resolved. In this essay I identify some of the presumptions that make their encounters so contentious. Much more must happen, I argue, for any discussions about disability policy and politics to be productive. Progress depends on constructing a neutral conception of disability, one that neither devalues disability nor implies that persons with disabilities are inadequate. So, first, I clear away the conceptual underbrush that makes us think our idea of disability must be value-laden. Second, I sketch some constituents of, and constraints upon, a neutral notion of disability.

**Disability & medicine**


Excerpt: “... Persons with disabilities constantly teach others about what our lives are like and, thus, what theirs may become. I take this educational role seriously, although I try to do it by just living my life. However, although it is desirable to aim for patience in frustrating situations, total equanimity is unrealistic. Sometimes people seem oblivious to the effect of their words or actions; saying something tart and corrective may vent our irritation and improve the situation (for example, motivate someone blocking our way to move). We must contend with being dismissed: "She's just upset because she's handicapped." Nonetheless, sometimes we should lighten up. Especially in casual contacts, one cannot alter firmly rooted attitudes. We frustrate ourselves rather than change minds. …”


(First 150 words:) Forty million to 50 million individuals in the United States now live with potentially disabling conditions. According to the Institute of Medicine (IOM), this number will likely increase substantially in coming decades.1 Aging baby boomers will fuel much of this growth as this enormous cohort enters age ranges with the greatest disease and disability risks. Although rates of some serious limitations among elderly individuals have declined,2 sobering reports warn of higher rates of potentially impairing conditions among children3 and working-age adults.4 These latter trends are multifaceted with diverse contributors, including major therapeutic breakthroughs that now save lives of severely impaired individuals who would once have died and increasing prevalence of overweight and obesity among youth and young adults, along with associated problems such as diabetes. As recent reports suggest, overweight and obesity cause particular concerns not only because they are associated with … [cut off after 150 words].
In this article, we present the results of a series of focus groups with people with disabilities, in which we took a cross-disability, lifespan perspective of disability. Consumers were asked about a broad set of barriers, such as problems with communication, transportation, and insurance, as well as about barriers related to physical accessibility. We used the Institute of Medicine's framework to categorize barriers as either structural, financial, or personal/cultural. Our results suggest that individuals with disabilities experience multiple barriers to obtaining health care and that these barriers are more pronounced for some types of health care than others. In addition, regardless of disability type, consumers consistently spoke about similar barriers. The results underscore the importance of taking a broad perspective when making policy decisions and the need for continued change and improvement in this area.


Background: Achieving patient-centered care requires effective communication between physicians and patients. Persons who are deaf or hard of hearing face considerable barriers to communicating with physicians. Objective: To understand perceptions of health care experiences and suggestions for improving care among deaf or hard-of-hearing individuals. Design: 4 semistructured group interviews, 2 conducted in American Sign Language (for deaf individuals) and 2 using Communication Access Realtime Translation (for hard-of-hearing individuals). Men and women were interviewed separately. Tapes of interviews were transcribed verbatim for analysis. Setting: Greater Boston, Massachusetts, and Washington, DC, in 2001. Participants: 14 deaf adults (23 to 51 years of age) and 12 hard-of-hearing adults (30 to 74 years of age). Measurements: Commonly expressed themes or views organized around dimensions of communication. Results: Concerns coalesced around 6 broad themes: conflicting views between physicians and patients about being deaf or hard of hearing; different perceptions about what constitutes effective communication (such as lip reading, writing notes, and sign language interpreter); medication safety and other risks posed by inadequate communication; communication problems during physical examinations and procedures; difficulties interacting with office staff, including in waiting rooms; and problems with telephone communication, such as lengthy message menus. Participants offered extensive suggestions for improvements, starting with clinicians' asking patients about their preferred communication approach. Having patients repeat critical health information (such as medication instructions) can identify potentially dangerous miscommunication. Conclusions: As the population ages, physicians will encounter many more persons with hearing limitations. Physicians are not reimbursed for making some accommodations, such as hiring sign language interpreters. However, ensuring effective communication is essential to safe, timely, efficient, and patient-centered care.


(First 150 words:) The following 3 cases represent substandard care for patients with disabilities, yet they occurred recently at US tertiary care medical centers with the latest technologies and well-qualified physicians. These failures resulted from basic, "low-tech" structural deficiencies—lack of accessible call systems, diagnostic equipment, and examination tables. Joe is paralyzed, dependent on a ventilator, and unable to speak. His hospital room was at the end of the corridor and had no accessible call system to summon assistance. When his ventilator became disconnected and then was not promptly recognized, Joe became extremely anxious about being in a hospital. Susan, who uses a wheelchair, had trouble breathing. She needed an echocardiogram, which was performed while she sat in her wheelchair. The echocardiogram was of poor technical quality and yielded little information. Chuck has paraplegia and new rectal bleeding. The gastroenterologist refused ... [cut off after 150 words].


OBJECTIVES: Primary care for people with disabilities often concentrates on underlying debilitating disorders to the exclusion of preventive health concerns. This study examined use of screening and preventive services among adults with mobility problems (difficulty walking, climbing stairs, or standing for extended periods). METHODS: The responses of non-institutionalized adults to the 1994 National Health Interview Survey, including the disability and Healthy People
2000 supplements, were analyzed. Multivariable logistic regressions predicted service use on the basis of mobility level, demographic characteristics, and indicators of health care access. RESULTS: Ten percent of the sample reported some mobility impairment; 3% experienced major problems. People with mobility problems were as likely as others to receive pneumonia and influenza immunizations but were less likely to receive other services. Adjusted odds ratios for women with major mobility difficulties were 0.6 (95% confidence interval [CI] = 0.4, 0.9) for the Papanicolaou test and 0.7 (95% CI = 0.5, 0.9) for mammography. CONCLUSIONS: More attention should be paid to screening and preventive services for people with mobility difficulties. Shortened appointment times, physically inaccessible care sites, and inadequate equipment could further compromise preventive care for this population.

Disability & Medical Education


Medical schools should play a pivotal role in efforts to produce physicians who are knowledgeable about the needs of patients with disabilities, yet only a handful of medical schools offer formal content about disability and this rarely reaches a broad cross section of students. This paper describes a curriculum for teaching medical students about disability at Tufts University School of Medicine where people with disabilities, in the role of "standardized" patients, portray patients with a common primary care complaint in simulated medical interviews, and give narrative feedback to students about their behaviors, attitudes, and skills in the interview. In recognition of the importance of the feedback aspect of the interview and of the standardized patient's role as an authority, information giver, and teacher, we use the term "standardized patient educator" to describe their role. The goal of the curriculum is to improve medical students' preparedness for communicating with persons with disabilities, regardless of their eventual specialties.

In this paper, we describe the disability curriculum in detail, including information about curriculum development, the role of the standardized patient educators, the process used for their selection and training, and development of the case and supporting materials, and conclude with a discussion about lessons learned, including strategies for enhancing what medical students learn about disability, and future challenges.


CONTEXT: Disability teaching is a core theme in undergraduate medical education. Medical students bring a range of experiences of disability to their medical training. AIM: The principal aim of this study was to explore the words that medical students associate with the term "disability" and to consider how the resulting information could inform teaching. A secondary aim was to see if a short disability course changed the word associations. METHODS: Students were asked to write down 2 words that came to mind when they heard the word "disability", before and after a 4-day course in disability. Words from 4 cohorts were analysed by frequency and the following word dichotomies: visual icons/personal attributes; loss/enabling, and medical model/social model. A random sample of students took part in focus groups at the beginning and end of the course. RESULTS: A total of 381 students provided 667 before-course words and 189 students provided 336 after-course words. Before the course, words denoting visual icons of disability, and loss were prominent, accounting for 85% of the words, and 74% of the words describing personal attributes were negative. Focus group responses at this stage reflected an eagerness to help but patronising terms were prominent, along with concern about political correctness. Students also expressed nervousness about encountering disabled people. In response, teaching was adapted to make it more learner-focused, to offer a safe environment in which students can test out their language, to build on the positive associations and to develop a range of pre-course creative activities with disabled people. After the course a considerable and significant shift in emphasis was observed, with a reduction in the use of visual icon words, an increase in words denoting enablement, and an increase in words relating to the social model of disability and to positive personal attributes (P < 0.001). Focus group participants at this stage reported greater confidence in approaching disabled people but continued to question political correctness. CONCLUSIONS: Medical students associate disability predominantly with depersonalised or negative words. A short disability course appears to change these associations. Reasons for this and implications for teaching are discussed.

Alleyna Claxton rightly emphasizes that medical education on the special needs of disabled people should start with undergraduates. But we need to decide what undergraduates need to know and how that knowledge should be imparted. Furthermore, because students learn much in medical schools that is instantly forgotten once the exams are over, we need to show that doctors have a positive role in their work with disabled people, so that at least some of what is learnt is likely to be retained. The most important message to impart is that the traditional model of diagnosis-treatment-cure is mostly inappropriate when dealing with disabled people. A cure (for the disability) is almost never likely, but that does not mean that doctors have no role. …


Cultural competence extends beyond understanding those values, beliefs, and needs that are associated with patients' age or gender or with their racial, ethnic, or religious backgrounds. People hold many simultaneous cultural associations, and each have implications for the care process. The "culture of disability" is a pan-ethnic culture for which a set of physician competencies are required to ensure appropriate, culturally sensitive care to persons with congenital or acquired disabilities. Such competencies include communicating with patients who have deficits in verbal communication and avoidance of infantilizing speech; understanding the values and needs of persons with disabilities; the ability to encourage self-advocacy skills of patients and families; acknowledging the core values of disability culture including the emphasis on interdependence rather than independence; and feeling comfortable with patients with complex disabilities. Medical schools have developed programs to increase students' exposure to persons with disabilities and it is suggested that such programs are most effective when they are the result of collaboration with community-based facilities or organizations that serve persons with disabilities in the natural environment. Combining lecture-based instruction and structured experiences with the opportunity for students to interact with patients in their natural environments may facilitate development of competencies with respect to patients with disabilities. The culture of disability should be included as one of the many cultures addressed in cultural competence initiatives in medical school and residency curricula.


In this study, we sought information from medical students about their attitudes toward disability, their medical school education about communicating with patients with disabilities, and their suggestions for teaching future medical students about interacting with patients with disabilities. We conducted focus groups interviews with students as they neared completion of medical school. For our purposes here, we narrowly defined disability as impaired vision, hearing, or mobility; another set of focus groups considered psychiatric disabilities.


Persons with major mental illness often have chronic diseases and poor physical health. Therefore, all practicing physicians should learn about communicating effectively with these patients. Few efforts to teach medical students communication skills have specifically targeted patients with major mental illness. Indeed, most of the limited literature on this topic is decades old, predating significant scientific advances in cognitive neuroscience and psychiatric therapeutics and changes in social policies regarding major mental illness. To gather preliminary insight into training needs, we interviewed 13 final-year students from 2 Boston medical schools. Students' observations coalesced around 4 themes: fears and anxieties about interacting with persons with major mental illness; residents "protecting" students from patients with major mental illness; lack of clinical maturity; and barriers to learning during psychiatry rotations. Educational researchers must explore ways to better prepare young physicians to communicate effectively with patients with major mental illness.

(First 150 words:) The US Surgeon General's Call to Action to Improve the Health and Wellness of Persons With Disabilities1 was released in 2005 on the 15th anniversary of the Americans With Disabilities Act. The report noted increasing evidence that individuals with disabilities have worse health status than those without disabilities and that resources for persons with disabilities to maintain health, prevent secondary conditions, and optimize wellness are inadequate. The failure of medical education programs to teach concepts of disability was identified as a root cause, and educators were encouraged to "increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity." Professional education about disability is a critical element in achieving quality health care, and having core competencies for health care professions education about patients with disabilities may help to achieve . . . [cut off after 150 words].


There is a current need to improve health care delivery to deaf and hearing-impaired persons. The author designed an educational workshop for medical students and others as an initial step to address this need. The workshop was offered electively during 1997 and 1998 to first-year and second-year medical students at Dalhousie University, Nova Scotia, Canada. The workshop involved a broad, multidisciplinary scope, may have been the first of its kind in Canada, and is still one of the few documented ways to approach medical education about deafness and hearing impairments. Attendees explored general information on hearing impairments, communication between the hearing-impaired patient and his or her physician, and multicultural, technological, and ethical aspects of caring for hearing-impaired patients. There was an initial questionnaire, group exercises, lectures, student interviews of volunteer deaf "patients," discussions, and a "hands-on" materials display. The workshop was a low-cost and easily reproducible method of educating medical students about hearing impairments. If found to be educationally effective through future research, this type of workshop may foster better care to deaf and hearing-impaired persons by inclusion into medical school and continuing education curricula.


Patients with chronic disabilities often perceive a lack of sensitivity among physicians. They complain of being treated as objects rather than as persons during clinical encounters. Physician behaviors that reinforce this impression include examples such as addressing the companion of a patient who is in a wheelchair instead of talking to the patient directly, or leaving a disabled patient in a disheveled and uncomfortable state after completing a physical examination. There is, therefore, a need to ensure that physicians in training are aware of and practice appropriate etiquette in treating disabled patients. Emphasis on humanistic aspects of patient care has increased recently. General competency skills established by the Accreditation Council for Graduate Medical Education (ACGME) include items such as demonstration of caring and respectful behavior when interacting with patients, and respecting the dignity of patients and colleagues, including those with disabilities. However, there is a lack of objective, reliable, and standardized tools to teach or evaluate these skills. We have developed several objective structured clinical examination (OSCE) stations in an attempt to evaluate and teach these skills in a structured format.

Books


**Video/DVD**

Body & Soul: Kathy & Diana (Welcome Change Productions).

Dad’s in Heaven with Nixon (Showtime)

Emmanuel's Gift (2005 documentary)

How's Your News? (1999 documentary)

King Gimp (1999 documentary available from Video Press)

The Diving Bell and the Butterfly (French; Le scaphandre et le papillon) (contrast with Million Dollar Baby, Warner Bro)

Murderball (documentary; available on Netflix)

My Flesh and Blood (2003 documentary)

Rolling (Gretchen Berland, see http://www.thirteen.org/rolling/thefilm/)

Sound and Fury (2000 documentary)

Southern Comfort (2001 documentary)

Temple Grandin (HBO).

When Billy Broke His Head (Fanlight Productions; available on VHS at Enoch Pratt Free Library, Baltimore, MD).

Vital Signs: Crip Culture Talks Back (Brace Yourselves Productions)

**BLOGS**

Bad Cripple - [http://badcripble.blogspot.com/](http://badcripble.blogspot.com/)


Mysteries and Questions Surrounding the Ashley X Case – http://huahima.wordpress.com/


What Sorts of People – http://whatsortsofpeople.wordpress.com/

WEBSITES

ADAPT – A national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. http://www.adapt.org/.

The ARC of Baltimore - To ensure that people with developmental disabilities have maximum opportunities to actively participate in all aspects of community life and to offer programs and services that support them in doing so. http://www.arcofbaltimore.org/

Disability Rights Education & Defense Fund – Founded in 1979, DREDF is a leading national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities. DREDF’s mission is to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. http://www.dredf.org/

Hearing and Speech Agency of Baltimore – HASA is a private, non-profit organization, that provides hearing and speech services, offers an information resource center and advocates for people of all ages with communication disorders/disabilities. Can provide emergency ASL interpreters. http://www.hasa.org/

Maryland Department of Disabilities – MDOD is charged with unifying and improving the delivery of services to people with disabilities by working collaboratively with all state government agencies; and develops and facilitates the implementation of the State Disabilities Plan, calling for collaborative partnerships with state agencies to improve services for people with disabilities. http://www.mdod.maryland.gov/

Maryland Disability Law Center – MDLC is the designated Protection and Advocacy agency for the State of Maryland, mandated to advance the civil rights of people with disabilities. It is a non-profit legal services organization that uses an array of strategies, including information and referral, direct representation, abuse and neglect investigations, technical assistance, community outreach and training, to advance the legal rights of people with disabilities and ensure equal opportunities to participate in community life. http://www.mdlclaw.org/

Rehabilitation Institute of Chicago – Browse the largest source of information specific to people with physical disabilities. Locate disability organizations, government agencies, support groups, and health information on key areas of life, including books, videos, magazines, and multimedia learning resources. http://lifecenter.ric.org/

Amanda Baggs, In My Language, autism (8-minute video): http://www.youtube.com/watch?v=JnylM1hl2jc

Lynn Manning, Weights, a solo show that shares his life from childhood poverty through his evolving creativity as a blind artist [Google: “Lynn Manning presents Weights”]