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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

he recovers. C.B.'s mother also fostered this notion of not learning to use adaptive devices, trial commode chairs or power mobility, promising she would provide all care until he fully healed and that these devices would preclude recovery (ie, ambulation) in the future. In addition, he did not view adaptive equipment as a goal that would make him less dependent.

The physiatrist and psychologist conferred as C.B.'s participation in the treatment gym had begun to wane. Discussion centered on whether the patient, an adult, should be told his prognosis while alone, and whether the patient's right to know takes precedence over his mother's request to withhold information. It was decided that initially seeking consensus from the mother, out of respect for their relationship, would be the most effective approach, given that the family unit was so clearly structured and C.B. would follow her lead when it came to any decision-making. At the onset of the meeting, C.B.'s mother was told that she was being consulted before the team members discussing issues of diagnosis, goals, and prognosis with her son. The objective was to enlist her help in establishing with C.B. the goal of functional independence in as many areas as feasible because this would promote improved quality of life, decrease the potential burden of care on the family, and perhaps most importantly, allow him to move forward with his residual abilities. C.B.'s mother also was made aware that because of her son's age, with or without her permission, a discussion would ensue with him regarding the benefits of learning his prognosis as a means of enhancing his sense of control, of establishing reachable goals, and maximizing function.

C.B.'s mother assented to meet with the physiatrist, psychologist, and C.B. to discuss the goals of rehabilitation. The psychologist spoke with C.B. ahead of time for permission to include his mother in the discussion and to develop questions that he was interested in exploring. In the team meeting, the nature of his injury was discussed, including prognosis. The changeable role of hope, adaptability, and the importance of being as

independent as possible as a precursor to returning to school, the work force and social activities were all addressed. With ongoing discussions, C.B. agreed to trial adaptive devices and power mobility.

In this scenario, the 4 ethical principles were addressed. Autonomy, as it related to disclosure and informed consent, was the primary issue. Beneficence related to functional restoration to reduce dependency. Nonmaleficence, to maintaining and not harming the patient's relationship with his mother, and justice (fairness), engaging the patient's mother in the process even though it was not necessary as her son could give consent.

A patient's right to know his/her prognosis can occasionally run counter to family wishes. It is imperative, however, to find an opportunity to provide sufficient information so patients can knowledgeably evaluate and determine how they can best transition from the hospital to the community and be as independent as possible. Encouraging patients and families to refocus their goals based on a new reality and providing a sense of autonomy through a sensitive and empathic discussion of their prognosis can help to improve quality of life and inspire hope.

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Prognosis Disclosure in Neoplastic SCIs

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Introduction

SCI is considered one of the most devastating injuries one can experience. In the cancer setting, epidural spinal cord compression is among the most debilitating complications of metastatic spinal cancer and can lead to neuropathic pain; sensory and motor loss; gait disturbances; and bowel, bladder, and sexual

dysfunction. Metastatic epidural cord compression has been associated with reduced life expectancy and quality of life. Treatments for cord compression often are considered palliative; they aim to alleviate pain, preserve neurologic function, and assure spinal stability [1].

Delivering information on diagnosis and prognosis creates a communication dilemma across specialties, because it involves much more than the simple transmission of information. Oncologists reportedly are more frank with patients who have a better prognosis. Similarly, physiatrists often are eager to share a "good

prognosis” with patients who have neurologically incomplete injuries.

“Bad News”

Historically, doctors have avoided telling their patients the truth about diagnosis and prognosis. In 1672, Dr. Samuel de Sobiere contemplated the idea, but concluded that it might seriously jeopardize his practice. In 1961 a landmark paper by Oken revealed that 90% of surgeons in the United States would not routinely discuss a diagnosis of cancer with their patients [2].

It is not difficult to understand why clinicians may want to avoid sharing bad news with patients. Traditionally, there have been 2 main justifications for keeping patients in the dark: first, the facts will likely be upsetting; and second providers, and sometimes patients’ close relatives, presume that patients do not really want to know [2]. In the rehabilitation setting, some physicians may feel that discussing the poor prognosis for neurologic recovery with an individual soon after injury may be a source of anxiety and depression. This anxiety and depression may in turn affect that individual’s willingness to participate in comprehensive rehabilitation. There have been no published data in the rehabilitation literature, however, to support this perception [3].

When it comes to medical diagnoses, withholding bad news in an attempt to protect the patient from the truth is usually a judgmental error and reportedly often arises from a desire to protect the holder of the information [3]. Naturally most clinicians feel uneasy when in this position and perhaps anxiety about how to share this information underlies most of the arguments of not being open with the facts [2]. Difficulties with open communication may be related to uncertainties about the most effective treatment options, extent of neurorecovery that can be expected, and medical comorbidities that may impact recovery. Furthermore, many physicians have had limited training in counseling and often are pressed for time during busy clinics [2].

Changing Attitudes

More recent studies in the oncology literature have shown that a growing number of patients want to know about and understand their diagnoses. Meredith et al studied 250 cancer patients in Scotland and found that 79% of patients wanted to know as much as possible about their disease and 96% specifically wanted to know whether their disease was cancer. Almost all patients wanted to know the chances of cure and details about treatment side effects [2]. Gratitude, piece of mind, positive attitude, reduced anxiety, and better adjustment are benefits individuals have reported from having been told their prognosis, even if the prognosis was poor [3].

Breaking the News

Patients with cancer who have spinal cord involvement often arrive to rehabilitation units and clinics with the question, “what is my prognosis?” Consider beginning this discussion by asking the patient what he/she believes about their diagnosis and prognosis. This will help clarify whether they are referring to their oncologic or neurologic prognosis and what they already know. Inquire if they have discussed prognosis and future treatments with their oncology team. Patients and family members may not have had the opportunity to ask, such as in the setting of urgent surgical decompression for high-grade cord compression. They may have been too frightened to ask, choosing to focus their attention on treatments. They may admit they did, but understood very little of what was said after hearing the word “cancer.”

If a patient is inquiring about oncologic prognosis, it is best to involve the oncology team (medical oncologists, radiation oncologists, surgeons) in the discussion. Even as educated physiatrists, we are not in the position to address oncologic prognosis alone. We can, however, provide support, answer follow-up questions, and help the patient understand and adapt to his or her diagnosis and prognosis.

In contrast, patients may have knowledge about their cancer diagnosis and overall prognosis but no understanding of their neurologic impairments and prognosis. Patients undergoing surgical decompression may have neurologic deficits at the time of diagnosis but expect complete resolution postoperatively. Others may believe that their paresthesias and weakness are related to chemotherapy or that their bowel dysfunction is related to pain medications. Patients typically do not equate their impairments to an SCI. Furthermore, they may not hear the words SCI until being evaluated by a rehabilitation specialist or even understand what an SCI means.

The manner in which neurologic prognosis is delivered can have a significant impact on the patient’s perspective of illness, compliance with treatment, and long-term relationship with all treating providers. Neurologic prognosis must be conveyed with sensitivity, especially if poor. Sensitivity in delivering prognosis includes communicating the information slowly and clearly and allowing the patient to adapt to the news [3].

Be prepared to answer patient and caregiver questions knowledgeably [3]. This includes having knowledge of type, level, and severity of injury; treatments to date (including surgery, chemotherapy, and radiation therapy); laboratory results; imaging findings; and current medical and functional status. One should also be prepared to communicate with the oncology team about expected oncologic prognosis and planned future treatments as these often affect potential for neurologic recovery and tolerance of rehabilitation interventions.

Finally, remember that unless you have personally suffered from an SCI or cancer, you cannot really know the experience of the patient and should therefore

refrain from uttering statements such as “I know what you are going through.” Also avoid phrases that extinguish hope, such as “there is nothing more that can be done for you.” When possible, use supportive statements like, “I can only imagine” and words such as “help” and “assist” to convey empathy, assurance and security that the treatment team is interested and will do their best when providing care [3].

Hope

Hope is a multifaceted concept that involves appraisals of one’s desired goals, position in relation to goals, abilities to develop and initiate behaviors to make progress towards goals, and determination to move towards goals [4]. Hope enables a patient to feel reassured that some parts of their present situation will get better [3].

When discussing prognosis with a patient, explore their hopes. Ask about what they enjoy doing, what things are important to them, and what they would like to accomplish. Each person has some unique goals but many probably fall within certain common categories. These categories include pain management, symptom minimization, maintaining function, information seeking, decision making, psychosocial goals, and spiritual goals. Listen carefully, treat patients as in-

dividuals, and encourage them. Use the information obtained to determine how rehabilitation efforts can help in pursuit of these goals [4].

Conclusion

Discussions of diagnosis and prognosis are an important part of any physician’s job. A primary goal of the discussion regarding prognosis is to begin the healing process. Learning how to communicate prognosis empathetically and effectively is an acquired skill. There are several resources available to help us in this respect. It has been aptly said that “if the breaking of bad news is done badly, patients and their families may never forgive us; by contrast, if we get it right they will never forget us”[2].

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Breaking the Bad News: It’s Not What You Say, It’s What They Hear

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In the summer of 1986, my stepdaughter Vicki, then 22 years old, dove into a swimming pool, hit her head against the side, and realized as soon as she broke the surface of the water that she couldn’t feel her arms or legs. She was rushed to the hospital, where the radiographs indicated a C-6 spinal cord injury. Her father, who had been a medic in the army, looked at the radiographs and feared the worst. What nobody knew, and what none of the medical people made clear, was how long the paralysis might last. Instead, the family heard things like: “Nobody knows the future.” “Miracles happen.” “She can continue to recover movement and feeling for as long as 2 years.”

Amid such rose-colored scenarios, the bottom-line prognoses, when they were finally delivered, seemed brutal and almost heartless. After surgery, the orthopedic surgeon explained to her father: “Look, if you drop an egg on the kitchen floor, you can’t expect me to put it back together.” Vicki, in a room with 2 patients who were given rubber balls to squeeze, asked the nurse: “Shouldn’t I be doing that, too?” “No,” she answered. “That won’t help you—you’re a quad.”

After those abrupt prognoses, Vicki spent 3 months at the Rehabilitation Institute of Chicago. She credits her time there with helping her gain acceptance of her disability and developing the skills and confidence that she would need to create her own future.

Vicki finished college, went to graduate school, and became a successful wheelchair athlete. Today, she is happily married, the mother of a 21-year-old daughter, 3 stepchildren, and 2 grandchildren. For 23 years, Vicki has worked as a vocational rehabilitation specialist for the state of Connecticut, where she is now a supervisor.

In the end, was the way Vicki learned her prognosis an important factor in the successful way she has coped with her injury? My personal experiences, both then and now, suggest it was not.

As the founder of FacingDisability.com, * a website that offers information and support to families facing SCIs, I have conducted on-camera interviews of almost

* Note: FacingDisability.com was launched in 2011 with the primary purpose of connecting families dealing with SCIs with the life experiences of others like them. The website now contains more than 2000 videos of family members answering real-life questions about how they cope, as well as interviews with top medical experts on spinal cord injury topics. The website averages 2500 unique visitors a week, about 140,000 a year.

100 people with SCIs and members of their families. "How did you develop an understanding of the injury?" is a question we almost always ask. We put the best and most helpful answers on the website.

When I surveyed those answers, I discovered—regardless of how and when the prognosis was delivered—people only "got" the news when they were ready to hear it. What's more, no matter how wrenching, how anguished, how great their initial resistance to hearing the news—and no matter how clumsily or carelessly the bad news was delivered—it did not seem to affect how they coped with their injuries or the way they led their post-injury lives. The following examples emphasize this point.

Marie, who was injured in 1998 at the age of 22, and has quadriplegia: "...Denial is a great thing. I knew in the back of my head what I was dealing with, but there was always that hopeful piece—'Maybe the injury isn't quite as permanent as they're saying.' You know, and that just kind of came gradually. It was just a gradual process... I was being practical, and planning, and trudging forward, and doing my therapy, but not completely losing hope that I would regain some movement."

James, injured in 1976, at age 27, also has quadriplegia, and says something similar: "Time, it took time. You know, I didn't want to hear what they were telling me. The likelihood of walking again was pretty slim, the chances, I didn't want to hear that. Even after I got out of the hospital into rehab I said, 'No, I'm going to walk out the door someday, you'll see.' It took a long time for that to settle in, to sink in."

Hector, who has paraplegia, and was injured in 1979 at age 19 fought it all the way: "They put the wheelchair next to my bed, I would not even look at it, I didn't even want to get on it, they had to force me, put me in the chair. It took 2 nurses to get me up and put me in the chair, I couldn't accept not walking again."

Joel, who was paralyzed with paraplegia in 1998 at age 17 was in the dark for a while: "...Nobody would talk to me. You know, I just remember the doctors passing by and just saying: 'T11, ASIA-A complete' but nobody would explain that to me....when I was finally told, the doctor was just very blunt. I asked him, 'Hey doctor, I can't feel my legs, you know, when's the feeling going to come back? When am I going to walk out of this hospital?' And he was very nonchalant, like, 'Well, you're never going to walk again.' You know, instantly my world just shattered."

Nick, paralyzed with paraplegia in 1998 at age 17, heard the news right away: "Right after I awoke from surgery—and my mother was by my side—the doctors came in and they just bluntly told me that I was paralyzed, and that I'd never walk again...that it'd be physically impossible to walk again. And I was devastated and began to hate who I was."

Darren, paralyzed with quadriplegia in 1993 at age 20 resisted the prognosis: "Coming to grips with the idea that I was somehow going to be this member of this group of

quadriplegics, which I'd only heard about, and never, you know, could imagine what it would be. Just me saying 'There's no way in the world I'm going to be one of those'."

Molly, injured in 2005 at age 15 and left with quadriplegia, literally took years to absorb her diagnosis: "From the get-go, I didn't really understand what it meant to have a spinal cord injury, and all the things that it was going to affect. And I think that actually made it easier at the beginning, because I wasn't looking really far ahead in terms of, 'How am I going to college?' and 'How am I going to have a family?' and 'How am I going to do all these really difficult things from a wheelchair?' I just kind of, in my head was like, 'Oh, I'll be better by next summer. If not next summer, maybe the year after. I certainly would be better by the end of high school.' So, it took me a long time to really internalize all the things my spinal cord injury was going to affect. So, I think I came to understanding really slowly. I think it was a good thing."

For Megan, paralyzed with paraplegia in 1995 age 18, what her injury would mean also took a long time to sink in: "The overwhelming sense of—my life is never going to be the same. You know, the acceptance that everything is different. That the way that your family looks at you, the way that your friends look at you, everything is different, and the hardest thing to imagine is that you're ever going to be able to put your life back together again. Initially it's almost unfathomable that you're ever going to have a life. You know, eventually it gets there, but it takes, I think, a very long time."

Perhaps the most valuable thing to take away from these experiences is that regardless of how they were told and when they actually absorbed the news—all the people I've quoted have ended up, leading full and rewarding lives. Like Vicki.

Marie coordinates the SCI mentoring program at a major rehabilitation hospital.

James coordinates all volunteers for a large rehabilitation hospital.

Hector sells urological medical supplies to hospitals.

Darren has an MBA and is an executive at a Fortune 500 company.

Nick is a competitive bodybuilder, wheelchair dancer, and successful motivational speaker.

Joel is social worker in a renal medical facility.

Molly is in her second year of medical school.

Megan has nearly finished her PhD; she is a consultant to nonprofits and government organization on anti-poverty programs.

And I didn't just pick the highest achievers. My sample is drawn from website interviews of people of different ages and backgrounds who got the news

of their injury in different ways, and all of them heard it in their own good time.

So what is the best way to deliver the news? A recent pilot study [1] that surveyed 56 subjects with complete SCIs above T10 found that the majority of patients wanted to know their prognosis early after injury and to get the news from a physician “in a clear and sensitive manner.”

At a plenary session on “Difficult Conversations in SCI Practice” at the September, 2016, Academy of Spinal Cord Injury Professionals Conference, there was general agreement that the way to deliver the prognosis has to depend on the individual. Also, that it is always important to tell the truth in a way that helps the patient develop the understanding that a successful, good life after his injury is possible for him. Sometimes, it is best to deliver the news in pieces, when the patient appears ready to hear it, rather than all at once.

Guest Editor’s Comments

Gayle R. Spill, MD

After reading and rereading these thoughtful pieces on the subject of prognosis disclosure in SCI, one word keeps coming back to me: time. It is clear that time is an important element of this process in many ways. First, physicians and other health care professionals need to take the time to listen to their patient’s questions, fears, and concerns about their injury. Then, we need to take the time to explain the physiology, neurology, and rehabilitation process in a way that makes sense to the patient and at a pace that is comfortable for the patient. It is important that we do this at the right time, when the patient appears ready to hear the information. We need to recognize that the disclosure process may need to happen several times before full understanding is reached. We need to give our patients and their families time to absorb the information and adjust to it. Acceptance and understanding may fluctuate with time and we

This is an issue with which the medical community will continue to struggle; however, it may be comforting to know that based on my research, it seems that how and when patients get the news may not matter nearly so much as one might expect over the long haul. In the end, the fact that the people in this article have gone on to create successful lives after their injuries may simply be a testament to the resiliency of the human spirit.

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have to be patient and generous with our time. Lastly, we have to address the issue of hope, both at the time of diagnosis and throughout a patient’s lifetime. Most people with an SCI never stop hoping for a cure, but with time, they begin to hope for some of the same things that their nondisabled peers hope for, such as success in school and career, good relationships with family and friends, healthy, happy children, and a long life.

The role of the physiatrist is to allow the patient to hope for the cure but not at the expense of ignoring achievable and realistic dreams. Although Ms. Flaum points out that how we disclose the prognosis may not ultimately affect a person’s outcome, it seems clear that many of the patients she quotes have negative memories of the moment in time that they heard the news. I think we should all strive to do better to make that moment less traumatic. As the saying goes, “no one cares how much you know until they know how much you care.”

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