

Tracing the 'blurry line' between hospital and at-home care

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(PhysOrg.com) -- When patients come home from the hospital after major surgery or a transplant, they often are not well enough to care for themselves, and more importantly, have complex medical needs that need to be monitored by others.

Family members and friends often step in as the “unrecognized long arm of the [hospital](#),” because specialized home nursing care can be too expensive, says Cameron Macdonald, an assistant professor of sociology and a scholar with the Institute for Clinical and Translational Research.

Macdonald has long been interested in the “blurry line” between hospital care and that given at home, which, she says, “we understand as being things we do out of love, not out of professional ability.” She learned about that line firsthand after her late husband received a [bone marrow transplant](#) in 1999.

With a grant from the National Institutes of Health, Macdonald interviewed 30 families from Wisconsin and the Upper Peninsula of Michigan before bone marrow transplants, during their hospital stays and once patients returned home, following the families for more than two years.

Bone marrow transplant provides a good case study because of the complexity of care required once the patient returns home, she says.

“It’s extremely risky. So if you make a mistake the results can be really

devastating and even life threatening,” Macdonald says. “They’re sort of like the canaries in the coal mine of complex home care ... if something tough is going to happen after discharge from a procedure, it’s going to happen to bone marrow transplant patients over and over again.”

In the course of her interviews, Macdonald discovered something alarming: many of the patients were too sick to remember the instructions nurses provided before they were discharged.

“Even though the nurses do great training in the hospital, a lot of patients didn’t remember their hospitalizations because they were so ill,” Macdonald says.

Macdonald also identified situations where the caregiver and patient, once home, argued about when to call the doctor. That prompted UW Hospital’s bone marrow transplant unit to develop a one-page handout to post by the phone that details when to call 911, when to call the clinic immediately, and when to call the clinic within 24 hours.

“As nurses, we think it’s pretty clear-cut, ‘If you have ‘X,’ then you call.’ But, of course, for patients, it’s scary to think you may have to come back into the hospital,” says Bethaney Campbell, an oncology, hematology and bone marrow transplant clinical nurse specialist. “So what Cameron was able to describe are the arguments between the caregiver and the patient: the patient downplaying symptoms or not wanting to call and the caregiver saying, ‘Look, we need to call.’”

Macdonald’s findings also led the unit to revamp its patient education materials; they now clarify patient and caregiver needs, and present information in shorter sections.

“To get a whole big packet of stuff without some guidance ... is overwhelming, and people tend not to read any of it,” Campbell says.

Macdonald recruited undergraduate students enrolled in her medical sociology class to research and write drafts of instructions for patients and their families. The only requirements were that they planned to work in health care or had personal experience caring for a family member with cancer.

“It was the first time undergraduate sociology students were able to dig in and get into the hospital,” says Shannon Patterson, who graduated in August with degrees in psychology and sociology. Her mother survived a bout with breast cancer after being diagnosed in summer 2009. “A lot of time you think, ‘Oh, sociology, how is that really connected to medicine?’”

Laura Saltzman, a sociology major on Macdonald’s research team, saw firsthand when her father was undergoing chemotherapy for lymphoma how caregivers must be involved. “My dad has a fabulous memory ... but he would not remember things that were happening, and it was really important that my brother was there every single day,” says Saltzman, who is graduating in May.

Kelsey Dullinger, who graduated in May with a biochemistry degree and is applying to medical schools, says working on the project was an unparalleled experience. “I actually feel like we helped patients,” she says. “I spent a lot of time in hospitals doing shadowing and volunteering, but you don’t really get to influence [patients](#) that much and this is a huge influence on their process.”

Another conclusion Macdonald reached in her research was that caregivers who were not able to spend a lot of time in the hospital with the patient were at a major disadvantage when it was their turn to take over when at home. It was a stark contrast to caregivers who could take time off from work and help nurses in the day-to-day care of the patient. In those cases, by the time the patient went home “there wasn’t this big

huge leap into taking care of the patient themselves,” she says.

Macdonald recommended that the hospital develop classes and support groups for caregivers who are saving time off from the job so they can help at home. The hospital agreed.

“We need to be more accommodating of the caregiver — and their schedules and their needs — when they’re trying to work to maintain insurance,” Campbell says. “So I think that’s one thing that will definitely change our practice in the future.”

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