Medical RehabConnection

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Contacts

Chris MacDonell
Managing Director
cmacdonell@carf.org

Mary Jo Fitzgerald
Account Manager
mfitzgerald@carf.org

Cathy Rebella
Resource Specialist
crebella@carf.org

Kelly Silberschlag
Resource Specialist
ksilberschlag@carf.org

Cathy Ellis
Resource Specialist
cellis@carf.org

The *Medical Rehab Connection* provides CARF news and updates from around the world along with information about upcoming educational events, valuable resources, standards updates, and more.

In this issue:
We are highlighting the promising, peer-infused community transition programming implemented by Shepherd Center in Atlanta, Georgia. This programming represents an excellent example of the type of practices that will be outlined in CARF's upcoming spinal cord specialty program standards, due to be released in Standards Manual Year 2017. CARF completed the field review this summer.

Making the shift: Improving SCI outcomes with enhanced person-centered care

Shepherd Center in Atlanta, Georgia, is beginning to share the results from a three-year research project on the outcomes of an enhanced person-centered care initiative (including spinal cord injury peer mentorship) and how those strategies can be affordably replicated elsewhere.

"**It takes a lot** for someone who is going through a major life event, like a traumatic injury, to psychologically adjust to being a different person," says Mike Jones, vice president of research and technology at the Virginia C. Crawford Research Institute, Shepherd Center. Jones is discussing the origins of Shepherd Center's recent research journey, which began three years ago in response to reduced engagement and lower participation in Shepherd's education programs and discharge planning processes for patients with SCI and their families. According to Jones, a number of factors were contributing to the disengagement, namely a reduction in inpatient lengths of stay and growing publicity and focus on physical recovery. "Of course we don't want to dampen someone's hopes," says Jones. "But I think the growing emphasis on a cure, or on recovery of walking, probably

Vicki Scott
Resource Specialist
vscott@carf.org

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delay the amount of time it takes someone to make that shift in their thinking and accept the fact that they are now a person who has to manage this condition for the rest of their lives. To improve engagement, our question became: how do we help these people come to terms earlier rather than later?"

At the time Shepherd Center began to recognize dropping participation rates, it already had comprehensive educational courses and a generalized (versus one-on-one) peer support program aimed at helping patients with SCI and family members during that transformational period. Even though those programs contained thorough information and provided a nurturing environment, there was clearly a need to better engage patients in a manner more specific to them. The challenge was to enhance services to better assist individual patients make sense of their injury and reconstruct their habitual ways of thinking moving forward. This became the focus of a major revision in how Shepherd Center provides patient-centered rehabilitation services to people with SCI.

In 2013, Shepherd Center received a grant from the Patient-Centered Outcomes Research Institute and a gift from the local Robert W. Woodruff Foundation to develop, implement, and evaluate the effectiveness of several enhancements to its discharge planning services. This research project included intensive (one-to-one) peer mentoring, peer-supported education, and development of an electronic patient portal with links to resources supporting self-sufficiency post discharge. Many of these concepts were based on the work of Kate Lorig and her chronic disease self-management program, which involves peer mentoring, peer-led education, and emphasis on specific problem solving.

"It all goes back to the concept that you learn better from a person like you, 'somebody like me,'" says Julie Gassaway, director of health and wellness research and senior clinical research scientist, Virginia C. Crawford Research Institute, Shepherd Center. "A person's perception of their own disability can be influenced by seeing someone else who is working in the hospital and has a disability just like theirs. The perception can go from one of not in any way being able to envision how you could function in this new, injury-influenced life that you're going to lead to seeing somebody who has figured it out and is doing it quite

Seventeen years ago, Minna Hong knew nothing about spinal-cord injury, rehabilitation, or peer mentoring. She was a stay-at-home mom who had been out of the workforce for a decade. But in 1999, she was involved in a rollover car accident that claimed the life of her husband and added her to the population of 450,000 people in the United States living with SCI. Today, she is the SCI Peer Support Manager in Shepherd Center's Transition Support Program.

The road between then and now has been long. Following her injury, Hong's natural feelings of anger and guilt compounded the obstacles she faced in her recovery and education. Despite receiving what she refers to as terrific therapy from Shepherd Center, it was her experience with the peer mentors that truly allowed her to navigate the days, months, and years that followed. "The mentors were the key to my sanity," she says. "I could speak with them without filter and they understood."

But the challenges Hong faced during her inpatient rehabilitation paled in comparison to what would come post discharge. "While in rehab, we are in a cocoon of protection," she says. "But the reality of this injury comes to life when you are at your home, surrounded by things that are familiar to you. It's familiar but not the same. The sense of loss is amplified in the beginning."

Hong actively stayed in contact with her peer mentors–including professional women, mothers, single women, and others–who were

successfully. And perhaps most importantly, is really quite happy."

But what defines success and happiness differs from person to person. For one person, it may mean being active in sports and in the community. For another, it may mean starting a family or going to school and starting a career. The individual needs, interests, and desires of a person can have varying effects on his or her self-evaluation and recovery after an injury. To help a patient come to terms with his or her injury, it is important that services address specific problems and aspirations during the rehabilitation process, which peer support is very effective at doing. What makes the intensive peer mentor program at Shepherd noteworthy is the organized and deliberate way that it addresses each individual patient.

able to provide tips and demonstrate life skills. She vividly recalls having particular difficulty mastering a car transfer–independently getting to and from her wheelchair to a car and loading her wheelchair. She says that watching another person with an injury completing the task showed her it was possible. "Seeing was believing for me."

Proactively staying in touch with her mentors and reviewing educational materials accelerated Hong's progress and led to her becoming involved as a mentor herself. "Having received so many valuable and practical tips from people who are living with SCI successfully, I thought it only fair that I passed the same information along to new patients."

The intensive peer program has four full-time staff mentors (program managers) who recruit, train, and manage a large pool of more than 200 volunteer mentors. They are able to match patients with specific mentors and evaluate the results. The goal is to match patients with a mentor as soon as possible in their admission. The ideal mentor is one who is close to the same level of disability, or in a similar place in life, but has at least several years of experience living with SCI. This is coordinated by keeping a detailed database of available mentors segmented by background information (marital status, age, children, etc.), level of injury, date of injury, type of employment, transportation status, what procedures they have had, topics of interest to them, availability, etc. Once a mentor has been matched with a patient, the program managers follow up with both the patient and mentor on the interaction to evaluate compatibility. "I think the uniqueness of the program is that we have this nice marriage, if you will, between consistent, regular staff members who are employed and people that just want to give back to the community," says Gassaway.

Traditional vs. intensive peer support models at Shepherd

Minna Hong, the SCI Peer Support Manager at Shepherd Center, describes the difference between the traditional and intensive peer programs with one word, "Manpower." The grant-funded research project has allowed Shepherd to infuse peer mentors throughout the rehabilitation continuum, and actively connect with patients in practical ways that were not previously possible. That requires involving a lot of the right people and starts with quality recruitment and training.

"We recruit mentors from everywhere: events, sports programs, schools, and so on," says Hong. "Our team is very savvy in actively recruiting potential mentors. We want mentors who are active in their community and represent success after injury. We decline more than we accept."

Once selected, each volunteer peer mentor is first trained by the Christopher and Dana Reeve Foundation. The new mentor then participates in

Traditional

Personnel: One full-time and one part-time staff position, plus several volunteers
Educational/self-care courses: Clinician-led with peer sit-in, anatomy/physiology focused
Post-discharge support: Invitations to social events and social media groups

Intensive

Personnel: Four full-time staff positions, 200+ peer volunteers
Educational/self-care courses: Peer-led with clinician sit-in, problem-solving focused
Therapy sessions: Co-treatment sessions with clinicians and peers
Counseling sessions: Emphasis on one-on-one or group settings that include peer mentors
Post-discharge support: Weekly contact for 90 days, invitations to social events and social media groups

Shepherd's volunteer training and must pass a background check. Finally, each mentor completes "clinical training," which involves instruction from clinicians and the peer support program managers, attending education classes and meetings, and being observed in interactions with patients. The training of, and services offered by, peer mentors is done in complete cooperation with other clinical departments (therapy, nursing, etc.) and has been integrated into those rehabilitation processes.

"Mentors are the living example of Shepherd Center rehabilitation. We are its product," concludes Hong. "We are fortunate to have cultivated a large group of wonderful mentors from all walks of life, ranging from newly injured SCI survivors to those who have been injured 45 years or more."

But the program goes beyond simply having peer mentors available when needed. In the past, peer support was introduced only when requested by clinical staff, education sessions included peer mentors but were taught by clinicians, and counseling sessions tended to have little peer involvement. With the expansion of the program, the use of peers has been prioritized and the educational approach has shifted to actively address individual problems and solutions. "The focus of our interactions with patients now is to address their issues of that day," says Gassaway. "Let's discuss issues that patients raise rather than provide an extensive physiology lesson on how your body functions before and after injury. We really try to focus on problem solving. What are you struggling with, what has worked for you, what can we help you with, how can we solve it, and let's move on to tomorrow."

"People are pretty focused in their problem-solving strategies," adds Jones. "We're going to go after the information that we want or need. If we don't know that we need it, and aren't sure why we would want it, then we aren't going to learn."

Focusing on problem solving means immersing into the individual challenges faced by patients. It means using common language, real-life application, humor, and personal stories to engage them and their families. It means making time for private counseling and personal connection. The intensive peer support program accomplishes this across a variety of fronts. First the mentors emphasize one-on-one time with patients while admitted plus regular follow-up contact post discharge. Second, peers are incorporated into co-treatment sessions with occupational and physical therapy to demonstrate necessary functions like hand movement or getting from the floor into a chair. Third, peers run support groups and classes on various topics, including men's and women's sexuality, general peer support, and even caregiver support for family members. And, finally, peers are the focal point of patient self-care classes.

Contrasting the old versus new paradigm of educational sessions specifically, Gassaway says, "During the new-style classes, peers introduce the topic of the class (e.g., bladder, bowel, or skin management) with video production and then ask the participants what it is that's bothering them that day, or what concerns they might have. Peers lead the classes,

"The most significant result that Shepherd has been able to demonstrate is that people

which allows them to pull patients into discussions, even if the patients seem reluctant to participate, by engaging them with personal stories about how they self-manage. Often these stories are funny, which helps to put everyone at ease and feel comfortable discussing sensitive subjects. The patients are interested because they want to be able to do the same things for themselves. That's very different than sitting in a lecture and having an able-bodied clinician tell you what to do."

who received intensive peer support have fewer rehospitalizations than those who don't."

Another component of the peer support program at Shepherd, and one necessary to ensure long-term success, is continued guidance in community and other familiar settings. Peers assist therapists in taking patients into real environments, such as restaurants, malls, or city buses, to demonstrate the importance of what is being learned in therapy sessions. The lessons range from overcoming unexpected obstacles (e.g., lack of curb cuts, inaccessible doorways, or how to remove money from your wallet) to learning practical self-advocacy skills. Peers also host organized social events in the community to engage patients with community members and help develop new networks of support. The overarching principle is to 'meet the patients where they are.' In addition to the major approaches already outlined, mentors encourage conversation during admission and after discharge through emails, phone calls, and a dedicated Facebook page. Informative videos (produced by the peer support team) and interactive dialogs are very effective in continuing learning and support that began during inpatient rehabilitation.

Gassaway sums up the philosophy of the peer support program as follows: "You become more confident when you work more on problem solving on things that matter to you, things that you are worried about, and quite frankly that you know are going to happen. So if you hear about how other people successfully manage them, and you are pretty confident that you can manage them too, then that can really reduce your reliance on the healthcare system."

The enhanced person-centered care approaches implemented at Shepherd Center are proving to be effective. Over the past three years, the research branch of Shepherd Center, the Virginia C. Crawford Research Institute, has conducted rigorous research to evaluate the multiple components of the initiative. Preliminary findings are compelling and all analyses are projected to be complete by August 2017.

Response Shift Theory and Transformative Learning

The person-centered care initiatives at Shepherd Center were influenced by two important concepts: Response Shift Theory and Transformative Learning. These related concepts both deal with psychological adjustments that people make around self-worth, confidence, identity, and willingness to change.

Response Shift Theory seeks to measure shifts in a person's self-evaluation of specific measures (like confidence or satisfaction) in response to changes in their internal standards or values.

Transformative Learning seeks to understand the process by

To evaluate the peer mentorship program, the clinical trial included 158 patients randomized to an experimental or control group. The experimental group received the intensive peer mentorship while the control group received traditional peer support. The mentors met one-on-one with every patient in the experimental group for, at minimum, an hour a week while admitted plus follow-up contact each week for 90 days post discharge. All patients completed telephone surveys at 30, 90, and 180 days post discharge to report on utilization of healthcare services (including rehospitalization) and their perceptions of self-efficacy (confidence in managing injury conditions), depression, community participation, and quality of life. The most significant result that Shepherd has been able to demonstrate is that people who received intensive peer support

which adults alter thinking about themselves and their lives in the face of new and ongoing challenges.

According to Transformative Learning, a person trying to make sense of a traumatic injury, such as SCI, will initially attempt to use habitual frames of reference to evaluate and perceive what the impact will be on their life. That person's readiness and willingness to reconstruct their ways of thinking can affect engagement with new information and, by extension, their ability to self-manage disability and life goals in the future. In short, it affects that person's ability to make a positive response shift. Understanding this process means that services can be developed in response to life-altering events to help people come to terms sooner with an injury.

have fewer rehospitalizations than those who don't. The data also show a positive increase in self-efficacy measures, which translates into improvement of a person's ability to self-manage. These findings are huge for other rehabilitation providers considering a peer support program of their own but questioning how to do it and whether it is worth the cost. When coupled with that fact that the program aligns with components of the Affordable Care Act, this type of peer support programming represents a worthwhile investment for other operators to consider. Of the findings, Jones says, "This is really something that others will want to replicate. There's an initial investment and some maintenance costs, but it's not expensive if you consider the reduction in hospital readmissions."

For evaluation of the peer-supported education program, patient care classes were videotaped and reviewed to measure points of positive and negative engagement. Positive engagement included activities from attendees such as asking questions, participating in conversations, or certain gestures. Examples of negative engagement would be use of a cell phone or napping. Evaluation was conducted on both the new, peer-led problem-solving classes and the traditional, nursing-led didactic lectures. Shepherd has observed significantly more positive and fewer negative points of engagement in the new-style classes compared to the old. Patients also reported they enjoyed the new-style classes and participated more actively. "It's a more effective means of education, and you have greater levels of engagement," says Jones. "It just makes intuitive sense that this would be the direction to go in."

These results give Shepherd Center reason to actively share not only the results of the study, but also the processes. Gassaway, Hong, and Jones have been on a tour of national conferences to present the findings and consult on how to implement similar programs. This fall, they will be presenting at ASCIP and ISCoS conferences in September and the ACRM conference in early November. They will also be conducting a CARF webinar titled *Peer Mentoring and Patient-Directed Transition Support After Traumatic Spinal Cord Injury* in September. As analyses are completed on additional measurement categories, those findings will be included in their courses.

As healthcare fields are moving further away from the historical fee-for-service paradigm, providers must make active efforts to upgrade services to focus ever more on outcomes. Peer support programs offer potentially win-win solutions for providers to successfully navigate the changing healthcare environment and push the envelope of person-centered care in a way that makes fiscal sense. "Of course, our peer programs will continue at Shepherd after the expiration of the grant funds," says Gassaway. "But others want to know; how do you pay for it? We believe the positive outcomes demonstrate that value, and a lot of dissemination will help others to see it as well. It's an approach that is beneficial both to patients and families and the staff that provides care."

The patient portal

The final component of Shepherd's patient-centered care research project was the creation of a patient portal. In a single place, this 'electronic notebook' provides patients and families with many of the tools needed to manage the multiple aspects of traumatic injury. This includes current lists of medication, equipment, and supplies; contact information for pharmacies, suppliers, and other providers; and a brief medical profile describing a person's injury. The portal can be populated by Shepherd (with discharge information such as instructions, medication lists, summaries, and advance directives); the electronic medical record system; or patients, caregivers, and clinicians themselves with links or documents that are meaningful to the patient. The portal also provides links to many resources that may be helpful in transitioning back to community living. All information in the portal can be shared with other healthcare providers or caregivers.

Meet the contributors

Michael L. Jones, Ph.D., FACRM
Vice President, Research & Technology Director
Virginia C. Crawford Research Institute, Shepherd Center

Dr. Jones is the vice president for research and technology at Shepherd Center and co-director of the Wireless Rehabilitation Engineering Research Center, a joint research program of Georgia Tech and Shepherd Center. His research interests address the design and management of programs and services that promote full inclusion of people with disabilities. Prior to joining Shepherd Center, he was executive director of the Center for Universal Design at North Carolina State University. Since 2012, he has served as a scientific reviewer for PCORI's Communication and Dissemination Research program. He is also a longtime CARF surveyor.

Julie Gassaway, MS, RN
Director Health and Wellness/Senior Clinical Research Scientist
Virginia C Crawford Research Institute, Shepherd Center

Ms. Gassaway is the director of health and wellness and a senior clinical research scientist at Shepherd Center. Julie has been involved in clinical outcomes research for more than 25 years, with the past eight focused on spinal cord injury rehabilitation. Current funded projects focus on patient-centered care management and research for persons with disabilities. She has authored over 60 peer-reviewed publications and serves as a reviewer and occasional guest editor for several rehabilitation journals.

Minna A. Hong
SCI Peer Support Manager, Transition Support Program
Shepherd Center

Ms. Hong has fifteen years of experience working with the SCI population. She has been interviewed for and written articles in over fifteen national publications on living with SCI and related topics. She has lectured a series on relationships after SCI for workers' comp adjusters;

created an email listserv of SCI peers to gather and share information; helped develop peer-centered education modules; and established women's, Latino, and caregiver support groups. She has also guest lectured at several Georgia universities about SCI related topics.

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September 22, 2016
Peer Mentoring and Patient-Directed Transition Support After Traumatic Spinal Cord Injury

CARF 101 Training:
A regional CARF 101 is coming up.

September 29–30 — Grand Rapids, MI
MED 101: Preparing for Successful Accreditation in Medical Rehabilitation

As the ability to be away from work becomes more challenging, CARF is exploring new ways to provide CARF 101 training. Stay tuned for more information on the 2016 training events.

CARF needs you!

We ask our accredited organizations to seek feedback from their stakeholders, and CARF embraces this same philosophy. We are interested in hearing your thoughts, ideas, and suggestions about this newsletter.

If you are interested in contributing to this newsletter please contact either Chris MacDonell at cmacdonell@carf.org or Kelly Silberschlag at ksilberschlag@carf.org.

If you have feedback or would like to contribute to future newsletters, please contact Kelly Silberschlag.