Identifying Challenges to Using Home-Based Palliative Care for Patients with Serious Illness

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What was the project about?
Patients with serious illnesses such as heart failure or advanced cancer often have pain or other severe symptoms. Palliative care focuses on improving quality of life by preventing and treating suffering. Patients also receive spiritual and mental health support. Home-based palliative care, or HBPC, relieves patients’ pain and symptoms at home. But patients and doctors often don’t take part in HBPC programs or research.

At first, the research team planned a study to learn how well HBPC improves physical and mental well-being compared with usual care. But the team had trouble enrolling patients. As a result, the team did a study to learn more about the challenges in taking part in HBPC programs and research.

What did the research team do?
The research team did interviews with 68 people in California. Of these, 17 were patients, 8 were caregivers, 31 were doctors, and 12 were healthcare administrators. The team talked with patients and caregivers who did and didn’t enroll in HBPC programs.

The research team also held nine focus groups with 25 people at HBPC agencies, such as doctors, nurses, and other health professionals. Groups met in person or virtually.

Patients, caregivers, doctors, and policy makers helped plan the study.

What were the results?
People described challenges to taking part in HBPC programs and research. The research team grouped these challenges into four main topics:

- Identifying patients for the HBPC program. For example, doctors didn’t have much time to determine which patients should take part in HBPC.
- Timing of enrollment. For example, some people didn’t enroll in HBPC because they were feeling overwhelmed with their own care or their family member’s care.
- Lack of knowledge about palliative care. People were confused about what it is and when doctors should refer patients to HBPC.
- The newness of HBPC. As a new type of care, programs may differ in the services they offer. Also, patients’ insurance may not cover the programs.

The research team also learned what might make people more willing to take part in HBPC programs and research:

- Building relationships between HBPC and healthcare staff
- Having healthcare staff personally introduce patients to HBPC program staff
Explaining differences between HBPC and hospice programs

What were the limits of the project?
The study took place in California. Findings may differ for patients and doctors in other places.

Future research could look for ways to address the challenges to taking part in HBPC found in this study.

How can people use the results?
Health systems and doctors can use these results when looking for ways to increase enrollment in HBPC programs and research.

To learn more about this project, visit www.pcori.org/Enguidanos388.