



Patient-to-patient coaching catches on

By Jerry Berger | June 8, 2018

Across the nation, care organizations of all sizes and missions are tapping a vibrant resource to better support patients and improve outcomes: other patients.

Whether it's a new parent looking for support, an orthopedic patient prepping for surgery, or a family member struggling to help a relative with a devastating new diagnosis, patients who have "been there, done that" are proving to be an excellent first line of defense in providing empathy and advice when patients need it most.

"It is an ancient instinct to connect with other people," says Susannah Fox, a former healthcare chief technology officer who studies peer-to-peer interactions in the electronic era.

A 2011 Pew Research study found that professionals hold sway on technical issues, but peers are better at helping

with more personal issues, such as coping emotionally with a health issue.

"Clinicians can tell a person what to take; a peer can help someone understand why and how best to take it," Fox says.

In sync with organizations like Virginia Mason Health System, which offers peer-to-peer support and guidance to orthopedic patients before and after their surgical procedures, health systems and advocacy organizations are harnessing the power of patients through moderated online message boards, facilitated face-to-face conversations, or a combination of the two.

Here are five such organizations committed to improving their quality of care, one relationship at a time.

Massachusetts General Hospital

Peer counseling is one option in Massachusetts General Hospital's toolkit for helping people with substance use disorders. The Boston hospital employs 10 recovery coaches, mostly in primary care but also in outpatient settings, including a new clinic for mothers and families affected by substance use disorder. The coaches have sustained recovery or remission themselves and have received state-sponsored recovery training, as have the full-time recovery coach supervisor and clinical site supervisors.

Sarah Wakeman, medical director of the Substance Use Disorder Initiative and the Addiction Consult Team, says the coaches "offer the type of support and perspective that we can't offer in the medical system, that sort of true kind of shared experience of knowing what it's like to be in the shoes of patients and being able, because of that, to build a relationship and communicate with patients in a way that healthcare providers really can't."

That support includes things not traditionally in the purview of the doctor's office, from helping patients get a picture ID to going to court with them.

Wakeman says patients who connect with a recovery coach have a decrease in hospital admissions and an increase in outpatient appointments with primary care and behavioral health specialists. And patients taking buprenorphine for opioid use disorder who worked with a coach were able to stay sober for a longer duration of time, Wakeman says.

Centering Healthcare

The CenteringPregnancy model of care offers expectant mothers both one-on-one time with a healthcare provider and group learning in a facilitated setting.

Started by midwife Sharon Schindler Rising in the early 1990s, the non-profit Centering Healthcare Institute now reaches more than 60,000 women and parents-to-be each year in more than 500 sites nationally, says communications manager Nicole Lewis.

Centering follows the American College of Obstetrics and Gynecology guidelines of 10 prenatal visits after the first trimester, during which women meet in group sessions facilitated by a provider and a nurse or other support staff trained in Centering. Topics include stress management, labor and delivery, and breastfeeding – subjects that sometimes get lost in an individual care model.

The physical space typically has a circle for group interactions, an area for self-assessment (women are encouraged to engage in their own care by taking their own weight and blood pressure), and a soft barrier area of the room for belly checks.

The Centering model is not just good for patients, it benefits providers as well, who find that "doing group care brings more joy and gets them back to the feeling of doing care" in a less-rushed timeframe, Lewis says.

Data show the model reduces the incidence of low birth weight and preterm births to below the national averages and raises the frequency of breastfeeding. In addition, the risk of admission to a neonatal intensive care unit during the first year of life is reduced by 63 percent.

A pediatric model called CenteringParenting continues that pregnancy model into the first two years of life, bringing together parents with caregivers in the same facilitated structure.

A third model ready to launch, CenteringHealthcare, is an adaptable model for group care that can be used for other health conditions, in particular around chronic disease and other patient populations.

Alzheimer's Association

The Alzheimer's Association offers moderated online support for patients and caregivers as well as a 24-7 help line and face-to-face groups in its 78 chapters throughout the country.

Its ALZConnected moderated message boards are a great resource for caregivers who want to be able to post a question any time, says Beth Kallmyer, vice president of care and support.

If you post a question there, you'll get a response ... sometimes within an hour," Kallmyer says, adding the boards enable new or overwhelmed visitors to anonymously "lurk," get a feel for the discussions or take advantage of ample archives. "Any question or problem that a family is dealing with, you can do a search and see multiple peer responses from other people in that situation telling them what they've done to handle the situation."

The boards are moderated by trained peer volunteers, "super users" who apply for the position, attend monthly meetings and welcome new users and refer them to programs. Moderators follow strong community guidelines that encourage civility and support while also correcting what little bad information that surfaces. "We make it clear it's peer information. They correct each other."

While the association has not done specific research on efficacy, Kallmyer says, the boards are popular: Based on data from fiscal 2017, the boards drew 891,887 total visits, with 407,635 unique visitors and 5.8 million pages viewed.

Dana Farber Cancer Institute

At Boston's Dana Farber Cancer Institute, trained social workers conduct scheduled sessions with groups of patients coping with women's cancers.

While peer-to-peer groups and social media forums have value, women with a diagnosis of gynecologic cancer, whether in active treatment or years later, need regular, facilitated support, preferably in the familiar surroundings where they receive their care, explains Bebe Nixon, MSW, who leads support groups at DFCI.

Nixon says facilitation is crucial for the patients she works with, particularly because "recurrence is so unfortunately common for these cancers."

"We're dealing with a population that is always going to be coming back to the hospital for care or for at least monitoring," says Nixon. "The looming possibility that they will have a recurrence makes them both vulnerable to anxieties and concerns about where they are, and also very open to seeking support from fellow cancer patients."

A structured, facilitated group offers safety and stability, giving members more confidence to share powerful intimate thoughts in an environment where someone is available to make sure that things don't get too emotional. Nixon says DFCI has not done any studies on the success of the model because the "data sample is small and constantly shifting," and it would be difficult to codify highly subjective experiences into a testable model of outcomes.

That said, Nixon knows anecdotally that patients appreciate conversation that stays focused on their concerns in a group that's coached to listen, learn and share experiences and compassion.

Rush University Medical Center

A five-year study underway at Chicago's Rush University Medical Center aims to weigh the benefits of home-based care for advanced Parkinson's patients against the increased demand placed on their caregivers.

Jori Fleisher, M.D., a neurologist and the study's principal investigator, says the research pairs a current caregiver with a mentor – who either is actively caring for a Parkinson's patient or has in the past – to model active listening and engagement, including establishing and maintaining boundaries. Each patient-caregiver pair participates for one year, she says.

The NIH-funded longitudinal study focuses on a number of outcomes including caregiver strain, anxiety and depression. It is also gathering data on the Parkinson's patients themselves, including quality-of-life measures and whether and when they transition from the home to an institution, says Fleisher, who also holds a master of science degree in clinical epidemiology.

A 16-week structured curriculum enables caregiver and mentor to connect in person or with a computer tablet via a videoconferencing app. The program is in addition to the regular support groups offered by Rush, based on the recognition that Parkinson's experiences vary, depending on the stage and patient age at the onset of the disease.

"We're hoping that by providing support from someone who's really been there – contemplating putting a loved one into an institution and having to cope with that decisions – we're really hopeful this can shed some light on Parkinson's patients but on people with other diseases as well."

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