

Enabling optimal care after spinal cord injury - an online curriculum for personal care assistants

Recorded April 2020 [Listen to it here](#).

JEANNE ZANCA: 00:02

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CAROLANN MURPHY:
00:18

Enabling Optimal Care After Spinal Cord Injury - An Online Curriculum for Personal Care Assistants. Welcome to Kessler Foundation. My name is Carolann Murphy, and I am the foundation's senior writer. This episode features Dr. Jeanne Zanca, senior research scientist in the Center for Spinal Cord Injury Research and co-investigator for the Northern New Jersey Spinal Cord Injury Model System. Dr. Zanca serves as associate editor for the Journal of Spinal Cord Medicine and is a fellow of the American Congress of Rehabilitation Medicine and a member of the ACRM's board of governors. Today we will focus on Dr. Zanca's development of a web-based curriculum for training personal care assistants in the type of care needed by individuals with spinal cord injury. Dr. Zanca is the director of this project which was funded by a major grant from the National Institute on Disability, Independent Living, and Rehabilitation Research. Dr. Zanca will update us on the design of this web-based educational resource and share her perspective on how its utilization can improve quality of life as well as the personal assistance received by people living with spinal cord injury. Dr. Zanca, this project was inspired by feedback from individuals with spinal cord injury who raised awareness of the far-reaching impact of issues related to managing their personal care needs. How will this project help those who rely on others for their daily personal care?

ZANCA: 01:47

We've designed this project to help reduce the burden of training that is currently borne by people with spinal cord injury and their loved ones. The inspiration for the project came from a prior study funded by the Department of Defense in which we had the opportunity to speak with people with spinal cord injury, their loved ones, clinicians, and personal care assistants. And one of the things we heard most frequently was that there's a lot of turnover of personal care assistants, and it's quite common that new assistants have very limited knowledge of spinal cord injury. And this isn't surprising. Spinal cord injury is not a very common condition compared to stroke and dementia and many other conditions with which home healthcare aides and other kinds of personal care assistants may be more familiar. And so we identified a great need to provide some basic information about spinal cord injury to help personal care assistants understand it better and to lay a foundation for the hands-on training that they would receive from their agencies or perhaps directly from a person with spinal cord injury him or herself as they prepare to provide assistance to them in the community.

MURPHY: 02:50

Can you provide a preview of the online curriculum? What will caregivers learn from this course that will help them assist individuals with spinal cord injury?

ZANCA: 02:58

The content for the course is driven by input we've received from several stakeholders, including personal care assistants working on the front lines of care, people with SCI, and their families, as well as SCI professionals. And I should clarify

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that when I say personal care assistant here, I'm speaking about someone who's not already a friend or family member of someone with spinal cord injury who's hired to provide assistance to them in daily activities such as dressing and bathing and moving from bed to wheelchair. So the content of the course that's geared to these personal care assistants is divided into several chapters or modules. The first of these talks about what spinal cord injury is, what the spinal cord injury helps to control, and how spinal cord injuries may happen. The next module talks about the physical functions that are affected by SCI. And then we move onto another module focusing on personal and social challenges created by spinal cord injury. We also address common misunderstandings that people in the general community and in the home healthcare community can often have about people with spinal cord injury, how secondary complications can develop, and what personal care assistants can do to help prevent those. And then finally, we will offer some resources to assist personal care assistants in applying what they've learned and give them some more in-depth information on other supplemental topics, such as tips for building a positive working relationship with their clients with spinal cord injury, helping to manage blood pressure, which is a common problem for people with SCI, equipment and SCI, which is very important for daily life but often involves some specialized things you might not ordinarily see when working with other populations, and tips for safe transfers, which was identified by our stakeholders as a major area of focus.

MURPHY: 04:43

Sounds very comprehensive and most useful to those who will be caring for people with spinal cord injury. How will this resource be made available?

ZANCA: 04:52

Well, we're going to take advantage of the Kessler Foundation Learning Center at kflern.org which has been previously established by other scientists in the organization. And this is a web-based form of education. It's a platform that's powered by Thinkific, one of several different services available to assist instructors in providing online education. And the course will be programmed into that interface so that it can be viewed on any device that's connected to the internet, so a laptop, a desktop, a tablet, a smartphone. And this'll be particularly important because we know that there are a number of individuals in the home healthcare community who may not have easy access to computers but do have better access to smartphones. And so the course will be distributed in a way that will be friendly to users of all different kinds of devices.

ZANCA: 05:40

And there's several strategies that we're going to use to raise awareness of this course. So as you know, Kessler is a member of the Spinal Cord Injury Model Systems program which is a network of 14 centers around the country that provide specialized care to people with spinal cord injury. And so we will use our connections through that network to help individuals with spinal cord injury, their loved ones, and healthcare professionals at those centers be aware of the course. There's also different centers that are accredited by the Commission on Accreditation of Rehabilitation Facilities that have specialized SCI programs of care that we'll reach out to. And we've also partnered with home healthcare agencies. In the project steering committee, we have representatives from BAYADA and from Medside Healthcare, which is very active in the southeastern portion of the United States, and they're advising us on the content of the course and will help us pilot test the course and also raise awareness within their organizations about its availability. And finally, we have

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consumer organizations that we've partnered with on past efforts, including United Spinal Association and the Christopher & Dana Reeve Foundation, that we will connect with to help raise awareness of this course among people with spinal cord injury and their loved ones and other interested individuals. So our hope is that by making this available online in a format that's easily accessible to personal care assistants and sharing it with people at all levels of the rehabilitation continuum, both those clinicians who are working with people with new injuries and helping them transition into the community and individuals with SCI who have lived for many years in the community, that we'll have a broad reach for this program and help encourage its use by those whom it can benefit.

MURPHY: 07:18

Dr. Zanca, tell us about the collaborators that you worked with on this project?

ZANCA: 07:22

This is a collaboration between Kessler Foundation and Shepherd Center. At Kessler, I'm fortunate to work with Drs. Trevor Dyson-Hudson and Denise Fyffe. And at Shepherd Center, I'm collaborating with John Morris who is also a member of the prior project funded by the Department of Defense that laid a foundation for this work.

MURPHY: 07:41

This project update is relevant to our recent experience with the COVID-19 pandemic which has placed new emphasis on healthcare workers and on the advantages of online education. By addressing this important element of daily life for so many with spinal cord injury, this project promises to ease the difficulties of managing personal care for both individuals and their caregivers. This, in turn, will enable people to engage more fully at home, in their communities, and in the workplace. Thank you for speaking with us today, Dr. Zanca. [music]

ZANCA: 08:13

You're very welcome.

ANNOUNCER: 08:15

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