

UNINFORMED CONSENT:
BIASED DECISIONMAKING FOLLOWING
SPINAL CORD INJURY

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The decision to refuse medical intervention and end one's life is intensely personal. Yet people with newly acquired disabilities, such as a spinal cord injury, frequently may face such decisions with little information and no previous life experience. What information they do receive usually comes from health professionals, "experts" whose own experiences are largely clinical and reflect society's negative biases about quality of life with disability. Members of ethics committees need to consider that a decisionmaking process resting on such biases may result in "uninformed consent."

The desire to improve quality of life is the overriding force that drives the medical profession in general and physical medicine and rehabilitation in particular (1). It is the justification, for example, when costly and even heroic surgical procedures are performed. Some extend longevity more than others, but all purport to increase the quality or quantity of the days, months, or years that remain. Rehabilitation medicine, similarly, justifies its existence by the improvement of function and life satisfaction for those who have survived severe injuries or have other disabling conditions. Indeed, enhancing quality of life is rehabilitation's ultimate goal (2).

Yet, the medical profession also determines and intervenes when quality of life is deemed inadequate or absent. A mother, told her unborn child has a genetic anomaly or disability, may end her pregnancy if the child's quality of life is expected to be poor. The belief that future suffering will outweigh life satisfaction motivates a severely ill patient to terminate medical treatment. The family of an individual with a new spinal cord injury, on the basis of information provided, rejects aggressive interventions.

But quality of life is an elusive and intangible concept. One author writes that "quality of life has to do with family, good friends, an active and productive life, and a feeling of satisfaction..."(2); another describes it as life satisfaction, well-being, and general affect (3). Many social scientists have struggled to quantify and objectively measure quality of life. They have identified such indicators as good health, work, active recreation, learning and education, the presence of family and social networks, a good marriage, and the availability of material comforts (4).

Not everyone agrees that quality of life can or should be assessed by objective measures alone. To do so, argues one writer, may result in little more than a projection of the researcher's own values and priorities (1). Others have pointed out the value-laden nature of quality-of-life assessment (3). For these researchers and writers — and for much of society — quality of life remains largely a subjective concept, something that is understood on a deeply personal and intuitive level. But however vague our concept of quality of life may be, our sense of its definition sharpens when it is thought to be lacking or absent.

Disability, spinal cord injury in particular, brings quality of life into question in a dramatic way. Sir Ludwig Guttman, called the "father of modern spinal cord injury management," described it as one of the "most devastating calamities in human life" (5). Its consequences are well known: in addition to paralysis and changes in sensation and bowel, bladder, and sexual functioning, spinal cord injury also causes on-going and lifelong care and health needs, financial stress, and other societal disadvantage for many of its survivors. High level quadriplegia exacts an even higher toll. Its survivors may be ventilator-dependent, require round-the-clock care, and may have communication impairments.

Consequently, many people believe that an acceptable quality of life after spinal cord injury is not possible, that it's virtually impossible to lead a normal life, and that death is preferable to survival with so devastating a disability (6) (7) (8). These beliefs are imbedded in the health profession itself, and in society as a whole.

Bias On Many Levels

Many health care professionals — those who work to preserve quality of life — have ambiguous feelings about life after spinal cord injury. A recent survey of emergency care providers — physicians, nurses, emergency medical technicians and paramedics who care for spinal cord

injury survivors in the earliest stages of their injuries — found that 41% felt resuscitation following injury often is too aggressive. If injured themselves, 45% of these emergency care providers said they would want nothing more than pain relief; only 22% would want every intervention necessary to ensure their survival (9).

Other research has examined health care professionals' perceptions of disability and disabled people. The presence of negative attitudes among nurses (10), medical students and residents (11), and occupational, physical, and speech therapists in-training (12) has been reported, and it also has been suggested that such attitudes increase the likelihood that necessary treatment will be withheld or be sub-standard (13).

The attitudes of health professionals mirror those of society and its cultural institutions (12). In the art world for example, the well-known theatrical production, *Whose Life is it Anyway?* (14) features a lead character — an individual with high level quadriplegia — who argues eloquently for his right to end his "hopeless" life. This plot has often been repeated in real life as other severely disabled people, such as Larry McAfee, Elizabeth Bouvia, and Hector Rodas appeal to the courts for permission to die (15) (16) (17). The media — the press, television, radio — feed our uncertainty about quality of life following severe disability, and feed *on* that uncertainty. They exploit the real life dramas played out in our nation's courtrooms, as quality-of-life battles like those above continue to be fought. Headlines are made, editorials written, and public opinion is formed.

McAfee, Bouvia, and Rodas all ultimately won the legal system's approval to choose death over continued life with a disability. And in each case the perceptions of emergency providers, health care professionals, and the public were reinforced: a high quality of life with a severe disability is not possible. These perceptions make their way to the survivors and their families. Faced with a trauma as overwhelming and seemingly hopeless as a spinal cord injury, many acutely injured persons — in the emergency room, the intensive care unit, and especially during the days and weeks immediately following injury — consider non-intervention (and ultimately death). Some die, often with the support of their families, friends, physicians, care givers, and peers.

Another Perspective

How accurate is this perception that quality of life is absent after severe spinal cord injury? Not very, according to some compelling research.

There is now evidence that health care providers are simply incorrect in the assumptions they make about disability. They overestimate the amount of depression, anxiety, and denial their patients experience (18), as well as the importance they place on normal sexual functioning (19). What health care providers assume it is like to live with a disability often is worse than what disabled people report (9) (20) (21).

Stensman, for example, in a study involving 36 severely mobility-impaired individuals, found only slight differences between his subjects and non-disabled individuals on several quality-of-life measures (20). Weinberg reported that many of the traumatically disabled persons she studied were so satisfied with their lives that hypothetical offers to make them able-bodied again were viewed as either downright unattractive or, at best, only partially attractive (21). In another study, many disabled individuals indicated that the adjustment they made to their disabilities was not the most difficult of their lives; only 7% thought the disability was the worst thing that had ever happened to them (22). And, disability was ranked only sixth on a list of life's most stressful events. Ranking higher were death of a spouse, divorce, marital separation, imprisonment, and death of a close family member. Marriage was stressor number seven and pregnancy was ranked number twelve (23).

There is also research specific to individuals with spinal cord injuries. In one outcome analysis of a large sample of spinal cord injury survivors, life satisfaction increased after the first year post-injury. Moreover, this satisfaction was not related to the severity of the disability (24). Gardner and his colleagues surveyed 37 spinal cord injury survivors who had been mechanically ventilated at the time of their injuries. Injured between one and six years prior to the survey, the majority were glad they had been ventilated, and 86% would choose to be ventilated again if necessary. Most were glad to be alive and did not feel their families would have been better off had they been allowed to die (6).

Similarly, Whiteneck and his colleagues surveyed a 216 survivors with high quadriplegia (C4 and above), many of whom were chronically ventilator dependent (25)(26). Among these individuals, only 10%

rated their quality of life poor, but 92% were glad to be alive. To a great extent, they led active lives in and out of their homes, going to school, working, entertaining and visiting friends, as well as engaging in passive activities such as watching television. In response to self-esteem-related questions, these individuals scored high.

Moreover, on tests designed to assess self-esteem (27), the results of the individuals with quadriplegia were very similar to those of non-disabled persons — in particular, to the emergency nurses, physicians, residents, paramedics and emergency medical technicians who had answered the same questions (9). It was not until these health care professionals were asked to *imagine* themselves with quadriplegia and how they might feel about it, that striking and significant differences between the two groups appeared. The table below provides some examples.

	<u>Non-disabled emergency providers</u>	<u>Spinal cord injury survivors</u>	<u>Emergency providers <i>imagining</i> life with SCI</u>
Percent agreeing with the statement:			
I feel I am a person of worth	98%	95%	55%
I feel I have a number of good qualities	98%	98%	81%
I take a positive attitude	96%	91%	57%
I am satisfied with myself, on the whole	95%	72%	57%
I am inclined to feel I am a failure	5%	9%	33%
I feel I do not have much to be proud of	6%	12%	33%
I feel useless at times	50%	73%	91%
At times I feel I am no good at all	26%	39%	83%

In addition to assuming a lower self-esteem for themselves if spinal cord injured, many of these emergency care providers did not think they would be glad to be alive and imagined a much lower quality of life and level of activity than the quadriplegia survivors reported.

These are just a few of the misunderstandings that may affect spinal cord injury outcomes. Other misconceptions include such myths as these: that spinal cord injury causes marital failure, that employment after spinal cord injury is rare, and that both depression and suicide are more common than they really are (28). Although other researchers have

not found life satisfaction and quality-of-life ratings among less severely disabled spinal cord injury survivors to be quite as high as the studies reported above, it is interesting to note that such lower ratings tended to be correlated less with the severity of the disability itself and more with such issues as perceived health, control and social support (29).

The Implications:

It's difficult, if not impossible, to imagine what it must be like to have a spinal cord injury; it's difficult, if not impossible, to imagine how one could cope with a severe disability. This point is not particularly surprising or enlightening. Its implications, however, are.

It has been argued that those who can't imagine themselves coping with a spinal cord injury or other disability cannot deal effectively with others who have that same disability (30). Instead, they employ myths and presumptions that substitute for the knowledge they don't have (20) — myths that have the power to affect the survival of the person with a new spinal cord injury.

At a time when decisions are made on behalf of the patient — decisions that frequently are irrevocable, are almost always made without the patient's help, and seldom include input from a family that itself understands the long-term implications of spinal cord injury — the provider's biases can determine what interventions are administered and the aggressiveness and quality of the care provided (13).

At the very least, their biases affect the tone or flavor of the information they provide to patients and their families. In place of accurate information, they may offer untested assumptions that increase the likelihood of hasty decisions that result in the early death of individuals who might have lived satisfying, productive lives (28).

In the days and weeks following a severely disabling injury, individuals may die for the wrong reasons — they may die because of what they don't know rather than what they do know. That this happens on an individual level is concerning, and, at least in some cases, seems to speak of the failure or inadequacy of informed consent. However, much more alarming are the pervasive societal ramifications. Each time a newly-spinal-cord-injured person chooses death over life — and is allowed to die — society is shown "proof" that it's better to be dead than disabled.

If death is preferable to life with a spinal cord injury, aren't those who are surviving with such injuries profoundly devalued? What should

non-disabled people think of them? Will we relinquish our belief that "all human life, irrespective of its quality or kind, is equally valuable?" (31). And, why do we not apply these same standards to other classes of people?

When a depressed housewife takes her own life, her neighbors do not conclude that all housewives lead miserable existences. When a black teen, jilted by his girl friend, hangs himself, it's a tragedy. It seldom implies that blacks have less reason to live or that teenagers have no future. When a banker or accountant kills himself, no one assumes that it's because bankers and accountants are better off dead. Yet, when a newly spinal-cord-injured person dies, or is allowed to die, the message that life with spinal cord injury is unbearable remains undisputed.

The result, is an untenable contradiction: the empowerment — in civil rights and social opportunity — realized by disabled Americans during the 1990s is undeniable; yet their lives continue to be undervalued.

Uninformed Consent

What of informed consent? Many would argue — convincingly and justifiably — that one individual's right to self-determination overrides the widespread invalidation of other survivors. The decision to live or not, people hope, will remain in their control. But, for many people with disabilities, the issue is less about control over dying than it is about the anticipated lack of control over living. This is clearly reflected in a case recently heard in Nevada. Kenneth Bergstedt had lived for more than 20 years with ventilator-dependent quadriplegia, cared for since his injury by his parents. Several years ago, with his mother already dead and his father's death apparently close at hand, he worried about his future quality of life, as the court put it, "without the attentive care, companionship and love of his devoted father." He petitioned the courts for permission for another individual — one who would be guaranteed immunity from prosecution — to administer a pain relieving sedative and remove him from his ventilator. The justices hearing his case determined that, in addition to several other prerequisites that would have to be satisfied prior to ruling in Bergstedt's favor, they would need to be assured that Bergstedt had been fully informed of governmental and private support systems and care alternatives — beyond his family — that might be available to him. They indicated that what Bergstedt lacked in his decision-making process was "assurance that society would not cast him

adrift in a sea of indifference after his father's passing" (32). Though Bergstedt died before the court's decision was rendered, the empowerment offered by accurate and comprehensive information is manifest.

In yet another case, Larry McAfee, another survivor of quadriplegia, successfully fought for and won from the courts in Georgia the "right to die," but chose not to exercise the option. The turnaround, not surprisingly, was a deluge of ideas from other long-term survivors and offers of assistance, resources, and support from the community (33).

The issues for the long-term survivor and for the newly-injured person may differ radically. If nothing else, Bergstedt and McAfee both had years of experience of living with disability on which to base their decisions. Still, although it can be argued that newly disabled people have neither the experience nor the perspective to choose death, their option to do so must be protected. For some of them, life truly may be unlivable; for them, the best choice — one that would be unchanged by firsthand experience — may be death. For others, the best choice — from the moment of injury — is equally clear and obvious: to survive. It is for the large number of persons who fall in between — those who see options to be weighed, choices to be made — that bias has the most potential to do harm. In its presence — and in the absence of accurate, balanced information — there can be no true informed consent. At present, neither society, nor care givers, nor those who are newly disabled are adequately "informed."

Solutions?

The solution is education. Care givers of all aspects of medical care, but particularly in emergency medicine and other acute areas, need to understand their own biases, misconceptions, and fears. They need to be sure that the informed consent that their patients give — regardless of the decision — truly is "informed."

Patterson and his colleagues contend that informed consent may not even be possible immediately after a new, acute spinal cord injury. Informed consent, they argue, has only occurred when the patient has obtained a "demonstrable understanding of the potential for long-term rehabilitation" (28). And here what is meant is rehabilitation in the broadest, most extra-medical sense of the word.

Disabled activists often echo Patterson's thinking, despite the fact

that they see self-determination as a cornerstone of progressive disability rights and thus are reticent to deny choices — including the right to die. Marilyn Golden, in the *Disability Rag*, writes:

"at a minimum, a right-to-die policy must be formulated from a position of genuine understanding about the full potential and quality of life available to people with disabilities. Any and all available disability-related resources, both psychological and material, must be brought to any decision maker before the decision is made. Such knowledge may well enable a different choice to be made, a choice toward life" (34).

Herein may lie a role for the long-term disability survivor — as an educator, counselor, role model, and peer to all those involved in the decision-making process.

But how is this information provided? And to whom? Golden wants this information go to the decision makers (31) — seemingly not only the survivor, but family members, attorneys, and judges. Clearly all need to be educated. Patterson, on the other hand, focuses on the survivor as the key decisionmaker. He writes that information should be provided gradually through a number of sources. Information about the physiological consequences of spinal cord injury is necessary but not sufficient; information about long-term psycho-social function after spinal cord injuries should also be provided, including "the prospects of marriage and employment, the possibility of depression and suicidal ideation, and information about the overall quality of life" (28). Clearly, accurate information about outcomes, abilities, possibilities and life satisfaction following spinal cord injury is needed (9).

But who informs the informers? For professionals and other front-line staff to provide this level of information, they too must be educated. They need to understand outcomes after spinal cord injury and other disabilities — outcomes as experienced and reported by actual survivors, not those that non-disabled people imagine. They need to understand how spinal-cord-injured persons really do feel about the quality of their lives and how they value themselves, their relationships and their futures. Most importantly, professionals, in dealing with newly disabled persons, need to understand the broader societal implications of "uninformed consent."

Attitudes must be reexamined, and shifted. The shortcomings of

quality-of-life assessment need to be recognized. We need to realize that we cannot imagine what someone else's life is like, and that we should not and must not rest policies or decisions on what we imagine or presume. The words of disability activist Anne Peters are particularly insightful:

"What gives life its quality? We know it isn't the things society says it is. We've lived without those things; and yet we are human — and reasonably happy.... Average people, who have no disabilities yet, look at our lives and see deprivation.... They conclude that our disability has prevented us from having a quality of life. They are wrong: a life without the luxury of autos, restaurants, jobs and condos can still be a quality life. And they are also wrong to believe that disability is the villain that prohibits quality in our lives. The villain is usually society..." (35).

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