PM R 7 (2015) 962-969

www.pmrjournal.org

Original Research

Perceived Quality of Life With Spinal Cord Injury: A Comparison Between Emergency Medicine and Physical Medicine and Rehabilitation Physicians

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Abstract

Objective: To explore the attitudes of health care providers who treat patients with spinal cord injury (SCI) and examine whether Emergency Medicine (EM) and Physical Medicine and Rehabilitation (PM&R) physicians differ in their judgments about quality of life (QOL) after SCI.

Design: Questionnaire survey of PM&R and EM physicians.

Participants: Board-certified PM&R and EM physicians listed in the American Academy of Physical Medicine & Rehabilitation and the American College of Emergency Physicians and/or faculty from academic PM&R and EM departments in the United States and Canada.

Main Outcome Measurements: Evaluating various aspects of perceived QOL if the physician hypothetically sustained an SCI, including impact on leisure activities, social relationships, happiness, meaningful work, satisfying sexual relationships, and overall QOL.

Results: A total of 91 EM physicians and 89 PM&R physicians completed the surveys. PM&R physicians were more likely to agree that they would have a better QOL compared with EM physicians, regardless of the level of injury or aspect of life ($P < .01$ in all cases). Female physicians, regardless of specialty, were more likely to choose a lower level at which they would choose to die, rather than live, if they sustained an SCI ($P = .03$). Physicians in both groups were more likely to disagree that they would have a high QOL at a lower level of injury if they disagreed at a higher level of injury ($P \leq .02$).

Conclusions: Regardless of specialty, PM&R and EM physicians have their own personal perceptions of QOL with SCI. PM&R physicians tend to believe that they would have a higher QOL with an SCI compared with EM physicians and likely have a more optimistic view of SCI. Patient care may be improved by interdisciplinary discussion, as evidenced by the disparity exhibited by practitioners in these 2 specialties who care for the same patient population.

Introduction

Each year, approximately 12,000 new traumatic spinal cord injuries (SCIs) are sustained in the United States [1]. In addition to paralysis, persons with an SCI typically have impaired sensation, pain, spasticity, respiratory insufficiency, and bowel, bladder, and sexual dysfunction.

From the time of initial injury until eventual discharge home from rehabilitation, numerous complex medical decisions need to be made by patients and/or their families. Some of these decisions may involve life and death, such as the decision about whether to continue ventilator support. Patients and families, in the midst of an emotional and physical crisis, look to physicians for guidance and expertise. The attitudes of physicians can have a significant impact on medical care, and many studies have shown that physicians underestimate the quality of life (QOL) of persons living with disabilities. Although findings in the literature are mixed [2,3], many studies have demonstrated that people who sustain SCI have excellent self-reported QOL [4-6]. However, physicians tend to have a more pessimistic view [7,8].

Although the link between attitudes of practitioners and medical decision making is complex, beliefs and attitudes may affect the way that information is communicated, which options are pursued, and the

1934-1482/$ - see front matter
http://dx.doi.org/10.1016/j.pmrj.2015.03.008

patient's subjective experience of his or her acquired injury. This effect of beliefs and attitudes is even more pronounced in a sociocultural context that devalues disability and may have a significant impact on the care patients receive in these settings based on physicians' views of what they themselves would want. The cognitive strategy of "putting oneself in the patient's place" has been termed "Golden Rule" thinking [9]. In one study in which physicians reported their personal preferences for end-of-life care and what they thought their patients wanted, there was no relationship between the choices of the physicians and patients, but a correlation was found between physicians' personal preferences and what they believed their patients wanted [10,11]. Golden Rule thinking limits the ability to imagine an unfamiliar situation accurately. Furthermore, the examination of implicit associations or attitudes toward disability is growing in the medical literature [12]. These associations, which are typically negative, can also have an impact on medical decision making.

Little is known about whether physician attitudes about QOL after SCI vary by specialty. After a traumatic SCI, emergency medicine (EM) physicians are usually the first physicians who provide care for the patient, and they often witness the initial awareness by the patient and/or family of the sudden loss of function. After the acute care hospitalization, patients usually complete rehabilitation under the care of a Physical Medicine and Rehabilitation (PM&R) physician. PM&R physicians are typically involved with the recovery, day-to-day experiences, and adjustment to disability of the same patients. PM&R physicians also have extensive training related to long-term care for patients with SCI. Presumably, PM&R physicians would have more favorable views of QOL with an SCI. In a prior survey [7,13], only 18% of EM staff (including attending and resident physicians, nurses, and medical technicians) imagined they would be "glad to be alive with quadriplegia." This figure is in stark contrast to 92% of persons with tetraplegia who stated that they were glad to be alive. The "disability paradox" as described by Albrecht and Devlieger [14] has 2 components. First, people with disability have a high self-rated QOL despite significant impairments. Second, health care providers (who are typically grouped together in research studies) and the general public believe that people with disabilities have a poor QOL.

The purpose of this study is to explore the attitudes of health care providers who treat patients with SCI and examine whether EM and PM&R physicians differ in their judgments about QOL after SCI. Specifically, we asked EM and PM&R physicians a series of questions about how they would perceive their lives with an SCI. Our hypothesis was that although PM&R physicians are likely more aware of how positively patients with an SCI view their own lives, both PM&R and EM physicians would be unlikely to envision themselves with a good QOL if they acquired an SCI resulting in tetraplegia or paraplegia.

Methods

Subjects

Participants were initially recruited by a postcard mailed to a random sample of board-certified physicians of the American Academy of Physical Medicine & Rehabilitation and the American College of Emergency Physicians, who were directed to an online survey. Random lists were generated by the physician groups. A second mailing was also sent. Because of a low response rate (5% of 500 postcards sent), the participant pool was expanded. A direct e-mail message was sent to the academic department chairs of all PM&R and EM academic departments in the United States and Canada (210 e-mail messages), asking them to distribute our survey to their faculty. In all communications, the participants were asked to complete an identical 5-minute survey on "their perceptions of quality of life with various levels of spinal cord injury." Subjects were asked 9 demographic questions at the end of the survey, all in the same order, as demonstrated in Appendix 1. All responses were anonymous and self-reported, and investigators could not track the respondents.

Survey Instrument

We designed a survey similar to one used by Gerhart et al [7], who conducted a study of EM physicians. We modified the survey (see Appendix 1) to address various aspects of perceived QOL, including leisure activities, social relationships, happiness, meaningful work, satisfying sexual relationships, and overall QOL. Our questionnaire was also modified to address different levels of SCI to explore the role of the extent of injury in perceptions. Questions were framed so that a positive response—that is, slightly agree or strongly agree—corresponded to better imagined QOL. In the survey questions, explanations were not included to explain the functional implications for each category of SCI (C1-C4 tetraplegia, C5-T1 tetraplegia, T2 and below paraplegia), and the definition of a "complete" SCI was not provided. These explanations and definitions were deliberately excluded to simulate the real-world experiences of EM and PMR physicians (in which the physician may make clinical decisions while lacking this specific knowledge) and to avoid biasing respondents by supplying this information.

Study data were collected and managed using the Research Electronic Data Capture (REDCap) tool hosted at our academic institution [15]. REDCap is a secure, Web-based application designed to support data capture for research studies. Incomplete surveys were excluded from the analysis.