

# Home as a Site of Care for Acutely Ill Patients with Cancer



## *A conversation with Kathi Mooney, PhD, RN, FAAN*

**D**r. Kathi Mooney is a distinguished professor at the University of Utah College of Nursing and holds the Louis S. Peery and Janet B. Peery Presidential Endowed Chair in Nursing. An investigator and co-leader of the Cancer Control and Population Sciences Program at the National Cancer Institute-designated Huntsman Cancer Institute, Dr. Mooney leads research programs in patient remote symptom monitoring and management, technology-aided interventions, cancer family and caregivers, outcomes improvement for patients with cancer in rural and frontier communities, and innovative cancer care delivery model testing.

### **OI. Would you share a little about your career path and the development of the Huntsman at Home model for patients with cancer?**

My background is as a nurse and, for more than 20 years, I have been in the academic setting, involved in research through the University of Utah College of Nursing and the Huntsman Cancer Institute. My research has always grown out of a very strong interest in improving approaches to symptom management that lead to better quality of life for patients with cancer and their families.

A lot of early cancer symptom management research focused on studying a single symptom, looking at the symptom, its frequency and pattern during treatment, and then developing interventions for the symptom. Most patients who are being treated for cancer have multiple symptoms, and I decided to take a different approach in that I wanted to know if we could deliver comprehensive symptom care in a better way than current approaches.

Unfortunately, the history of cancer care is that most acute symptom care occurs in the ED, and, more than half the time, patients are then admitted to the hospital to treat these acute episodes.

What I saw was that the standard of care was to give patients education prior to the start of treatment, hold chemo classes, provide a notebook with symptom care tips for patients, and tell patients to call the oncology team if they had a problem.

What I learned in my research is that patients were not using those materials, and they rarely called their oncology team about their poorly controlled symptoms. As a result, poorly controlled symptoms escalated to acute levels and patients ended up in the emergency department [ED]. Unfortunately, the history of cancer care is that most acute symptom care occurs in the ED, and, more than half the time, patients are then admitted to the hospital to treat these acute episodes.

It seemed to me that we should be more proactive around symptom management. When I considered how we might do this—well, treatment is given on an outpatient basis and patients spend most of their time at home. So how do we proactively know how patients are doing? Instead of waiting and expecting patients to contact us, how can we intervene before symptoms get out of hand and monitor patients at home?



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Based on that idea, a colleague and I developed an automated remote monitoring platform, Symptom Care at Home, that patients could proactively call on a daily basis and report their symptoms.<sup>1</sup> Or, if patients had not called in, the system would call them. The platform provided a daily check on patients' symptoms that were occurring and their severity level. Then, through a triage system, patients could receive automated coaching using the same content covered in the patient notebooks but tailored exactly to the symptoms and severity level reported that day. Symptoms that were worsening or out of control—moderate and higher levels—would trigger an alert to the oncology care team. In my studies, nurse practitioners [NPs] conducted the call backs to patients with poorly controlled symptoms, and we found NPs to be highly skilled in providing virtual symptom care.

Our studies demonstrated that, in fact, symptom reporting and proactive intervention are very effective in reducing symptom burden and decreasing ED utilization for care.

The remote symptom monitoring and care worked well to decrease symptom burden, but there were still times when acute symptom episodes resulted in unplanned healthcare utilization.

I was a part of a University of Utah health system committee

looking at ways to decrease unplanned hospitalizations. And I was intrigued by the hospital-at-home model that is a common acute, home-based care model in single-payer countries but not in the United States. I found it interesting that this model had not been used in cancer. Mainly, hospital-at-home programs are geriatric focused or aimed at management of other acute, short-term conditions. But I thought that hospital-level care at home and acute oncology care could go together. Perhaps a focus on the home as a site of care—especially for the management of symptoms before they get out of control and to treat acute episodes that would otherwise require ED care or hospitalization—would offer a new way to improve care. Fortunately, there was a group of us at Huntsman Cancer Institute who were also interested in studying this model for oncology, and we were propelled forward through this interest and generous philanthropy, which was necessary to mount a demonstration project.

We started Huntsman at Home™ in 2018 before COVID-19, but as it turned out with the COVID-19 pandemic, keeping patients out of the ED and hospital became a high priority. CMS [the Centers for Medicare & Medicaid Services] provided a Medicare waiver for reimbursement of hospital-level acute care in the home during the pandemic.<sup>2,3</sup> This [reimbursement] allowed many healthcare systems to consider their own hospital-at-home programs even if they did not have philanthropy or other financial backing to begin.

However, I think there is still hesitancy on the part of health systems and oncology practices to jump into the hospital-at-home space until there is an assurance that there is going to be a permanent payment model for this setting. So payment, moving forward, is the uncertainty. From the research that we published in the *Journal of Clinical Oncology* in 2021, we have demonstrated that the oncology hospital-at-home model has value in terms of decreasing unplanned healthcare use and even the potential for substantial cost savings.<sup>4</sup> [For more, turn to “Delivering Hospital-Level Acute Care at Home: Learning from Huntsman at Home” on page 22.]

**OI. Were you able to expand the model to three rural communities, as planned, despite the pandemic?**

Yes, we have done that. Our timetable was delayed a bit because of the pandemic, but we began in August 2021. We've served about 80 patients in the three communities of Emery County, Carbon County, and Grand County in southeastern Utah—a two- to five-hour one-way drive from Huntsman Cancer Institute.

**OI. Can you say more about those rural communities? Is the in-home acute care like the care provided in the local Salt Lake City program? Is the rural program structured with an NP lead?**

We adapted the Huntsman at Home program for delivery in our rural communities, primarily to address the added coordination needs between local healthcare resources and Huntsman. The

rural program does have the same structure, with an NP lead, and we work with local home health agencies for the registered nurse care. When we started, we had an NP from our Salt Lake City program go out into the community for three days each week and conduct telehealth visits the other days. More recently, we have hired an NP who lives in the community. He serves as the primary NP for the three counties being served with telehealth support from our Salt Lake City program.

One component we adopted in our rural program that we did not do in the Salt Lake City program is the addition of a nurse navigator care manager who lives in the community. We found her knowledge of the people who live in her community to be incredibly important because of the social determinants of health that are impacting these patients. For example, travel to Huntsman Cancer Institute can be barrier to care—these communities are a two- to five-hour drive away, one way. We found that the coordination of care between the Huntsman at Home team, local home health agency, local safety-net hospitals, and patients’ oncology team required someone who could effectively manage care across all those care settings. We found that it is important to determine which visits require travel to Huntsman Cancer Institute and which visits can be facilitated through telehealth. That level of scheduling—the discernment about when you need to see the patient in person and when a high-quality visit via telehealth is appropriate—is a huge benefit in terms of decreasing some of the transportation demands on patients and family caregivers, while still providing high-quality access to care paired with the ability to stay home. The nurse navigator care manager has been vital to effective care coordination and close monitoring of patient status.

In addition, we took a different approach to how patients are admitted to the rural program. In the Salt Lake City program, patients are primarily referred for admission. In the rural locations, we look at which patients are on active treatment or having active appointments at Huntsman for continuing care. We look at the frequency of patients’ cancer care visits. Patients who have been to the ED and patients experiencing a range of escalating care needs, we directly contact to assess their needs and whether they would benefit from the program. So identification of patients who could benefit from acute or subacute services is more proactive for patients in the rural communities.

**OI. Is the nurse navigator care manager also an NP or is that individual an advanced nursing provider who has had experience as a navigator?**

She is actually a nurse in our Doctor of Nursing Practice [DNP] program, so she’s on her way to becoming an NP. She has a very well-rounded skillset that includes case management and home health experience. Plus, she is a member of the community where she practices, and that really makes a difference.

**OI. Have there been staffing challenges? Challenges in finding enough qualified nursing professionals in that area to work with the NP?**

**We do provide additional education to all the home health nurses because the home health support we need requires a knowledgeable background in oncology and an understanding of acute changes.**

There is turnover among the home health agency nurses, but I don’t know that their shortage is any worse than what is being experienced across all nursing right now.

We do provide additional education to all the home health nurses because the home health support we need requires a knowledgeable background in oncology and an understanding of acute changes. The assessment and understanding of the disease process and cancer symptom management is not a regular component of home health care. So, when there is turnover, it puts the onus on us to continually develop the home health nursing staff.

**OI. Is the Huntsman at Home training for NPs and home health nurses in person? Online?**

The training is hybrid. For NPs, some training modules are accessed online, such as the palliative care courses. Then, NPs spend about six weeks at Huntsman Cancer Institute, with time in the Supportive Oncology Clinic, rotations with the hospitalists taking care of acute inpatients, and going out on home visits with NPs in the Salt Lake City program. So there is a very systematic in-person training program, plus online education. For the home health agency RNs, the lead NP primarily does the education, plus some online courses, and that works quite well. They have in-person sessions, which allows the NP to identify patients the RNs have taken care of and to discuss current patients to develop their skillset.

**OI. During a recent Modern Healthcare virtual briefing on hospital-at-home models, several presenters talked about hospitalist-led programs (these were not oncology-specific models). The Huntsman model is NP-led. ACCC is an advocate for oncology advanced practice providers (APPs) working at the top of their licensure. Why do you believe NPs are well-suited for this lead role in the cancer-care-at-home model?**

I would certainly agree that we want NPs to work at the top of their license, and the Huntsman at Home program is a good demonstration of that. I don’t think there are any studies comparing hospitalists and NP care outcomes. We could answer that question by doing a study. We have found an NP model to be a safe, effective, and economical model. We do have an excellent medical director who has been key in training and providing backup for the NPs. The NPs also work closely with the patient’s oncologist.

NPs are now well integrated in oncology. They work in oncology ICUs [intensive care units] and with hospitalists on inpatient units. NPs run the day-to-day care of patients in the inpatient unit. The fact that NPs would take that approach into the home makes a lot of sense. I think it is important to have a physician as a consultant for patients who are not responding as you would expect to first-line approaches to their medical care, but the NPs are very experienced at caring for this patient population. Our medical director, who is both an oncologist and a palliative care physician, is very much involved as an active consultant and support resource to the NPs when needed.

Our Huntsman at Home NPs are experienced in symptom management and primarily work with the patient's oncologist. Some of the symptoms that we are trying to get ahead of—like dehydration from nausea and vomiting due to chemotherapy—NPs can address. But many of the issues we see relate to disease progression. As symptoms develop, there is always the question of whether it is an acute episode related to treatment or whether it is something related to disease progression. In these instances, the NP will reach out to the patient's oncologist to discuss imaging, treatment planning, and so forth. We find that the NPs work closely with the patient's oncologist, and this collaborative partnership seems to be important and useful in terms of proceeding with treatment and connecting back to the oncologist for treatment decision making. Our model is a hybrid of both acute, short-term problems related to side effects of treatment and also addressing disease progression as it occurs. An oncology NP can walk in both these worlds and make sure that physician involvement is incorporated for what is happening with the patient.

**OI. Thinking about the role of technology in the delivery of care in the home, is there any specific technology used by Huntsman at Home that allows the program to go forward; for example, electronic patient-reported outcomes (ePROs)?**

Although I'm not a techie myself, to provide care to patients at home and in the home, it is important to use technology. I think *how you use* the technology is more important.

Consider ePROs, increasingly recognized as an important tool to improve monitoring and responding to patient-reported symptoms at home. Technology does enable innovative solutions to support both early intervention and greater patient engagement in their care. As I mentioned earlier, over the past 20 years a colleague and I have developed an automated remote monitoring platform, Symptom Care at Home, that empowers patients to call in proactively and report symptoms they are experiencing.

This approach fits beautifully for patients in the subacute component of Huntsman at Home who are not getting daily visits but still experience symptom flare-up. The clinical team monitors the daily reports and steps up care when symptoms warrant it. The Symptom Care at home platform is an example of a technology-enabled system that makes outreach and monitoring of patients at home feasible and efficient.

When you talk about technology, everyone assumes you're talking about internet-based technology and telehealth, but—as

we know—not everyone has access to the internet or a smartphone. Our Symptom Care at Home platform is an IVR [interactive voice recording] system that sends data over telephone lines. All you need is a telephone—it does not have to be a smartphone. We added web and app access for patients who prefer engaging with those systems and have the technology. So there is a range of technology now that can be used to remotely monitor and capture patients' experience and their reports. It is important to engage patients as they prefer and have ways for patients to report symptoms that are available to everyone.

One way to think about it is that the technology enables the reporting. But the quality of the symptom care is the key. If the symptom care isn't good, it doesn't matter whether it's delivered by whiz-bang technology or not.

In terms of hospital-at-home for acute episode care—for example, the patient is dehydrated, needs fluids, needs electrolyte replacement, and so forth—you need a nurse in the home to manage that care. So that is a high-touch situation. The patient may have some instability in their vital signs, and so you may also use remote vital signs monitoring to continue monitoring once the nurse has left the home. We do not use remote patient monitoring with all our oncology patients; we use it for some patients who have issues around blood pressure, heart rate, or oxygenation that we are concerned about. So we may include acute episode monitoring technology, plus the nurse in the home, and telehealth linkage with the NP. It is a combination of resources.

After an acute episode in oncology, I think it is important to have continuing subacute care as follow-up for, perhaps, 30 days. We know in oncology that many symptoms tend to reoccur—especially pain and some of the others, such as nausea and vomiting. These are the patients who end up going to the ED several times a month. If you can monitor and manage those patients at home proactively, you may stop symptoms from escalating. Continued automated symptom monitoring can detect early symptom recurrence as it develops. I think technology is important in providing care at home. It is a partner.

**OI. Is there research around the oncology patient experience of hospital-at-home care? The caregiver experience?**

We're currently doing a study to address that. I hope to close data collection within the next few months. Besides the patient experience, it is also looking at family caregiver burden. I think it's legitimate to ask, if you kept the patient in the hospital, would it be less burdensome to the family? But with COVID-19, families were not allowed to go into the hospital, and this added a great deal of stress for both the patient and their family, who would have preferred to be at home. And when visitation is allowed, is it really less burdensome for a family member to visit and support the person in the hospital, while they're trying to run their household, care for their children, and work? Hopefully, this study will shed some light on the family caregiver perspective and the patient.

In the general hospital-at-home literature, the studies usually report high patient satisfaction, but the caregiver perspective is often not described.


**OI. Barriers standing in the way of this model's advancement seem to be reimbursement, patient selection, staffing, and resource capacity and availability. Do you see these as the main challenges?**

The big one is reimbursement. I think more programs will develop once clear reimbursement models for acute and subacute levels of cancer care at home are established. The hesitancy to adopt this as a model is based around reimbursement and the investment needed to deliver these types of services. To date, cancer care has not involved the home—other than hospice care. We've always brought patients to us. To stand up a model that is home-based requires a huge amount of infrastructure and resources because you're including a whole new site of care. It [hospital-at-home care] really is a disruptive change in that it requires coordination and communication among systems—for example, our EHR [electronic health record] system doesn't work with the home health system's EHR and billing system. And how will pharmacy dispense drugs for care delivered in the hospital-at-home setting when they only have an inpatient model for dispensing these types of drugs and infusions? Much of the U.S. healthcare system infrastructure and regulations are not set up to embrace the home as a site of care. Health systems are not going to set up totally new infrastructure only to have payers say they are not going to reimburse the cost. So I think the reimbursement issue is the primary challenge that must be overcome for this model to be widely adopted in the United States.

In oncology, I don't think it is a really difficult question on who to admit to a hospital-at-home care model. Certainly, there are enough of the acute side effects of dehydration, constipation and bowel obstruction, nausea and vomiting, and infection that land people in the hospital—symptoms that we have demonstrated can be safely managed with the hospital-at-home model. Could hospital-at-home be beneficial for treatments like CAR T-cell therapy or bone marrow transplant or early surgery discharge? These are areas for us to branch out to and study. I think we've demonstrated the basic kinds of challenges that happen to patients with cancer that end up as hospital admissions who can be safely

cared for at home. I see reimbursement and, therefore, how you stand up a [hospital-at-home] program as the challenge. The need, safety, acceptability, and positive outcomes are clearly established.

**OI. Some cancer programs and practices have implemented components of at-home care for their patients, so at present there appear to be different models underway.**

Besides those which came out of an academic setting, such as our cancer-specific Huntsman at Home, and those that came out of a health system that provide care for a number of conditions, there are start-up companies that are looking at how to help scale this for health systems or community practices where it is less efficient for the health system or community practice to develop by themselves. It is a new opportunity to examine how we provide care and where we provide care. With these new models, we have an opportunity to achieve real progress in improving quality of life and decreasing the morbidity of cancer and its treatment by more responsive monitoring and prompt treatment of adverse side effects and symptoms as they emerge. 

*Amanda Patton is a freelance writer in Richmond, Va. She served as associate editor of Oncology Issues for 17 years.*

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