Nurturing a Collaborative Culture

By Diana Mahoney

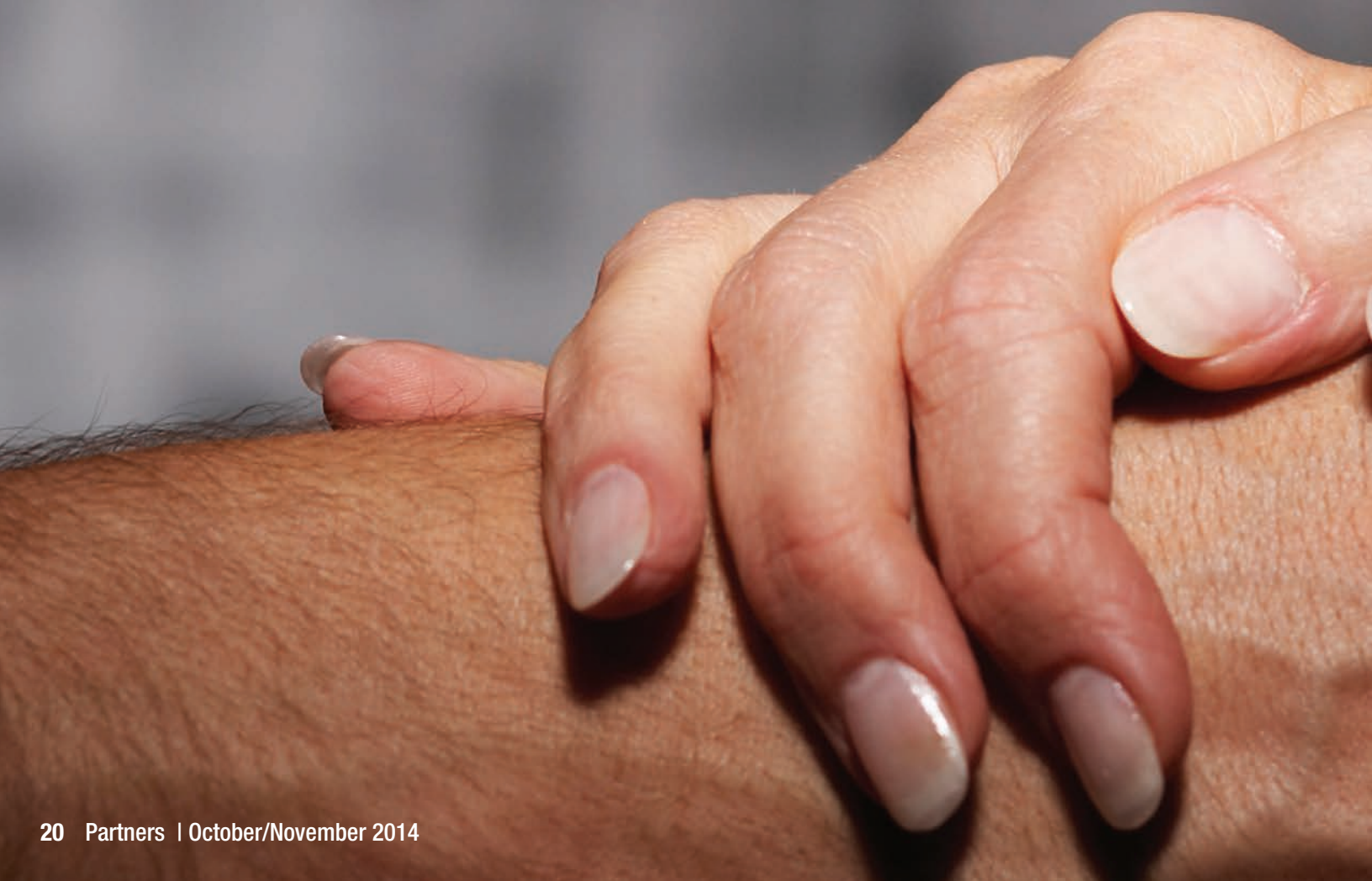
A novel approach to engaging family members in patient care activities brings family-centered care to the ICU.

The menu given to family members of patients in the Weinberg intensive care unit (WICU) for surgical oncology at Johns Hopkins Hospital is unlike any they've probably seen before. It doesn't list food options, nor does it ask about environmental preferences. Instead, it offers opportunities for family members to become part of the patient-care team.

Called the Family Involvement Menu, the tool lists 10 daily care activities that family members are invited (but not required) to help with, ranging in intensity from pillow repositioning, feeding assistance and range-of-motion exercise to providing necessary oral care for patients on ventilators to prevent life-threatening infections.

"The idea is to acknowledge that patients' families and loved ones are very much the experts in the room when it comes to knowing what they want and need," according to former WICU nurse Rhonda Wyskiel, who currently serves as innovation coordinator for the Johns Hopkins Armstrong Institute for Patient Safety & Quality. Wyskiel conceived the menu idea and developed it in collaboration with other nursing staff in the 20-bed unit.

The menu has become a key intervention the Armstrong Institute's Emerge Project to redesign ICU care funded with a $9.4 million grant from the Gordon and Betty Moore Foundation. It is



an example of the kind of disruptive innovation the WICU has become known for in its journey to nurture a patient-centered culture.

"When the WICU opened in September 2000, we decided to challenge the status quo and open up our visiting hours to 24 hours a day, seven days per week," said Wyskiel. "There was resistance from some staff initially. This was a radical change—we were moving from 15-minute visiting periods, two times per hour, to where family members would sometimes be sleeping overnight in the ICU. There were questions from other departments and leadership about this decision, but those who stood on the periphery and weren't sure about it ultimately embraced it when they realized its value [to patients and families]."

The increased presence of family members in the unit made the possibility of engaging home caregivers and family members in daily care activities a practical option, both for the family members and for the nursing teams, Wyskiel said. "If you think about it, often some of these family members have been taking care of the chronically ill patient at home for years, and here we are just putting them in the corner, where they often felt helpless."

It was her first-hand knowledge of that feeling of helplessness that prompted Wyskiel to consider ways to better engage family members at the bedside. When her own mother was being treated in the intensive care unit of a community hospital, "I just wanted to be with her, to brush her hair, which was our ritual, but I was told I wasn't allowed to touch her because I might agitate her. And I was a nurse!"

The idea for the Family Involvement Menu grew out of that experience. "The [WICU] leadership embraced and expected family-centered care, so it was an environment and culture that embraced this idea," Wyskiel said.

The first step in the development process was an engagement exercise that was administered to unit staff. "This allowed us to provide results back to the staff that reflected what they, as a patient, would want if they were in the bed," Wyskiel said. "Not surprisingly, the results suggested that they wanted their families involved in their daily care."

When she polled families on the unit to determine their current involvement in patients' daily care at home and to gauge their interest in becoming actively involved at the hospital, "everyone wanted to do something, they just didn't know how they could help."

After collecting feedback from staff regarding the types of care activities they would be comfortable educating and engaging the families in, "we narrowed the list down to 10 'cares,' and developed education and scripting for the nurses, and provided an opening statement on the menu as an invitation to families to help us care for their loved one," Wyskiel explained. "We made sure all staff were aware of the kick-off date and hung a laminated menu in each room next to a dry erase marker, so it could be reusable."

Prior to implementation, one of the biggest conceptual barriers was the fear of causing harm

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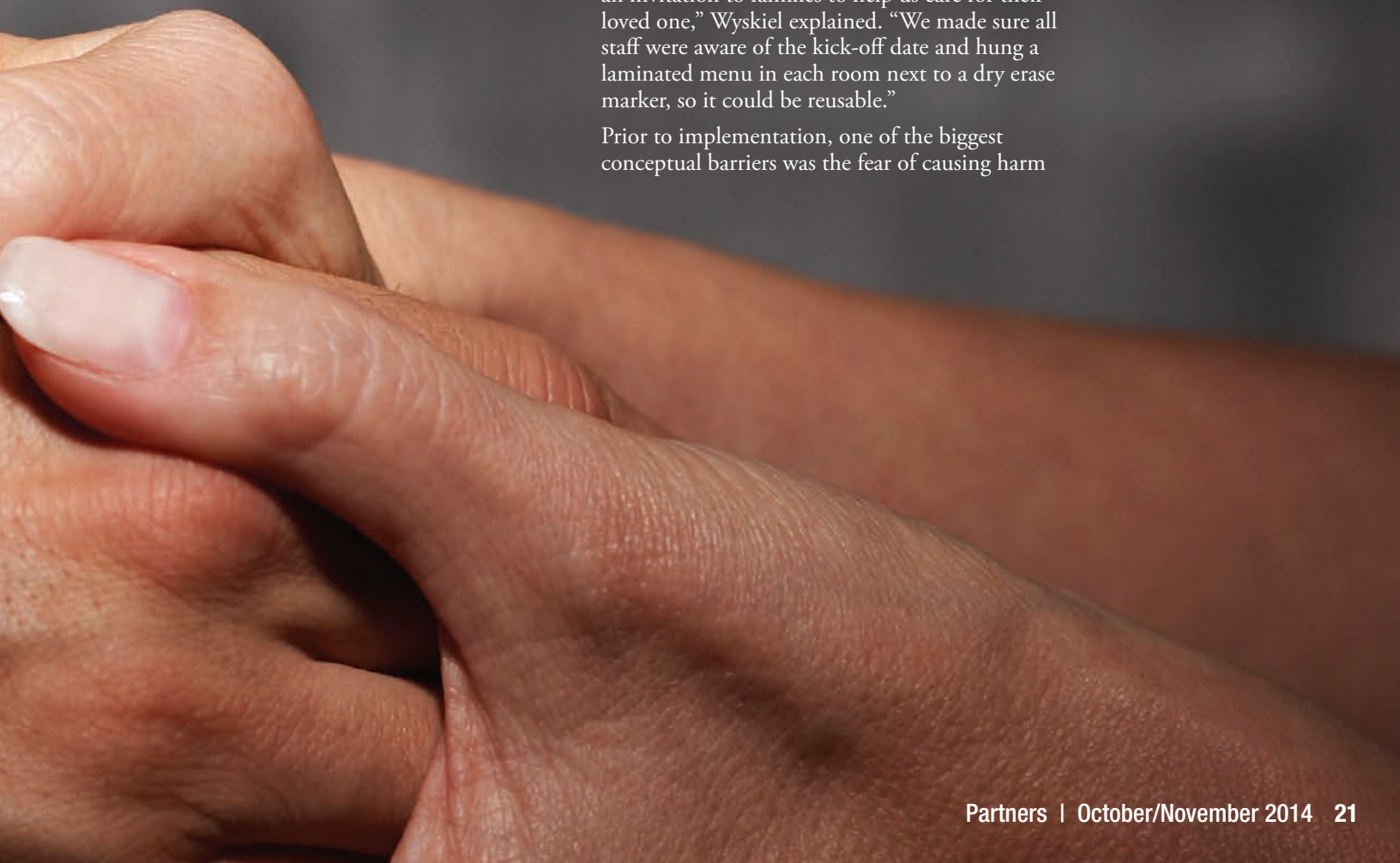

to patients. "Some of the staff worried that family members would do something wrong, while some family members were concerned they might hurt the patient," Wyskiel said. "In reality, Risk Management has been involved in this and they've given it a very low rating for risk. And to date, we haven't ever had an issue that can be linked back to the menu or to family member involvement."

What can be linked to family engagement, however, are some "stunning" results, said Wyskiel. "The families love it and the patients and nurses feel the benefit." For example, one of the menu items is range of motion, which helps increase early mobility. This is important for getting the patient out of the ICU quickly, but nurses don't always have enough time to walk their patients. "Now you see family members walking up and down the hallway them."

Similarly, family members who choose to provide oral care for patients who are on ventilators are taking a time-intensive task off of nurses' to-do lists. "Oral care has to be provided many times a day to prevent infection. When a family member takes over this job, it frees nurses to focus on other patient care activities," Wyskiel said.

Despite some initial hesitation, nurses on the unit like having the families engaged, and at the bedside. "We believe the patients are benefitting physically from their touch and emotionally from their presence," said Wyskiel. "And overall, as the families become more involved and educated about the patient's condition, the patient is that much more equipped to make the transition to the inpatient floor and then home."

Although the Family Involvement Menu is generally well received, "the level of involvement varies—some family members want to be very involved, some want only minimal or no responsibility. It depends on their comfort level,"

Wyskiel said. "When they do engage, it makes them feel empowered and it promotes a sense of trust and mutual respect between family members and care providers."

Earlier this year, the WICU received the Society of Critical Care Medicine's 2014 Family-Centered Care Innovation Award in recognition of its efforts to engage and partner with families of critically ill patients. In addition to round-the-clock visiting hours, the WICU also includes family members on daily rounds, and staff will bring family members to the patient's bedside during emergency situations. Additionally, through a program called the Family Meeting Project, the family of any patient that has been on the unit for more than seven days meets with the patient's full care team for a status update and to discuss treatment goals and next steps.

For her part, Wyskiel is working with other units in the organization and other health systems nationally and internationally that have expressed interest in implementing the Family Involvement Menu. "What I've learned from my work with other groups is that you have to wait until people want this tool. It doesn't work to push it from the top down if the culture of the unit or organization isn't ready for it," she said.

The menu itself is a work-in-progress. Families are always encouraged to suggest different care activities they might like to be involved with. Unlike some menus, this one accommodates special orders, Wyskiel said. "Nothing is off limits, even if you don't see it on the menu."