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# **Examining the Role of Primary Care Physicians and Challenges Faced When Their Patients Transition to Home Hospice Care**

Ariel Shalev, BBA<sup>1</sup>, Veerawat Phongtankuel, MD, MS<sup>1</sup>, Katherine Lampa, BFA<sup>1</sup>, M. C. Reid, MD, PhD<sup>1</sup>, Brian M. Eiss, MD<sup>1</sup>, Sonica Bhatia, MD<sup>2</sup>, and Ronald D. Adelman, MD<sup>1</sup>

Weill Cornell Medical College, New York, NY, USA

<sup>2</sup>The Mount Sinai Hospital, Brookdale Department of Geriatrics and Palliative Medicine, New York, NY, USA

#### Abstract

**Background**—The transition into home hospice care is often a critical time in a patient's medical care. Studies have shown patients and caregivers desire continuity with their physicians at the end of life (EoL). However, it is unclear what roles primary care physicians (PCPs) play and what challenges they face caring for patients transitioning into home hospice care.

**Objectives**—To understand PCPs' experiences, challenges, and preferences when their patients transition to home hospice care.

**Design**—Nineteen semi-structured phone interviews with PCPs were conducted. Study data were analyzed using standard qualitative methods.

Participants—Participants included PCPs from 3 academic group practices in New York City.

**Measured**—Physician recordings were transcribed and analyzed using content analysis.

**Results**—Most PCPs noted that there was a discrepancy between their actual role and ideal role when their patients transitioned to home hospice care. Primary care physicians expressed a desire to maintain continuity, provide psychosocial support, and collaborate actively with the hospice team. Better establishment of roles, more frequent communication with the hospice team, and use of technology to communicate with patients were mentioned as possible ways to help PCPs achieve their ideal role caring for their patients receiving home hospice care.

**Conclusions**—Primary care physicians expressed varying degrees of involvement during a patient's transition to home hospice care, but many desired to be more involved in their patient's care. As with patients, physicians desire to maintain continuity with their patients at the EoL and solutions to improve communication between PCPs, hospice providers, and patients need to be explored.

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Corresponding Author: Veerawat Phongtankuel, MD, MS, Weill Cornell Medical College, 525 East 68th street, Box 39, New York, NY 10065, USA. vep9012@med.cornell.edu.

#### **Declaration of Conflicting Interests**

## **Keywords**

End of life; home hospice care; hospice care; care transitions; hospice; EoL care

## Introduction

In the United States, the Medicare hospice benefit provides end-of-life (EoL) care for terminally ill patients with life expectancies of 6 months or less. <sup>1</sup> This service is often delivered at home through an interdisciplinary team of physicians, nurses, social workers, and spiritual care counselors. <sup>2</sup>

Care transitions in home hospice are not uncommon.<sup>3</sup> These transitions can be burdensome for patients and caregivers and result in fragmented care.<sup>4–6</sup> Approximately 20% of hospice enrollments result in a live discharge and over 40% of discharges result in hospitalization.<sup>7</sup> While hospice care is interdisciplinary by design, certain providers (i.e., primary care physicians [PCPs]) may be more influential in impacting patients' decisions around EoL care transitions. Studies examining perspectives of hospice nurses and caregivers found that one reason patients return to the hospital is a desire to obtain care from their PCP during periods of crisis.<sup>8,9</sup> Involving PCPs in home hospice can be challenging, given that many home hospice patients are often too debilitated to visit their PCPs. Coupled with the fact that many PCPs do not perform home visits, it is not uncommon for there to be a shift in care between patients and their PCPs once a transition to home hospice occurs.

Given the short median length of stay (17.4 days) of hospice patients, maintaining continuity with their long-standing PCPs can be important in navigating the medical and psychosocial issues at the EoL which may impact care transitions. <sup>2,10,11</sup> One Canadian study found that among patients with chronic illnesses, home visits from PCPs were associated with a higher chance of an in-home death. <sup>12</sup> Additionally, patients consider physician continuity an important factor when choosing hospice, and both patients and families rate trust in their physicians as an important aspect of EoL care. <sup>13–16</sup> Although it is evident that patients value continuity, no studies have ascertained the perspectives of the PCPs.

Understanding PCPs' experiences when patients transition to home hospice care can help hospice and hospital systems identify gaps in EoL care transitions. Given the limited research on the involvement of PCPs in these transitions, it is unclear what roles PCPs currently play or desire to play in home hospice care. Accordingly, this study sought to understand PCPs' experiences, challenges, and preferences when their patients transition to home hospice.

## Methods

### Design

This qualitative study used content analysis to synthesize data collected in phone and inperson interviews with PCPs (eg, internists, geriatricians, house-call physicians). This study was approved by the Institutional Review Board at Weill Cornell Medicine.

## **Participant Recruitment**

We recruited PCPs from 3 practices: the Irving Sherwood Wright Medical Center on Aging, Weill Cornell Internal Medical Associates (WCIMA), and Mount Sinai Visiting Doctors Program. The Irving Sherwood Wright Medical Center on Aging is an ambulatory care practice serving older adults in New York City (NYC). The center is staffed by geriatrics and palliative care physicians who see patients in the practice, while a subset of providers make home visits. WCIMA is a NYC-based internal medicine practice staffed by internal medicine physicians who care for adult patients in the practice but do not make home visits. The Mount Sinai Visiting Doctors Program serves patients in NYC and consists of internal medicine and geriatric-trained physicians who make home visits.

We included English-speaking physicians who delivered primary care to patients in an outpatient or home setting. We excluded physicians who had not completed medical training, who only saw patients in an inpatient setting, and/or reported no experience with patients in home hospice care.

Initial recruitment for participants was conducted by introductory e-mail and interested participants were contacted and screened for eligibility. Interviews were subsequently conducted either in-person or by phone, based on participants' preference with written or verbal consent being obtained, respectively.

## **Phone Interview Methodology**

One investigator (A.S.) interviewed participants using a semi-structured interview guide with follow-up probes. New topics were introduced based on participants' responses. The interviewer had no known conflicts of interest that would have biased the interviews. Information was collected regarding medical specialty, years in practice, practice setting (eg, out-patient, home visits), and number of patients who transitioned to home hospice care over the past year.

Participants were then asked open-ended questions developed by a group of primary care and palliative care physicians (R.D.A., V.P., and M.C.R.) based on clinical experience and a review of the literature on EoL care transitions. These questions included (1) What has been your role in caring for your patients after they transition to home hospice? (2) Ideally, what role would you like to play in patients' care after they transition to home hospice; what are the barriers you see in achieving this role? (3) What do you feel is the most valuable contribution you provide to patients when they transition to home hospice? (4) What are the main challenges/concerns you've encountered when your patients transition to home hospice? (5) What do you think can be done to strengthen the continuity between patients and physicians when patients transition to home hospice? (6) How have you communicated with hospice providers and patients who have transitioned to home hospice?

Interviews were conducted between June 2016 and October 2016 and lasted between 10 and 40 minutes.

## **Analysis**

Audiotaped interviews were transcribed and analyzed using content analysis. Pairs of investigators (A.S., K.L., and V.P.) trained in qualitative research methods independently reviewed transcripts and systematically organized data into a structured format. Codes, categories, and themes were constructed individually and continually revised and reformulated after reviewing each new transcript. <sup>17</sup> No categories or themes were predetermined beforehand. The investigators then met to compare and discuss their findings and reconciled differing themes until there was an agreement on a framework of themes and their definitions. The final agreed upon framework was subsequently reapplied to each transcript. Qualitative software was not utilized. Thematic saturation was achieved after 16 interviews.

## Results

Twenty-nine physicians were contacted and 19 decided to participate in the study. Of the 19 participants, 13 practiced in an outpatient setting, while 6 made home visits. Ten PCPs specialized in geriatrics, 6 in geriatrics and palliative care, and 3 in internal medicine. The number of years practicing medicine ranged from 1 year to 35 years, with a median of 14 years. The number of patients who transitioned to home hospice within the past year in this group ranged from 1 to 30 patients, with a median of 9.

The interviews were designed to explore PCPs' role in home hospice care, their ideal role, the challenges faced when providing care in this setting, and possible solutions to these challenges. Major themes are outlined below and additional quotes are listed in Table 1.

### PCPs' Current Role in Home Hospice Care

Assisting with the transition to home hospice care—Primary care physicians (n = 9, 47%) noted that they help prepare patients for home hospice care by educating patients and families about hospice and setting expectations about home hospice. Primary care physicians also continue to reassure families about the decision to keep patients on hospice. "Trying to keep the family from relapsing, from wanting aggressive care again because they've chosen hospice ... to reassure the family that this is the right thing" (Geriatrician, outpatient).

**Providing psychosocial support**—The most commonly mentioned role (n = 14, 74%) was providing psychosocial support to patients and families. It often consisted of support to families and reassuring them about medical decisions being made by the hospice team. Primary care physicians noted that by providing psychosocial support they were able to maintain continuity, even if managing the patient's hospice care was not feasible.

I would like to remain as a support for families ... the saddest thing for a patient is when they feel they're dumped into somebody else's hands ... [But] truth be told, they're probably best cared for ... by a hospice doctor. (Geriatrician, outpatient)

Heterogeneous degree of involvement—Primary care physicians (n = 8, 42%) spoke about how their level of involvement in a patient's home hospice care was dependent on a

number of factors. One factor was related to the level of intimacy and longevity of the relationship with their patient prior to hospice care. Participants felt that involvement was also dependent on the hospice organization and the preferences of the hospice nurse, with certain organizations and/or nurses being more proactive in involving PCPs in the patients' care. "That seems to me a key variable. Does the hospice nurse reach out to the PCP?" (Geriatrics and palliative care, outpatient). Overall, PCPs described a variety of roles ranging from no involvement to close collaboration with the hospice team.

## Physician's Ideal Role in Home Hospice Care

**Provide psychosocial support and maintain continuity**—Primary care physicians (n = 14, 74%) noted their desire to provide additional psychosocial support and further ensure continuity of care. Many cited that given their established relationship with the patient and family, they were in a unique position to provide psychosocial support. As one participant stated, "We can provide a layer of emotional and psychosocial support to them because they might trust us better than a hospice team that's just coming on board" (Geriatrician, outpatient).

**Collaborate with the hospice team**—Many PCPs (n = 13, 68%) expressed frustration over the degree of involvement in their patients' home hospice care. Participants felt that their knowledge of the patient and family was a resource hospices did not take full advantage of. As one PCP stated, "We have a thorough history of what happened prior to the transition to hospice .... We can impart those things to the hospice team" (Geriatrician, outpatient). In addition, physicians desired more interaction with the hospice team and to be kept informed about their patients' condition.

**Defer certain responsibilities to the hospice team—**There were certain responsibilities that PCPs (n = 12, 63%) felt the hospice team was better equipped at handling due to a variety of factors which included time constraints, existing clinical responsibilities, and/or lack of palliative care training. In particular, day-to-day care, palliative care issues, and acute changes in care were mentioned as responsibilities PCPs preferred to defer to the hospice team. Although this theme was less common among house-call physicians and those with palliative care training, it was still mentioned. As one participant noted, "There have been really intensive pain problems and it would be easier for the hospice nurse to contact the hospice physician" (Geriatrics and palliative care, outpatient).

## **Physician Barriers and Challenges**

**Maintaining continuity**—Many PCPs (n = 14, 74%) were unsure how to remain involved in their patients' care once they transitioned to home hospice care. Participants voiced specific barriers which included lack of communication with the hospice team, uncertainty over who on the hospice team was caring for the patient, and the inability to make home visits or reach out via phone due to time constraints. Primary care physicians felt that updates from the hospice team were inconsistent and that improvements in communicating contact information of the hospice care team to PCPs were needed.

**Unclear role**—Another frequently mentioned challenge was the PCP's uncertainty concerning their role once hospice care was initiated (n = 8, 42%). Physicians noted that this in turn creates confusion for patients and families and that most families do not understand when to reach out to their physician versus when to reach out to their hospice provider. "There is this gap ... in terms of communicating what is needed from me and what the hospice providers want from us and what the patients really want from us" (Geriatrician, outpatient).

## **Physician Recommended Solutions**

Better communication with hospice team—This was the most common suggestion mentioned by PCPs (n = 16, 84%), with many desiring more frequent updates from the hospice team. Solutions that participants mentioned to improve communication involved participating in hospice team meetings and/or establishing a formal protocol for regular communication with the hospice team.

**Utilize technology to remain in touch with patients**—Various participants (n = 8, 42%) mentioned technology as a tool that could potentially address some of the challenges involved in maintaining continuity. However, some PCPs also noted that since they are not reimbursed for phone calls or e-mails, it can be hard to find time to connect with patients receiving home hospice care. As one physician said, "If our health care system could ever actually include time for non face-to-face care that would be amazing" (Internist, outpatient).

**Early establishment of role and expectations**—Primary care physicians (n = 10, 53%) noted that developing formal guidelines that explain their role in home hospice care would be beneficial to both physicians and patients. As one physician noted, "there should be more specific guidelines as to what [our] role is" (Geriatrics and palliative care, outpatient).

### Themes unique to house-call physicians

There were some differences between PCPs who made house calls and those who practiced in an outpatient setting. House-call physicians frequently described very collaborative relationships with the hospice team and the current and ideal roles they described were very closely aligned. However, house-call physicians noted many of the same challenges as physicians who did not do house calls, such as communication issues and role uncertainty, albeit to a lesser degree.

## **Discussion**

We found that PCPs played a wide variety of roles when patients transitioned to home hospice care; however, many focused on educating and reassuring patients and families about the transition in addition to delivering psychosocial support. Furthermore, PCPs desired more continuity with their patients and the hospice team during this transition, expressed a preference that day-to-day palliative care issues be managed by hospice and wished for better communication and a more defined role in this care transition setting.

These results complement findings from our previous work. <sup>7,8</sup> While hospice providers and caregivers see physicians as a vital part of hospice care, especially when care transitions occur out of hospice, physicians often expressed barriers to maintaining continuity with their patients and collaborating with hospices. Consequently, fragmented care can result in unmet needs of the patient/caregiver. Further research is needed to explore these associations and compare expectations and roles that PCPs, hospice providers, and patients/caregivers perceive of one another in order to identify solutions to improve continuity and reduce fragmentation among those delivering and receiving care.

In situations where PCPs reported maintaining care with their patients, we found a unique shift in role for many during this transition, from that of a medical provider to someone that mainly provides psychosocial support to patients and families. We suspect this shift is due to several factors, including PCPs' inexperience in providing EoL care to patients in the home setting, not having the ability to see their hospice patients due to their clinical responsibilities (i.e., outpatient physicians), and knowing that a hospice team is managing the patient's medical care. We found this shift less prominent among house-call physicians. Further studies are needed to clarify which factors are important in contributing to this shift and whether patients and families desire the support the physicians are offering.

A key challenge that PCPs expressed when patients transitioned to home hospice care is that their role is often undefined. Furthermore, many felt that communication with the hospice team regarding their patients' care was far from ideal. Often, PCPs desired to be better informed and desired more frequent and standardized ways to communicate with hospice teams. While PCPs expressed varying degrees of involvement, information and communication were important to them.

Other care transition models offer potential solutions to these challenges. One potential solution to improve communication and continuity is through implementation of a care management model for EoL transitions. Care management interventions have been shown to improve care and reduce health-care utilization in high-risk patients with advanced chronic diseases. These interventions often include a health-care professional who acts as a liaison for the patient, while facilitating communications between health-care providers. Modifying and utilizing this care model for home hospice patients could help improve the communication and continuity among PCPs, hospice providers, and patients/families.

Another potential solution is to integrate electronic medical record (EMR) system from hospital systems and hospice organizations. Some EMR systems have the capability to electronically obtain patient records for other health-care networks when consent is obtained from the patient or proxy. <sup>19</sup> On a larger scale, organizations like the New York City Clinical Data Research Network are building a network of medical records from 22 organizations, with the goal of sharing data to improve care. <sup>20</sup> These promising projects, which integrate and allow easier access to patient records for physicians and providers from different organizations, constitute a substantial undertaking but would allow important data to be shared with the goal of improving communication and care while reducing poor care outcomes.

Other solutions mentioned by participants included establishing the physician's role early in the transition process, using technology to share information, and having the hospice team provide more frequent updates to physicians. Outpatient PCPs who do not make home visits cited clinical responsibilities as a barrier to being more involved in a patient's care. We found that PCPs who routinely made house calls reported fewer communication issues with hospice teams. Therefore, incorporating solutions that incentivize home visits or facilitate telemedicine visits may lead to improved PCP involvement and collaboration. Table 2 outlines a list of potential strategies to improve communication between PCPs and hospice providers.

There are limitations to this study. Our study examined academic PCPs and therefore, these results may not be generalizable to community PCPs and/or specialists (i.e., oncologists, cardiologists). Furthermore, this study looked at the perspective from one group experiencing this care transition, while other important stakeholder groups (e.g., hospice providers and patients/caregivers) need to be examined in future studies. Lastly, while we used content analysis to analyze the data, we did not incorporate triangulation or member checking methodology.

In conclusion, this study provides new insights regarding the role PCPs play when their patients transition to home hospice care and the barriers they face trying to maintain continuity. While roles vary, there is a common shift from delivering medical care to providing psychosocial support to patients and caregivers. As with patients, PCPs desire continuity with their patients and potential solutions to improve communication between hospices and PCPs need to be explored.

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#### Table 1

### Participant Quotes Organized by Theme.

Current role: assisting with the transition to home hospice care

As a primary doctor, we do have long-term [patient] relationships that could facilitate that [hospice care] conversation ... the
preparation work is definitely what we can contribute. If we know there is a terminal diagnosis, we can lay the groundwork.
(Geriatrician, outpatient)

• It's almost always I've had the [hospice] conversation with [the patient] and we make the decision together and then get hospice involved. (Geriatrics and palliative care, home visits)

## Current role: providing psychosocial support

- I'm able to continue to do what I do [once patients transition to home hospice], maintaining that continuity of care prior to hospice referral and after, maintaining my relationship with the patient and their loved ones. (Geriatrics and palliative care, home visits)
- I like to still maintain a connection with the patient and the family ... you don't want the family to feel like they've been abandoned or the patient to feel like they've been abandoned. (Geriatrician, home visits)

#### Current role: heterogeneous degree of involvement

- [My role] depends on the family. If they've had a very good relationship with the hospice nurse, they might tend to call ... the hospice team. If ... they aren't as comfortable on home hospice ... then they'll tend to call me first. (Geriatrician, home visits)
- Sometimes I have very little communication unless I reach out. Other [nurses] have been really good with calling me. Sometimes [involvement] also [depends on] the agency .... There are agencies that ... know how our program works and reach out a little bit more than the others. (Geriatrics and palliative care, home visits)

Ideal role: provide psychosocial support and maintain continuity of care

- The continuity of care from their transition [is my most valuable contribution] ... as the primary doctor you've been there through
  the whole thing. Through all the transitions of their life. Which I think is helpful emotionally. (Geriatrics and palliative care,
  outpatient)
- I still want to be their primary care doctor. I don't want to abandon them. I think it's a critical time in their lives. And if I've gotten to know them over the years, I think it's unfair for me to say goodbye to them and not be with them through the whole process. (Geriatrics and palliative care, outpatient)

#### Ideal role: collaborate with the hospice team

• I would love to hear what the ... hospice social worker or other chaplains ... what they come away with after they visit the patients ... I would love to have more communication with the nonmedical members of the hospice team. (Geriatrics and palliative care, home visits)

Ideal role: defer certain responsibilities to the hospice team

- The truth is that I am not a palliative care doctor .... I'm not so good with pain management so ideally I would love the hospice doctor to take care of the pain issues. (Geriatrician, outpatient)
- As somebody who does not do home visits routinely, it is beyond my scope of practice to do that and I happily abdicate the dayto-day management decisions to the hospice team. (Geriatrician, home visits)

Physician barriers and challenges: maintaining continuity

- If you're not making home visits and the patient isn't coming to the office and it's hard to talk on the phone, it's not that straightforward that there would be an easy transition to some new form of relationship. (Geriatrician, outpatient)
- Its hard to manage things just by phone I think you do need some face to face to really get a picture of what's going on and for families to know that you actually know what's going on. (Geriatrician, home visits)

Physician barriers and challenges: unclear role

- What should we tell the families so that they're not confused? What can our house-call program do and not do? What can hospice do or not do? (Geriatrician, home visits)
- It's sometimes just not clear where the hospice physician jumps in and where [I jump in] .... Finding that balance between the
  roles for the hospice doctor and me is probably the biggest barrier. (Geriatrician, outpatient)

Solutions: better communication with hospice team

If there was a number where I could have easier access to contact [the hospice team] that would be better, instead of the general
number and then talking to 50 people to find out who is the nurse taking care of the patient today. (Geriatrics and palliative care,
outpatient)

• It would be beneficial to get updates through fax of what [hospice] nurses saw [on their visits] and how patients are doing. Even a phone call once a week saying look we just want to update you on the patient's status. (Geriatrician, outpatient)

Solutions: utilize technology to remain in touch with patients

- There might be a role for telemedicine ... it might be interesting to have a way to be there without having to make house calls, where [patients] can see me and we can sort of chat for a little bit. (Geriatrician, outpatient)
- [Maintaining continuity] could even be done with different tech methods. It could be done with video chat if doctors don't have the ability to go on house calls ... via something like Skype. (Geriatrician, home visits)

Solutions: early establishment of role and expectations

• It does get complicated sometimes when the expectations of the caregivers or the family members are not clear ... I would prefer it be laid out clearly, [for example,] the hospice doctor is now the primary [physician] and we're here for extra support. That would be helpful. (Geriatrician, outpatient)

### Table 2

Potential Strategies to Improve Communication Between Physicians, Hospice Providers, and Patients.

- Developing a care management model for hospice and end-of-life (EoL) care transitions
- Sharing data between physicians and hospice providers through integration of hospital and hospice medical records systems
- Establishing an introductory call between hospice providers and physicians to determine roles at the time of a patient's home hospice admission
- Having physicians contact their patients/families to discuss expectations regarding their involvement in care once a transition to home hospice care occurs
- Constructing clearer and relevant care plans between patients, hospice providers, and physicians
- · Utilizing telemedicine to remain in touch with home hospice patients when house calls are not feasible
- Giving physicians the opportunity to contribute to hospice interdisciplinary team meetings