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eventeen 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 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.
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

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**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,
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.

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.

The patient portal 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 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

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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
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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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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.