Overcoming Challenges: The Role of Rehabilitation in Educating Individuals with SCI to Reduce Secondary Conditions

D.L. Wolfe, P.J. Potter, and K.A.J. Sequeira

Education is the essence of rehabilitation for individuals after a spinal cord injury (SCI). Yet, there is very little research that examines the specific effects of educational interventions. This article provides several practical strategies and solutions for delivering educational programming that were derived from a study of community-dwelling individuals with SCI (D.L. Wolfe, et al., 2002). This study focused on the "collective wisdom" of individuals who have lived with SCI for some time and examined the particular strategies they felt might have been useful in the rehabilitation process. The strategies presented are designed to address the challenges of readiness/relevance, individual variation, and access. **Key words:** *patient education, rehabilitation, secondary conditions, spinal cord injury*

In the preceding article in this issue ("Challenges in Educating Individuals with SCI to Reduce Secondary Conditions"), we outlined challenges to providing an effective educational experience to assist individuals with spinal cord injury (SCI) prevent or minimize the effects of secondary conditions associated with SCI. The primary challenges identified included the difficulties associated with ensuring readiness and relevance during the time most associated with education – inpatient rehabilitation. Also noted were the increased demands required for managing the complexities of individual variation in learning and systemic issues such as accessibility to services that impede effective learning. In this article, we focus on specific strategies and solutions designed to address these challenges especially as applied to health promotion initiatives delivered during inpatient rehabilitation. The strategies form the basis for the development of the illustrative solutions, however, it should be noted that these strategies could just as easily be incorporated into other solutions that better fit the needs of a particular institution or environment. These strategies were developed from a recent series of studies investigating the collective experience of those living in the community with longstanding SCI in dealing with a variety of secondary conditions.[1]

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Overcoming Challenges of Readiness and Relevance

People who have just sustained a severe SCI must cope with a variety of overwhelming physical and psychological stresses. A certain degree of arousal is a requirement for learning, but stress acts as a major block.[2] In addition, some people may not have accepted their injury as a potentially permanent impairment; this makes information about preventing or dealing with long-term secondary conditions seem particularly irrelevant.

For rehabilitation providers, who have a primary responsibility for providing information to people about preventing secondary conditions associated with SCI, there are essentially two classes of solutions that relate to the issues of readiness and relevance. They can adopt strategies and programs that help individuals cope with and accept information more readily during their inpatient rehabilitation stay. They can provide solutions that enable individuals to find and utilize information more effectively after they are discharged (i.e., after they may have more fully accepted their disability).

Strategies of both types were noted in a recent investigation of community-dwelling individuals in which participants were asked to share their experiences and suggestions with respect to the most effective strategies for reducing secondary conditions.[1] In this study, a recurring theme involved the importance of formal and informal peer supports in the rehabilitation process. Similar findings were reported in a 2-year mixed-method (i.e., quantitative and qualitative) evaluation of community reintegration assessed in people who were 1–5 years postdischarge.[3] It is likely that effective peer support has multiple benefits to individuals with a recent SCI; peer support can help people cope or can help make relevant aspects of information related to self-care or particular prevention techniques. It should be noted that peer support programs are used to varying levels in many SCI rehabilitation centers; although there is some evidence of efficacy for peer support in the management of various chronic diseases,[4,5] there is little clear evidence of specific effects or efficacy in SCI rehabilitation. For the most part, the level of evidence for peer support in SCI rehabilitation consists of descriptive studies or studies that obtain acknowledgment of positive benefits from individuals with SCI.[3,6,7] Programs that utilize peer support must ensure that they are coordinated with and complement the professional psychological counseling and support services routinely used during inpatient rehabilitation.

Another key recommendation from the study of community-dwelling individuals[1] was the importance of delivering information in small chunks and, if possible, picking the time for information dissemination judiciously. Participants often noted feeling overwhelmed by information during inpatient rehabilitation. A specific example relates to the patient education manual that is commonly provided to clients during inpatient rehabilitation. This is often a fairly lengthy document that is given to the client relatively early in the rehabilitation process with the view that it could act as a reference manual describing life in the rehabilitation unit. The document is frequently presented as a manual to describe living with a SCI, including methods for preventing secondary conditions. One recommendation is to reformat the manual to produce a more customizable document (e.g., collated in a binder format allowing easy addition) that

initially is extremely sparse with only immediately essential information. As situations arise, this document can be added to by various care providers or by the client or family members. By "chunking" information in an incremental fashion, there is less chance of overwhelming the client. Throughout the remainder of this article, we will return to and enhance this specific example as other strategies for effective information dissemination are discussed, and we will note how these strategies might be incorporated into this SCI resource binder.

One strategy for information dissemination is the effective use of "teachable moments." Teachable moments are "brief windows of opportunity to educate individuals during routine encounters."[8] It is imperative that rehabilitation care providers embrace this concept as a means of reinforcing the adoption of healthy lifestyle habits. This strategy is consistent with the idea of providing information incrementally (chunking), and it is particularly effective given the competing demands and time constraints inherent in the rehabilitation process (i.e., requirement to provide direct care). The care provider needs to be prepared to take advantage of these teachable moments as they occur.[8] It is likely that much education is currently disseminated by employing teachable moments "on the fly" during inpatient rehabilitation (especially by nurses).[9,10] Program-wide continuing education and planning is required to ensure that all care providers use this and related concepts more effectively (e.g., adult learning principles) and that there is some coordination in implementation.

The SCI resource binder can be a valuable means for reinforcing the concepts imparted during these teachable moments. Care providers should refer to the binder to point out particular learning objectives. If the information is not already in the binder, the provider can add documentation to the binder that outlines the main teaching points, thereby providing an opportunity for further reinforcement of these points. Even in the best learning environment, learners require 5–10 repetitions of new information before it is well understood.[8] This repetition has the added value of increasing the likelihood that clients will view the manual as a "working" resource and possibly return to it after discharge from rehabilitation. This is an important consideration for all strategies or solutions; they should have built-in methods for facilitating knowledge transfer and utility beyond the time of inpatient rehabilitation, when an individual is likely to be more actively seeking information or problem solving.

Another strategy related to the issues of readiness and relevance can be found in solutions that focus on problem solving and in particular those that engender self-directed information seeking or behavior change. Adult learning is more effective if it is problem- and experience-centered and if it is collaborative, such that the teacher can give up some control over the teaching process and can share control of this process with learners.[2,11] The interdisciplinary rehabilitation process is often collaborative in nature and includes mutual goal setting. For example, the client and clinical educator (e.g., nurse or therapist) identify a specific goal that may be amenable to a problem-solving approach. The care provider then acts as a facilitator to help the client find pertinent information, develop possible solutions, and assess possible outcomes. Several initiatives designed to enhance problem-solving skills and thereby facilitate more independent

community living or improve health behaviors have been described in the literature.[7,12] The resource binder can reinforce these strategies. For example, problems typically encountered or information typically sought could be developed into a series of case studies that are adapted to meet the needs of a particular client. These case studies could be in the form of worksheets that help clients keep track of their experiences and record their progress or other important information. In addition, the initial information in the binder should be organized in such a format that it invites feedback or direction from the client as to requests for further information. Ideally, by utilizing a problem-based and client-directed approach in the binder, the clients might sense that they are creating their own unique resource for later use, which might implicitly assist them in regaining control over their lives.

Finally, adults typically learn best when they actively participate in the learning process.[2] This is related to the need for collaboration and is inherent in the problem-based approach noted earlier. This is also related to the requirement that education should focus on what is expected that the patient should do and not just the knowledge.[8]

Overcoming Challenges of Individual Variation

Rehabilitation care providers are particularly cognizant of the challenges associated with individual variation. The literature contains many references to the necessity of providing individualized, customized learning experiences for individuals with SCI.[8,13] The rehabilitation process typically involves many features that are customized to the individual (e.g., goals, treatment plan). However, it is still difficult to meet this challenge in practice. This is particularly true in two areas: (a) the assessment and accommodation for various learning styles, and (b) the creation of specific educational resources that will meet the needs of many patients but will allow individual customization. This latter dilemma is inextricably linked with the challenge of achieving relevance noted in the previous section. That is, if the educational resources or programs are customized to meet the needs of a particular individual, the information is far more likely to be deemed relevant.

Adults will generally learn best in an environment in which different learning styles are recognized and accommodated.[14] For effective patient education, learning styles must be characterized by ways in which individuals most effectively take in and process information.[15] There are various models that attempt to describe the particular features of a specific learning style. For example, the Felder-Silverman model classifies learners as having more or less of the following learning traits that can be assessed with a 41-item questionnaire: sensing or intuitive, visual or verbal, inductive or deductive, active or reflective, and sequential or global.[16] Other more straightforward approaches have been noted in the nursing literature, such as the distinction between visual, aural, and physical (i.e., doers) learners, which can be assessed informally with a few simple questions.[17] The degree by which SCI rehabilitation programs formally assess learning style is unknown, although it is likely performed in an informal manner by individual rehabilitation care providers. In a formal assessment, recommendations can be made with respect to a coordinated strategy across the interdisciplinary team.

After assessment, varied learning styles must be accommodated within the constraints of existing resources (personnel and otherwise). A common solution is the creation of a resource center, which houses an array of preexisting learning resources in a variety of formats (e.g., books, pamphlets, newsletters, videos, software, Internet websites). The rehabilitation care provider may try and ensure that appropriate resources are selected to match the client's learning style. However, to support a problem-based approach to learning, the provider might simply facilitate the client in an exploration of the various resources available.

Some centers have incorporated access to the Internet and the vast array of SCI on-line resources as a part of their education program. If appropriate for the individual, this access has the benefit of facilitating independent information seeking as part of a problem-based approach. The main advantages of Internet access are twofold: (a) there are greater numbers and more variety of resources, and (b) the accessibility of these resources will be relatively similar after discharge, which provides another conduit for information transfer after rehabilitation. The primary disadvantages include the potential of obtaining inaccurate, misleading, or dangerous health information; the possibility for information overload; disorganization leading to difficulties in finding pertinent information; and inaccessibility (due to computer cost, inadequate computer literacy, lack of user friendliness).[18] Therefore, the provider should assist the client in finding good quality information and should continue to work with the client in developing critical evaluation skills when exposed to new information. For a further discussion of Internet information, Cline and Haynes provide an excellent review.[18] In addition, the following online SCI Resource Centers also provide helpful information: the Spinal Cord Injury Information Network (http://www.spinalcord.uab.edu), which is funded through the University of Alabama at Birmingham Spinal Cord Injury Model System, and the Christopher and Dana Reeve Resource Center (http://www.paralysis.org/), which is a program of the Christopher Reeve Paralysis Foundation. These and several other online resources are included in a list of selected online resources at the end of this article.

Although learning style may vary between individuals, it is important to remember that these styles are not meant to represent discrete categories. Learners may have success with various teaching styles and, in fact, may actually benefit from a diversity of approaches. Therefore, it is important that information is conveyed various ways and in a variety of formats, albeit with a focus on methods that match the client's preferred learning style. It should be noted that adults are often visual learners[17] and learn best by doing, which means rehabilitation care providers should incorporate plenty of opportunities for demonstrating, modeling, and practicing of techniques.

The fact that adult learners are often active, visual learners has several implications for the SCI resource binder. At first glance, it may seem that a printed resource such as the binder might only serve a small segment of the population. However, it should be remembered that the binder is more effective when it is utilized as one component in an overall problem-solving approach. In fact, it is best used as an ancillary resource. That is, once a learning objective has been introduced, it could be reinforced with a binder insert that includes appropriate reference

information. As noted previously, the real value of this resource will be felt after discharge, when individuals are in the midst of trying to deal with a particular problem and ready to take on a more active role. If the rehabilitation team has been successful in demonstrating the effective use of this resource, individuals will continue to add to the content of the binder with information pertinent to their own needs and will utilize it for organizing information and problem solving.

In addition to learning style, there are other individual differences that must be considered when planning educational initiatives to help individuals with SCI reduce the impact of secondary conditions. These include a variety of biophysical (e.g., age, physical condition, vision, hearing, pain, fatigue, medication, etc.), psychological (e.g., anxiety, stress, depression, etc.), and sociocultural factors (e.g., occupation, education, culture, religion, language, etc.).[17] Many of these variables may be associated with increased occurrence of secondary conditions[19–21]; some of the variables may affect resource selection or may make modifications necessary to patient education resources (e.g., low-literacy manuals).[22]

Overcoming Challenges of Access and Service Delivery

There are clearly many factors that limit the rehabilitation specialist in the design and administration of effective health promotion programs that are aimed at preventing secondary conditions. It is beyond the scope of this article to address the policy or structural changes that might facilitate a more proactive approach; however, we will present two technology-based solutions for enhancing patients' access to the knowledge of the rehabilitation specialist, who is the most preferred source of information for community-dwelling individuals with SCI.[1]

The first of these solutions, telerehabilitation, has substantial infrastructure requirements, although there are an increasing number of telehealth initiatives across North America. At present, the literature contains only a handful of projects showing "proof of principle" for telerehabilitation applications for SCI[23,24] and other neurological disorders.[25,26] The SCI initiatives used video- or teleconferencing methods to deliver an educational intervention or to extend the expertise of specialized rehabilitation care providers to individuals after discharge as a means of reducing the occurrence of secondary conditions, particularly pressure sores.[23,24] These methods hold particular promise in two areas. First, they should meet the needs of individuals who are currently underserved with respect to follow-up services (e.g., residents of rural or remote areas).[25] Second, there may be particular benefits in providing support and information to general practitioners (GPs) by these means, especially those in underserved areas. Individuals with SCI living in the community have identified GPs as common sources of information about SCI, likely due to easy access, yet they also note the existence of a knowledge gap among GPs regarding specific SCI-related information.[1]

Internet-based applications also have promise for overcoming the challenges associated with clients' inadequate access to specialized rehabilitation services, especially concerning their need for obtaining accurate and up-to-date information about maintaining health while living with SCI.[27] Individuals with SCI living in the community who have used the Internet to find information

concerning health ranked the Internet as the highest quality information source with respect to accessibility and speed and the second highest in information currency.[1] These rankings of information quality were conducted between a variety of potential information sources, including various health care providers, peers, and several mass media sources. As noted earlier, the primary disadvantages of seeking health information over the Internet include potential issues of inaccuracy and information overload.[18] Given this, the profile of information quality noted for the Internet was particularly complementary to the information noted for SCI specialists, who were ranked the highest of all information sources with respect to accuracy, specificity, and currency of information but relatively lower on accessibility and speed.

The implication of these findings is that rehabilitation care providers would be advised to use existing high-quality Internet SCI websites as part of a problem-solving approach with their inpatients. By working collaboratively with their clients and by using high-quality websites, they will be guiding individuals in the use of specific information-seeking strategies that can be transferred postdischarge. A website that can be used in this fashion is the CareCure Community (www.sciwire.org), which was developed largely through the efforts of Dr. Wise Young, a neurosurgeon and preeminent SCI researcher. This is a multidimensional resource consisting of a series of moderated forums on various topics associated with SCI. Users of this resource have the benefits of belonging to a community; they gain a sense of interpersonal connection and obtain the insight of peers who have experience concerning a particular issue. In addition, the website offers specialist-quality information; moderators consist of Dr. Young and a group of experienced neuroscience nurse educators. There are also numerous articles posted to this site that critically review or summarize various topic areas in SCI. Several of these articles are included in the list of selected online resources at the end of this article.

Summary

Effective rehabilitation programs require collaboration among various stakeholders and a clear definition of roles and expectations. The primary role of the rehabilitation care provider is to provide "best practice" treatment and information within a collaborative relationship that facilitates adoption of healthy lifestyle and self-care strategies. The provider must be cognizant of individual barriers to learning and seek appropriate strategies to overcome these. Ultimately, it is the responsibility of individuals with SCI to take responsibility for their own care and health needs. It may seem like a difficult task at first; to facilitate this process, individuals are asked to be active participants in their rehabilitation program. Activities such as mutual goal setting and collaborative treatment planning are intended to promote the clients' sense of self-control. Educational efforts need to be directed at furthering this feeling of empowerment by focusing on proactive prevention, self-advocacy, and self-care.

The various strategies outlined previously are also designed to facilitate the clients' sense of regaining control. It is hoped that there will be improved understanding and adherence to healthy lifestyle practices. An understanding of the effect of educational

interventions on future behavior, especially as it relates to SCI rehabilitation, is lacking. Further research is needed to examine the efficacy of these interventions in reducing secondary conditions or as a means of enhancing quality of life for persons living with SCI.

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SELECTED ONLINE RESOURCES

Online resources pertaining to secondary conditions and of potential benefit to consumers, families, and rehabilitation providers:

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