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Ethical Legal Feature

Prognosis Disclosure in Spinal Cord Injury

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Feature Editor Introduction

The ethical issues around prognosis disclosure raise interesting questions about how, when, and why we disclose medical information. What are the barriers to disclosure and how can we learn from each other about the best ways to discuss prognosis with our patients? Gayle Spill, MD, has edited this column and invited guests to consider the complexities of this issue. As always, I welcome comments about the PM&R ethics/legal column at dmukherjee@ric.org.

Introduction

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No one likes to deliver bad news, including doctors, who often have to discuss a poor prognosis with patients and their families. The subject of prognosis disclosure has been well-studied in the oncology literature [1-3], but less so in rehabilitation. For many life-limiting diagnoses, cancer and dementia, for example, prognosis disclosure is confounded by the uncertainties of disease course and response to treatment. Spinal cord injury (SCI), on the other hand, is a life-changing diagnosis with more certainty about outcomes and prognoses based on a patient's American Spinal Injury Association Impairment Scale [4]. In theory, this should make prognosis disclosure easier, but it is not necessarily so.

In all cases of disclosing a "poor" prognosis, the goal is to maintain hope, promote shared decision-making, and engender trust. It is important to pay attention to what question the patient is asking and attend to their emotional and cognitive needs [5]. The questions "when will I walk again?" and "will I ever walk again?" are very different and require the physician to first acknowledge where the patient is in his/her understanding of diagnosis and proceed with expertise, honesty and compassion. In the face of a patient and family experiencing the emotional after effects of a trauma, this is often easier said than done.

For this column, I have asked several experts to give their perspectives and reflect on their experiences of prognosis disclosure in SCI. Dr. Joyce Fichtenbaum, psychologist at Kessler Institute for Rehabilitation, and Dr. Steven Kirshblum, Director of Spinal Cord Injury Services, Kessler Institute for Rehabilitation and Professor, Rutgers New Jersey Medical School, have published on this topic and offer us some general guidelines and a case study in prognosis disclosure. Dr. Lisa Ruppert, Assistant Attending of Rehabilitation Medicine Services at Memorial Sloan Kettering Cancer Center and Assistant Professor of Rehabilitation Medicine at Weill Cornell Medical College, has dual specialization in Cancer Rehabilitation and SCI medicine, and has unique experience and insights on the difficulties of prognosis disclosure in patients with metastatic SCI. Finally, Ms. Thea Flaum, president of the Hill Foundation and founder of the FacingDisability.com website and an advocate for people with SCI, shares some personal reflections about how prognosis disclosure affected people with SCI.

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Breaking Bad News: The Ethical Aspects of Delivering a Prognosis in Spinal Cord Injury Rehabilitation

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When it comes to breaking "bad news" to patients and their families in the rehabilitation hospital setting, person-centered treatment and the ethical principle of disclosure are paramount. Discussing a negative prognosis for significant neurologic recovery after a severe SCI is difficult for individuals and their families and equally unsettling for professionals in the rehabilitation setting [1-3]. In these situations, it is important to balance the pertinent information regarding paralysis and the dysfunction of other organ systems—including respiratory, bladder, bowel, and sexuality—based upon current medical information with sensitivity, hope, and promise for the future. It also is critical to help establish realistic goals, promote use of compensatory strategies, and maximize independence.

Patients most often want to learn about their prognosis as early as possible from a physician who can speak in an empathetic manner [1]. Those patients who ask pertinent questions usually are ready to hear their prognosis even if not an optimistic one. Patients report that beyond any initial discussion that may have taken place during their acute hospitalization, they would like follow-up discussions with their physiatrist in the rehabilitation setting. Some patients also recommend a psychologist be present when the physician breaks the news [1]. The physician has the knowledge and experience to discuss the medical background, whereas the psychologist is in position to know biopsychosocial aspects of patient and family dynamics and assist them both through the adjustment process.

Breaking "bad news" is not unique to the field of rehabilitation but at times, physicians are reluctant to do so as they will be seen as giving up or dashing patients' hopes [2]. In the rehabilitation setting, prognosis discussions occasionally may be complicated by the information patients were given while in the acute care hospital or the news that the patient and family took away from those earlier discussions. Patients, at times, focus on the fact they were told such things such as the "spinal cord wasn't severed" or "the surgery went very well." The meaning that patients and families apply to what they heard may require clarification by the rehabilitation team to establish realistic goals that facilitate informed and effective decision-making.

The 4 ethical principles that guide prognosis discussions in health care settings include respecting autonomy, which encompasses the concepts of disclosure and informed consent; beneficence, providing the best care for patients; nonmaleficence, obligation to do no harm; and justice, the principle of social obligation that encompasses being fair [3]. These ethical principles in conjunction with person-centered care (eg, patient values and psychosocial issues) can result in positive results such as increased engagement in rehabilitation [4-6].

SCI does not occur in a vacuum. For many individuals and their families, culture, religion, premorbid family relationships, and emotions conflict with the nature of distressing news. There are times when family members insist that their loved one who sustained the SCI, be it a parent, child, or spouse, should not be told their prognosis for recovery. A family member may believe that hearing such news will cause emotional harm, including hopelessness, reduced motivation and participation in rehabilitation, and increased depression or anxiety.

Conversely, nondisclosure of a poor prognosis to patients who have capacity may have long-term negative implications when it comes to understanding and directing their care. What if a family member wants to control or limit what the physician tells their loved one regarding poor prognostication for recovery? How does this family's demand impact informed consent, autonomy, beneficence, and the establishment of realistic and achievable goals?

This dilemma can be seen in the following case scenario. C.B., a 19-year-old man was injured in a car accident resulting in a C5 American Spinal Injury Association Impairment Scale A injury 2 weeks before being admitted to inpatient rehabilitation. His mother, who was at his bedside 24 hours a day, would not allow the physician to discuss specific prognosis as she believed she needed to protect her son from further distress, because he was showing symptoms of depression, but she also believed that he would recover. She would minimize negative information given by any staff member to the patient regarding his recovery. C.B. never directly asked about his prognosis.

As a result, the patient did not recognize the need to learn to use adaptive devices or other equipment and repeatedly stated he would wait until he could perform his activities of daily living the way he "used to," when