Patient Home Visits: Measuring Outcomes of a Community Model for Palliative Care Education

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Abstract

Background: Health care professionals may have limited exposure to home-based care. There is no published literature that has described the experiences and satisfaction of participation in patient home visits (PHV).

Objective: The objective of this article is to describe the characteristics of PHV, our approach, and evaluation by participants over a nine-year period.

Methods: We conducted a review of surveys completed by participants in PHV from 2005–2013. All participants anonymously completed the evaluation questionnaires at the end of PHVs. Different PHV assessment forms were used for the 2005–2010 and 2011–2013 time periods.

Results: A total of 34 PHVs were conducted with 106 patients and approximately 750 participants with a mean of 3 patients and 22 participants per PHV between 2005 and 2013. For 18 PHVs there are 317 surveys completed with 353 participants, making it a 90% response rate. Responding participants were physicians 125/543 (23%) and other professionals 418/543 (77%). In both time periods of 2005–2010 and 2011–2013 a survey with a 1 (completely agree) to 5 (completely disagree) scale was used. Agreeing that PHV was an effective teaching tool during 2005–2010 were 335/341 (98%); during 2011–2013, 191/202 (95%) agreed that PHV provided increased understanding and sharing of best practices in palliative care.

Conclusions: PHV was perceived by participants as an effective way of providing interactive community education. A broad range of themes were addressed, and the participants reported high levels of learning in all domains of palliative care. There were no cases of patient or relative expression of distress as a result of PHV.

Introduction

CANCER is the second leading cause of death in the United States.¹ It has been reported that approximately 70%–80% of terminally ill patients have expressed a desire to die at home.^{2–6} Palliative medicine addresses physical, psychosocial, spiritual, and family caregiver distress in patients approaching the end of life. The vast majority of palliative care training is conducted in hospitals or inpatient hospice facilities. One of the biggest challenges in the delivery of high-quality care near the end of life is the lack of training on the delivery of palliative care at home for physicians; nurses; midlevel providers (physician assistants, advanced practice nurses, nurse practitioners); and other health care profes-

sionals (HCPs).^{7–9} Palliative care education has recently shifted from the traditional didactic lecture format to a more patient-centered model. Clinicians working in inpatient facilities have limited access to patients in the community. Therefore, the hospital academic setting is not the most appropriate to teach about the psychosocial and financial challenges faced by patients and their families in the community.¹⁰ Community-based clinicians, including those working in home hospice and nursing home settings, may face complex challenges on a day-to-day basis.

Our team established a community education model in which palliative care is taught through visiting individual patients at home or inpatient hospice settings. This unique educational method called Patient Home Visits (PHV),

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was originally established in 1995 in Edmonton, Alberta, Canada, under the name of Bus Rounds. The PHV model was created as a method for providing community-based clinical education in palliative care.^{11–12}

Patients are visited at home by HCPs, faculty, and host hospice, with their cases discussed en route to the patient's location. PHV offers the opportunity to combine talents of both groups and presents an innovative community educational model to teach hospice and palliative care principles to all participating health care providers. Approximately nine PHV educational sessions are offered on a yearly basis. Participants are also asked to share their feedback on the experience through a survey questionnaire provided at the conclusion of each PHV.

There has been no published literature describing the experiences and satisfaction of health care professionals who have participated in PHV. Therefore, we aim to describe the cumulative experiences with PHV conducted in the last decade.

Methods

Patient selection and host hospice participation

Participation in PHV is offered to the medical and administrative directors of all hospices in the Houston metropolitan area. In the United States, hospice organizations provide care for more than 80% of patients in a home setting. The term "hospice" in this paper refers to hospice organizations. More than 80% of the PHV patients were visited at home. If a hospice expresses an interest in cohosting a PHV education event, a formal invitation letter is sent to the host hospice outlining their responsibilities to ensure the success of the program. The host hospice is required to identify three patients to visit, along with a fourth patient as an alternate visit should one patient not be seen during the PHV. Health Insurance Portability and Accountability Act (HIPAA) consent forms for each patient are required to be signed and returned prior to the visit. In addition, the hospice is responsible for creating an itinerary and a two-page patient case summary to be reviewed with the participants while en route to the patient's homes. For this case summary, the medical director or a designated member of the clinical staff of the host hospice is asked to conduct a complete assessment of the physical and psychosocial status of the patient and a medication review.

Participant selection

PHVs are announced to all medical directors of Houston area hospices. It has been regularly advertised to those invited to weekly grand rounds, the annual board review and educational symposium, and in a mailing list of palliative care programs and hospice organizations in the Houston and surrounding areas. The target population was clinicians involved in the delivery of palliative care and/or hospice, as well as trainees planning to become involved in the delivery of palliative care and hospice services.

Those interested in participating are asked to briefly outline their professional affiliation and reason for participation, and to preregister. A registration fee of \$25 is requested from every participant. Approximately 20 participants register for each PHV, along with 5 members from the host hospice. Two faculty and staff members also attend and moderate.

Patient home visits

The PHVs begin at 8:00 a.m. at the front entrance of the Mendelsohn Faculty Center at MD Anderson Cancer Center in Houston and end at the same location at noon. Transportation is usually provided via bus through a local provider. The host hospice organization and moderating faculty are introduced to participants, and the itinerary is provided. The representative of the host hospice presents the patients' histories on the way to the first home, inpatient hospice, or nursing home. Different settings present unique challenges, and future studies should further stratify patient demographic data to better characterize the themes and teaching experience in each of the different settings, such as home, nursing home, inpatient hospice delivered in general inpatient units, or residential inpatient unit. The moderating faculty will comment on the individual cases and identify key points to address. A discussion of the background and current symptoms will prompt questions from the participants. This dialogue will be used to identify opportunities to apply palliative care principles regarding treatment and decision making.

Participants are provided with copies of the case studies and a HIPAA form to be completed and returned, in order to receive a two-way radio. Participants are given this two-way radio with a built-in microphone for ease of communication. This unique audio system allows all participants to listen while another talks. This is also used in the event that a patient requests privacy and does not allow the participants in their home or room.

On arrival for the first visit, the host hospice and faculty most familiar with the patient and family confirm permission to enter the patient's home or room.¹⁰ The host hospice, together with the faculty, conduct the patient evaluation, and once complete, the PHV participants are prompted to ask questions and further the discussion. The case discussions take place after returning to the vehicle (for patients seen at home) or in a conference room (for patients seen in facilities).

Although the main purpose of the PHV is professional education, the discussion provides several recommendations that usually emerge for each case. These clinical recommendations are then conveyed to the host hospice for implementation by their clinical team.

At the conclusion, all participants anonymously complete an evaluation survey questionnaire. This brief survey allows a range of responses, on a scale of 1 (strongly agree) to 5 (strongly disagree). Its purpose is to elicit the participants' views on the usefulness of PHV as an educational tool to teach hospice and palliative care principles in the community setting.

Questionnaire responses and descriptive analysis

The survey questionnaire was provided for PHVs conducted from 2005–2013. The survey questions used for the period 2005–2010 were modified, and a new set of questions were administered from 2011–2013. The survey was modified in consultation with the Department of Continuing Medical Education University of Texas M.D. Anderson Cancer Center, to better capture the perception of participants regarding in-depth educational goals for PHV as outlined in our results (see Table 4). The responses were collected using a Likert scale of 1 to 5. Responses collected have been described using percentages. We further compared participants who identified as "physicians"

and “nonphysicians” as well as “registered nurses” and “social workers” using Fisher’s exact test. A *p*-value less than 0.05 is considered significant for this comparison.

Results

Participants’ demographics

There were a total of 34 PHV events, with 106 patients visited and 750 participants, including 1–2 faculty per event, with a mean of 3 patients and 22 participants per PHV event. The total number of surveys completed was 543. In both periods (2005–2010 and 2011–2013), MDs accounted for 125 participants (23%). The remaining 418 participants included nurses, social workers, and administrators (see Table 1).

TABLE 1. DEMOGRAPHICS

2005–2010		2011–2013	
PHV	<i>n</i> = 20	PHV	<i>n</i> = 14
Patients	<i>n</i> = 63	Patients	<i>n</i> = 43
Responding participants	<i>n</i> = 341	Responding participants	<i>n</i> = 202
<i>Professional discipline</i>	<i>n</i> (%)	<i>Professional discipline</i>	<i>n</i> (%)
MD	75 (22)	MD	50 (25)
RN	110 (32)	PhD	12 (6)
Social worker	59 (17)	Midlevel provider	13 (6)
Administrator	6 (2)	Other HCP	81 (40)
Pastoral care	24 (7)	Other	34 (17)
Other	55 (16)	Did not answer	12 (6)
Did not answer	12 (4)		
<i>Gender</i>	<i>n</i> (%)		
Male	63 (18)		
Female	216 (63)		
Did not answer	62 (18)		
<i>Type of practice</i>	<i>n</i> (%)		
Home-based (home care)	10 (3)		
Home-based (hospice care)	102 (30)		
Hospital-based	128 (38)		
Inpatient hospice facility	24 (7)		
Nursing facility	9 (3)		
Office-based	18 (5)		
Other (specify)	48 (14)		
Did not answer	2 (1)		
<i>Years in practice</i>	<i>n</i> (%)		
<1 year	44 (13)		
1–5 years	76 (22)		
6–10 years	43 (13)		
>10 years	99 (29)		
Did not answer	79 (23)		
<i>Time in hospice/palliative care</i>	<i>n</i> (%)		
<30%	91 (27)		
30%–50%	30 (9)		
51%–75%	12 (4)		
>75%	129 (38)		
Did not answer	79 (23)		

HCP, health care professional; PHV, patient home visits.

Themes addressed during 2005–2010

During 2005–2010 participants were allowed to pick themes from a list addressed during patient interaction and discussions. The three most common themes identified were pain (311/341, 91%); cognitive impairment and delirium (299/341, 88%); and psychosocial distress (297/341, 87%). The other themes that were identified include symptom assessment and management (284/341, 83%); communication (278/341, 82%); and constipation (263/341, 77%). The themes were chosen by the faculty in an effort to capture all of the main domains regularly addressed in PHV. By pre-selecting items, we may have inadvertently left out additional themes that should be addressed through future qualitative studies on this survey, after the additional items have been included (see Table 2).

Global evaluation of PHV by the participants for 2005–2010

Global evaluations for 2005–2010 characterized PHV as “time well spent” (332/341, 97%); “help better manage patients” (317/341, 93%); and “PHV effective teaching tool” (335/341, 98%). Participants further answered the questions regarding “identify common symptoms in advanced cancer” (327/341, 96%); “the approach to assess symptoms” (324/341, 95%); “manage symptoms” (329/341, 96%); and “identify similarities and differences of palliative care and hospice care” (304/341, 89% and 269/341, 79%, respectively) (see Table 3). Figure 1 summarizes the global evaluation for 2005–2010.

Comparison of the evaluations between physicians and nonphysicians, and between registered nurses and social workers for 2005–2010

Due to the different nature of the professional backgrounds, it might be possible that some health care providers found the PHV more useful than others. Therefore, we decided to compare their overall evaluation by physicians versus nonphysicians, and RNs versus social workers. We further compared the last three items of the global evaluation in Table 3 (“time well spent,” “will help better manage

TABLE 2. THEMES ADDRESSED IN PATIENT HOME VISITS AS REPORTED BY THE PARTICIPANTS FOR 2005–2010 (*N* = 341)

Themes addressed ^a	N (%)
Advance directives	127 (37)
Cognitive impairment and delirium	299 (88)
Communication	278 (82)
Constipation	264 (77)
Interdisciplinary approach to patient care	263 (77)
Medicare hospice benefit	179 (52)
Nausea and vomiting	239 (70)
Pain	311 (91)
Psychosocial distress	297 (87)
Spirituality	266 (78)
Symptom assessment and management	284 (83)
Other (specify)	26 (8)

^aParticipants could select more than one item.

TABLE 3. GLOBAL EVALUATION OF PATIENT HOME VISITS BY THE PARTICIPANTS FOR 2005–2010 (N=341)

	<i>Strongly agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly disagree</i>	<i>Did not answer</i>
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Identify symptoms commonly experienced by patients with advanced cancer	211 (62) 327 (96)	116 (34)	12 (4)	0 (0)	0 (0)	2 (1)
Describe an approach to the assessment of symptoms and quality of life in patients with advanced medical illness	218 (64) 324 (95)	106 (31)	12 (4)	1 (0)	0 (0)	4 (1)
Discuss in detail the management of one symptom experienced by a patient visited on PHV	256 (75) 329 (96)	73 (21)	7 (2)	0 (0)	0 (0)	5 (1)
Identify similarities in the provision of palliative care and hospice care	191 (56) 304 (89)	113 (33)	26 (8)	3 (1)	1 (0)	7 (2)
Identify differences in the provision of palliative care and hospice care	164 (48) 269 (79)	105 (31)	54 (16)	8 (2)	0 (0)	10 (3)
My time was well spent	278 (82) 332 (97)	54 (16)	6 (2)	1 (0)	0 (0)	2 (1)
I believe my participation in this round will help me better manage my patients	244 (72) 317 (93)	73 (21)	19 (6)	2 (1)	0 (0)	3 (1)
The PHV format was an effective teaching tool	279 (82) 335 (98)	56 (16)	5 (1)	0 (0)	0 (0)	1 (0)

PHV, patient home visits.

patients,” and “PHV effective teaching tool”) between physicians and nonphysicians, and found no significant differences ($P > 0.05$). We also compared these three items between registered nurses and social workers, and observed no significant differences ($P > 0.05$).

Global evaluation of PHV by the participants for 2011–2013

During 2011–2013, the majority of the participants expressed extraordinarily high satisfaction with PHV as

FIG. 1. Global evaluation for 2005–2010.

having “increased understanding and sharing of best practices in palliative care” (191/202, 95%). Participants further identified “evaluate, assess and manage cancer pain” (183/202, 91%); “identify and manage the complex symptoms” (191/202, 95%); “an improved upon psychosocial and spiritual care model” (192/202, 95%); “discuss issues with interdisciplinary team” (185/202, 92%); “effective ways of communicating with patients and caregivers” (199/202, 99%); and “the overall organization and quality of the program met my expectations” (176/202, 87%) (see Table 4). Figure 2 summarizes the global evaluation for 2011–2013.

The cost of PHV

The budget of each PHV included bus rental (\$513.00), office supplies (\$40.00), continuing medical education (CME) official expense (\$100.00), and food item (\$55.78). The cost of team faculty and staff members' time is not included in the budget. The registration fee was \$25 per participant. The total time spent by the administrative coordinator was approximately 10 to 15 hours for each PHV.

Discussion

We reviewed 34 PHV events from 2005 to 2013, including 106 patient cases and approximately 750 participants. Patient and/or caregiver expressions of symptom distress and discomfort can be common, but during the PHV there were no cases of patient or family member expression of distress or concerns with the PHV, thereby alleviating the fear of intrusion into the private home setting.

The majority of the participants expressed a very high level of agreement on gaining insight into hospice and palliative care assessment and management. The vast majority (98%) considered PHV an effective teaching tool.

There is limited palliative care education in undergraduate and graduate medical education, despite recommendations to make it a core component of the curricula.^{13–15} The lack of palliative medicine education is a barrier to the development of the discipline, with a need to implement innovative teaching models. Our main learning outcomes were to help health care professionals better identify and manage common symptoms in patients with advanced cancer (including pain, cognitive impairment and delirium, decreased oral intake, etc.), and to identify and manage psychosocial and spiritual distress among patients and family members. Additional outcomes include helping these health care professionals understand the special circumstances imposed by the home setting on the physical and psychological care of patients and the burden this presents on primary caregivers.”

Population studies have indicated that most people would prefer to die at home.^{16–21} End-of-life care at home requires a considerable amount of time from a community-based primary care team. The role of the primary care teams is to manage symptoms, provide education, coordinate care, and provide additional or enhanced support and care.²² However, primary care providers have a limited capacity to meet the multiple needs, due to limited resources and knowledge deficits, more so in rural areas. This creates a unique opportunity to develop a community-based palliative care teaching module.^{23–24} PHVs are a unique partnership between an academic institution and a community setting, and might be particularly useful for practitioners working with rural populations.

PHV has been used successfully in Lugano, Switzerland in association with their local program.²⁵ Training led by MD Anderson faculty in El Paso, Tyler, Lubbock, and Laredo, Texas have resulted in similar programs being implemented in Rosario and Buenos Aires, Argentina, and San Andres, Venezuela.^{11–12,26}

TABLE 4. GLOBAL EVALUATION OF PATIENT HOME VISITS BY THE PARTICIPANTS DURING 2011–2013 (N=202)

	<i>Strongly agree</i>	<i>Agree</i>	<i>Undecided</i>	<i>Disagree</i>	<i>Strongly disagree</i>	<i>Did not answer</i>
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Demonstrate an increased understanding and sharing of best practices in palliative care within a patient care setting	134 (66) 191 (95)	57 (28)	4 (2)	0 (0)	2 (1)	5 (2)
Appropriately evaluate, assess, and manage cancer pain in order to improve on patient's quality of life (knowledge, competence, performance, and patient outcomes)	112 (55) 183 (91)	71 (35)	5 (2)	1 (0)	1 (0)	12 (6)
Identify and manage the complex medical, ethical, spiritual, and psychosocial issues that patients face near the end of life	131 (65) 191 (95)	60 (30)	2 (1)	1 (0)	2 (1)	6 (3)
Provide and administer an improved-upon psychosocial and spiritual care model that is administered to patients and families during this stage of their illness	121 (60) 192 (95)	71 (35)	1 (0)	2 (1)	1 (0)	6 (3)
Discuss and manage difficult issues with an interdisciplinary team committed to improving the quality of health care delivery	132 (65) 185 (92)	53 (26)	2 (1)	1 (0)	2 (1)	12 (6)
Model/demonstrate effective ways of communicating with patients and caregivers that will lead to improving patient and family care	130 (64) 199 (99)	69 (34)	0 (0)	1 (0)	2 (1)	0 (0)
In general, the overall organization and quality of the program met my expectations	143 (71) 176 (87)	33 (16)	1 (0)	1 (0)	2 (1)	22 (11)

FIG. 2. Global evaluation for 2011–2013.

PHV is an intensive, patient-based and highly interactive education model aimed at bridging the knowledge gap between academic health care professionals and those in the community. Participants learn about the challenges of providing care at home, including issues such as access to the bathroom, bed, and furniture, and in some cases, very difficult conditions due to limited resources or lack of extensive family support. PHV also offers a unique opportunity to collaborate between academic centers and the community, thereby improving communication among team members from multiple disciplines. This enables participants to gain familiarity with the home setting and the unique challenges it brings, and to help with the transition of patients who choose to receive their care or die at home. In addition, it offers insight into new evidence to assess and manage complex physical and psychosocial issues in multiple settings.

Palliative care requires members from different disciplines to participate in patient care due to complexity and diversity of symptoms.^{27–28} Demographics of the PHV program indicated that among the interdisciplinary participants, there were physicians; registered nurses; social workers; administrators; pastors; PhDs (psychologists, postdoctoral fellows); midlevel providers (physician assistants, advanced practice nurses, nurse practitioners); and other HCPs. The top three themes identified during the PHVs included pain, cognitive impairment and delirium, and psychosocial distress. The participants indicated that our survey encompassed all domains of palliative care. In addition to covering physical symptoms, topics such as medical ethics, spirituality, social aspects, psychiatric aspects, team dynamics, organizational aspects, communication techniques, and different models of hospice and palliative care delivery

were discussed. The majority of the participants felt that the PHV educational model was a very effective teaching tool in the community setting. They also felt that the time spent was worthwhile and will help with future patient interactions.

A majority of the time, family caregivers experience significant distress as they watch their loved one suffer, or as they participate in key decisions for their loved one's care.^{29–30} The majority of the patients and family members from the PHV expressed gratitude for the visit, for the company, and for the participants' listening to their experiences. We did not measure the burden or benefit to the patient and family provided by the PHV program. In the future, we should incorporate survey questions to capture the impact of PHV on caregiver burden. One of the important outcomes monitored was any spontaneous expression of distress before, during, or after the PHV. This was carefully monitored by the hospice team. However, we did not obtain direct measurement of distress experienced by the patient or caregiver. It is possible that the patient or caregiver might express distress if they are asked, and this should be a focus of future research. We cannot rule out that some patients or caregivers may feel uncomfortable participating in the PHV event.

Charging participants a small registration fee will lessen the no-show rate and lower the overall cost of the event. The expense for faculty time would be substantial, but PHV is credited as a part of teaching time for all faculty members. The other items that added to the cost included bus rental fee, drivers' pay, gasoline, refreshments, and cost of administrators' time. The low cost of the PHV can easily be covered through the registration fees or a small contribution from a sponsor.

Despite high levels of satisfaction as demonstrated by the participants' global evaluations of PHV, there are limitations to

the format. These limitations include the variability in representation from different health care disciplines, the short duration of stay at patients' homes, and the space constraints to accommodate all participants in patients' homes. It is also not possible to engage in prolonged psychosocial evaluation and counseling. Nevertheless participants, patients, and families felt comfortable with counseling, albeit of short duration. For some patients and families, PHV acted as a useful screening tool to identify such issues. Perhaps for some of the complex cases, a formal case discussion in a bigger group would be ideal. "Case discussions" would allow participants to gather more detailed information and spend more time. This method is commonly used in health professions' education and may stimulate interdisciplinary discussion among colleagues with varying levels of experience, particularly for complex cases.^{31–32}

The focus of future research should be on the important standards in assessing the usefulness of educational tools, including assessing change of knowledge, attitude, and behavior of HCPs, and patient outcomes, which collectively are the main standard for the evaluation of medical education and the ultimate factor of success in educational studies. Future research should also focus on the impact of the PHV on the patterns of the practice of HCPs and their performance. This model allowed community-based groups to interact with hospital-based groups in exchanging evidence-based knowledge about patient care. In the future it may be useful to track participants over time to see if their knowledge, attitudes, and practice patterns have changed after PHV. The evaluations we received from our program have been overwhelmingly positive. However, while this patient-centered approach helps providers identify the challenges of care and helps discuss methods to provide patients a better quality of life for as long as possible, we need to expand these educational sessions to teach HCPs essential things like logistics and administrative work needed to provide palliative care in the community.

Conclusion

PHV creates a unique education model for bringing interdisciplinary palliative care to community settings. Our nine-year results show that PHV is a feasible and cost-effective educational model to teach palliative care. PHV is perceived by participants as an effective, patient-based, and interactive community education tool. A broad range of themes were addressed, and participants reported extraordinarily high levels of learning. It is a unique education model tailored to meet community needs in both urban and rural settings. This model has been well received by participants, patients, and families and has successfully been used in international settings. This program can have a huge impact on palliative care education in the future but should be a part of a comprehensive community education program.

Author Disclosure Statement

No competing financial interests exist.

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