

CARDIOLOGY NEWS

Close Family Members or Cosurvivors of Cardiac Arrest Patients Need Support

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Still reeling from having to perform cardiopulmonary resuscitation on her husband, who experienced a sudden cardiac arrest in the middle of the night, Kristin Flanary, MA, was asked to wait alone in a room without cell phone reception while clinicians at the hospital cared for her husband.

"They cut me off from my entire support system and from all the people that I was supposed to be relaying information to who were waiting on the edge of their seats to find out if our loved one was going to survive," Flanary said. Because of the hospital's COVID-19 restrictions, she was asked to leave the hospital while walking the halls searching for a cell phone signal.

Flanary, who is also known as Lady Glaucomflecken online, said what she experienced at the hospital is an extreme example—exacerbated by pandemic restrictions—of the sometimes-insensitive treatment of families and loved ones of patients experiencing cardiac arrest. She noted that clinicians and health systems too often fail to address the needs of family members or other surrogate decision-makers who face difficult decisions for their loved ones while coping with the aftermath of a cardiac arrest.

"Family members are experiencing trauma and are likely in shock,"

Flanary said. As growing numbers of patients survive cardiac arrest as a result of improvements in care,¹ Flanary said it is essential for clinicians to recognize and address the needs of the growing ranks of "cosurvivors." Other advocates, clinicians caring for patients experiencing cardiac arrest, and she are working to raise awareness and provide cosurvivors with the tools and resources they need.

SHARED TRAUMA

After 2 to 3 days of uncertainty about her husband's condition, Flanary received news that her husband, Will Flanary, MD, was neurologically intact. Dr. Flanary is also known as Dr. Glaucomflecken, an ophthalmologist and comedian famous for his online videos about medicine. After he was discharged from the hospital and she shifted gears into a longer-term caregiving role, Flanary continued to experience distress. She explained she could not process information or hold conversations well, and her friends said she had a "ghost-like" look in her eyes.

"People expected me to be relieved because he came home and was okay," Flanary explained. But Flanary said she struggled to sleep and process what she had experienced and remained on high alert.

Many cosurvivors feel the same. A study presented at the American Heart Association's 2023 Resuscitation Science Symposium that surveyed 163 close family members of cardiac arrest patients shortly before discharge found high rates of psychological distress from the uncertainty experienced throughout the illness trajectory.² In fact, two-thirds of the study participants reported experiencing anxiety; more than half had signs of moderate depression; and almost one-third had symptoms of posttraumatic stress disorder.

"Cosurvivors experience psychological distress at an equal if not greater extent than cardiac arrest survivors due to the fear of the unknown, the lack of information, and the life changes that result from this traumatic event," said the study's lead author, Sachin Agarwal, MD, MPH, an associate professor of neurology and director of the NeuroCardiac Comprehensive Care Clinic at Columbia University College of Physicians & Surgeons in New York City. "[Clinicians] have to be compassionate, empathetic, and provide as much information as possible to reduce family members' uncertainty in the first weeks after cardiac arrest."

Recent literature reviews show that distress can often be long-lasting as cosurvivors manage their

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feelings in addition to their loved one's ongoing care.^{3,4} Matthew Douma, MN, a clinical nurse specialist and team lead for the general systems intensive care unit at the University of Alberta Hospitals, noted that 1 in 5 cosurvivors may have prolonged grief.

"You have this incredibly stressful experience, and you don't have anyone to take care of you or acknowledge you, and after you go home, there is no additional support," Douma said. "It all starts with seeing and hearing these people and [recognizing their distress]."

CARING FOR CAREGIVERS

Agarwal said it is vital to consider families' needs at every point in the care continuum: from emergency medical services to the emergency department and the intensive care unit and after hospital discharge. His colleagues and he have integrated family care into their NeuroCardiac Comprehensive Care Clinic program. Attending to the needs of the families of survivors is also emphasized in a 2020 scientific statement from the American Heart Association that highlights the importance of building care for family members into cardiac arrest care.⁵

"They are patients, too, and they need to be treated as cosurvivors. Understanding the journey, from being a close family member to then a caregiver and later a cosurvivor, is essential to create the most efficient system of recovery," he said.

Agarwal said there is an essential role for primary care physicians to play in addressing the mental health needs of the family members in the aftermath of a cardiac arrest. Douma said hospitals must have systems, policies, and infrastructure to support family members. He said people also need places to sit, charge phones, and store personal possessions; bathrooms; and potentially kitchen access. He noted that some families want to be present during resuscitation efforts and oth-

ers may want to be nearby and have someone to provide support or information; hospitals need policies and protocols to support these requests. Individuals who are not at the hospital also need information and support by phone or video. He said that assigning a trained family liaison is one approach to consider to help meet the family's immediate needs.

Flanary agreed that basic accommodations such as having a cell signal or a comfortable place for a family member to sleep are essential. She also suggested having a designated person such as a social worker, chaplain, or even a palliative care team member provide family support. She said only one person—an intensive care unit nurse—asked how she was doing during her husband's hospital stay. The nurse acknowledged the difficult situation and told her she was doing a good job.

"It's just little things like that that indicate there is a place for you here and that we understand that what you are going through is difficult," Flanary said.

DECISION SUPPORT AND RESOURCES

Families also need good information and decision-making support. A survey of a diverse cohort of 550 family members found that information was their top need.⁶ In fact, two-thirds of respondents ranked it as their top need. The survey was led by Agarwal's NeuroCardiac Comprehensive Care Clinic research and patient-family stakeholder team.

"Family members dealing with their own trauma are thrust into the role of being a surrogate decision-maker for the patient," said Sarah Perman, MD, MSCE, an associate professor of emergency medicine at Yale School of Medicine in New Haven, CT. "They must make complex decisions with significant uncertainty about the patient's outcomes. Multiple family members are often involved in the decision-

making, requiring individuals to try to relay information they hear from clinicians."

To help family members make solid and informed decisions, Perman and her colleagues collaborated with experts in shared decision-making to develop printed materials that family members could use and share.

"These materials are focused on helping family members understand the complexities of post-cardiac arrest care and put it in a format they could share with others. This helps to strengthen the patient and primary caregiver's support system," she said.

Perman recently presented the results of a pilot trial testing the materials at the American Heart Association's 2023 Resuscitation Science Symposium.⁷ The trial enrolled 41 surrogate decision-makers who completed a survey before and after receiving the materials. Analysis of the surveys found ≈30% improvement in the surrogate's knowledge after receiving the materials; 85% said they liked the materials; and 91% said the materials made decision-making easier. Participants also reported that the tool helped them formulate questions for the care team.

"Families want information and transparency," Perman said. She said they provided clear and complete information about what was happening and the scenarios that they and their loved one might encounter.

Perman and her colleagues included an acknowledgment of surrogate decision-makers' emotional distress or feeling unprepared to make difficult decisions for their family members in the tool. She next plans to study whether the tool helps reduce symptoms of anxiety or depression in surrogate decision-makers and whether the tool helps improve patient outcomes.

To make information widely accessible for cosurvivors, Agarwal, Douma, and Kristin Flanary helped cofound an online informational

resource called Heartsight that provides comprehensive information and support for anyone affected by cardiac arrest, including survivors and cosurvivors.⁸ The multidisciplinary Heartsight team, including physicians, nurses, psychologists, social workers, cardiac arrest survivors, and their families, translated the scientific evidence into language that is accessible for patients and family members and blended this information with other survivors' and family members' lived experiences. Together, they prepared easy-to-understand, evidence-based information for anyone affected by a cardiac arrest, including survivors, cosurvivors, witnesses, bereaved individuals, and health care professionals. It is free and available in English, Spanish, and French.

Heartsight's content highlights and addresses key moments when people affected by cardiac arrest feel most uncertain. The site tackles many questions that individuals may have after a cardiac arrest, for example, questions about what they saw, heard, or felt while giving

cardiopulmonary resuscitation; how to talk with their loved one when they wake up; and how to prepare for hospital discharge. Agarwal and his colleagues at Columbia University Medical Center are conducting a randomized trial of Heartsight's impact on family members' psychological outcomes after cardiac arrest.

"Heartsight is the resource I wish I would have had," Flanary said.

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