

ORIGINAL RESEARCH

Perspectives of Primary Care Providers Toward Palliative Care for Their Patients

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Purpose: The need for all providers to deliver basic palliative care has emerged as patients' needs outstrip the capacity of specialty palliative care. Many patients with complex illnesses have unmet needs and are seen in primary care more than other settings. We explore primary care providers' willingness and perceived capacity to provide basic palliative care, and their concerns and perceived barriers.

Methods: We performed semistructured telephone interviews with 20 primary care providers about their perceptions of palliative care, including needs, practices, experiences, access, and what would be helpful for their practices to systematically provide basic palliative care.

Results: We identified 3 major themes: (1) Participants recognize palliative needs in patients with complex problems. (2) They reactively respond to those needs using practice and community resources, believing that meeting those needs at a basic level is within the scope of primary care. (3) They can identify opportunities to improve the delivery of a basic palliative approach in primary care through practice change and redesign strategies used in enhanced primary care environments.

Conclusions: Systematic attention along the multidimensional domains of basic palliative care might allow practices to address unmet needs in patients with complex illnesses by using existing practice improvement models, strategies, and prioritization. (J Am Board Fam Med 2016;29:748–758.)

Keywords: Health Resources, Palliative Care, Perception, Primary Health Care, Qualitative Research, Residence Characteristics, Telephone

Living with chronic illness can leave patients suffering with poorly controlled symptoms, inadequate emotional support, and fragmented health care.^{1,2} Currently about half of all adults in the United States have chronic illness, and 86% of all health care dollars in 2010 were spent on these individuals.^{3,4} Projections are for 70% of people

older than 65 years to have at least 1 chronic illness by 2030.⁵ Two segments of health care are known to meet the triple aim of improving patient's care experience, improving the health of populations, and reducing per capita health care costs for people with chronic illness: palliative care delivered by specialists,^{6–8} and primary care.⁹

The approach taken by palliative specialists has been described in a recent Institute of Medicine report as care that “. . . provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families.”¹⁰ Components of the palliative approach include addressing physical, psychological, social, cultural, and existential aspects to the illness experience and care delivery; addressing ethical and legal aspects of care delivery, including eliciting patient goals and advance care planning; addressing structural and process aspects of care, including care coordination and accessibility; and addressing care at the end of life, including bereavement.^{10,11}

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However, palliative care specialists cannot meet the palliative needs of all people with serious illness because of limitations of reimbursement for the delivery of nonhospice palliative services; limitations of hospice eligibility to the last months of life, despite the patient suffering that occurs throughout the trajectory of the illness; and a lack of adequate numbers of palliative specialists.¹² Recognition of these realities has prompted calls for the adoption of a palliative approach by all segments of our health care system, and for all providers to deliver basic palliative care.^{13–17} Basic or primary palliative care is the application of a palliative approach in patient care by non-palliative specialists.¹⁰ At a minimum, the recommended skill set for nonspecialist palliative care providers includes the following components at the skill level provided by the practitioner's training: (1) management of pain and other disease-related symptoms; (2) management of depression and anxiety symptoms; and (3) discussions about prognosis, treatment goals, suffering, and advance care planning.¹⁶

There is minimal discussion regarding the systematic integration of basic palliative care into primary care practice in the United States, and the conversation focuses on increasing the access to specialty-level palliative delivery.^{18,19} A major innovation in primary care over the past 20 years has been the development of the patient-centered medical home (PCMH), a team-based health care delivery model that emphasizes care coordination and communication to improve patient outcomes.²⁰ Primary care practices that have become PCMHs use a variety of transformative structures and processes that have led to their triple aim achievement.²¹ Recognizing this, we hypothesize that systematically integrating a basic palliative approach in primary care practice may better meet the triple aim. We further hypothesize that structures and processes used to transform primary care practices into recognized PCMHs might be used to achieve proactive, systematic integration of basic palliative care in primary care settings.

We began to explore our hypothesis about the systematic integration of basic palliative care by providers in primary care practices by asking such providers about their perceptions of how they provide or interact with palliative care. Specifically, we wanted to explore 2 issues: (1) their perceptions of palliative care—how it relates to their chronically ill patients and their practice; and (2) their percep-

tions of practice requirements to feasibly integrate the systematic delivery of basic palliative care in a primary care PCMH environment.

Methods

We used a qualitative descriptive approach to explore the primary care/palliative care context.²² Between May 2013 and July 2016 we conducted open-ended, semistructured telephone interviews with primary care clinicians recruited primarily from 3 primary care research networks,²³ prioritizing context variation through deep rather than broad sampling.²⁴ We focused on clinicians with some exposure to the PCMH model because they were viewed as having more familiarity with practice changes that would likely be required to integrate palliative care into primary care practices. The decision to use telephone interviews was mainly related to geographic considerations. The literature reports this as the main advantage of using telephone interviews for qualitative research, with some suggestions that the perceived anonymity of respondents may allow them to feel more comfortable and open when discussing sensitive subjects. While some concerns about the use of telephone calls in qualitative research exists because of the interviewer's inability to receive visual cues, potential difficulties in presenting visual data to interviewees, and potential challenges in creating a relationship, there are no data to suggest that the quality of information or outcomes are different with telephone versus in-person interviews.^{25,26} The study was approved by the Colorado Multiple Institutional Review Board.

Participants

Eligible clinicians were English-speaking primary care providers in practices engaged in PCMH activities or preparation. Most volunteer participants were recruited from either the Building Investigative Practices for Better Health Outcomes Research Network (BIGHORN), Colorado Research Network (CaReNet), or ACORN primary-care research networks.^{27–29} BIGHORN and CaReNet have 18 and 48 participating primary care practices, respectively, in urban, suburban, and rural areas in Colorado, whereas ACORN has 100 practices in Virginia. Network providers responded to E-mails from a research network administrator who then facilitated an E-mail introduction between provid-

ers and the study's primary investigator (DN). Two additional participants were recruited using a snowball technique whereby 1 of the authors or the research network administrator identified potential participants based on personal knowledge: 1 had left a CaReNet practice shortly before recruitment; another was recruited at a national primary care practice improvement conference where 8 conference participants initially expressed interest in learning about the project.

One participant had worked in a hospice setting earlier in their career, and another served on the board of a local hospice. None were palliative care specialists, nor did any function in a specialty palliative care role. Participants were E-mailed information about the project before the interview, including a guideline about primary palliative care previously developed by HealthTeamWorks.³⁰

Data Collection

We developed an interview guide (see Appendix) to elicit participants' views about palliative care and possible future integration of basic palliative care into practice. This semistructured guide was framed around the components of palliative care^{10,11} and features of high-functioning PCMH practices.³¹ Respondents were not shown the interview guide.

All participants gave verbal informed consent before commencing the interview. Interviews were conducted by experienced qualitative interviewers trained for this study (DN, CTN). DN is a physician with board certification in Family Medicine and a certificate of added qualification in Hospice and Palliative Medicine; he also practices and teaches each. CTN is an experienced social worker and qualitative research assistant who has participated in numerous palliative care-focused research projects. Interviews were digitally recorded, professionally transcribed verbatim, and checked for accuracy. Interview duration ranged from 50 to 70 minutes.

Data Analysis

The transcribed interviews and debriefing notes from each interview provided the main source of data for subsequent analysis. Data analysis commenced with the first interview, and data management was supported with Atlas.ti version 7.2 (Scientific Software Development GmbH). We used our well-established team-based general inductive

approach to analysis to explore participants' views.³² The primary analyst (CTN) and the primary investigator (DN) initially coded a sample of transcripts, discussing similarities and differences until consensus was reached, creating a codebook. The resulting codebook guided coding for the remainder of the transcripts. As new codes emerged, they were discussed with the team and, if appropriate, added to the codebook.³³ We searched for contextual patterns and themes within the data, both within and across practice settings. Research team meetings included a senior qualitative researcher and nurse (JJ), a qualitative analyst with experience in palliative care research (CTN), and 2 primary care/palliative care physicians (DM, DN). Meetings were used to review emerging themes, discuss confirming and disconfirming cases, and more fully contextualize the landscape of primary palliative services as viewed by primary care providers.³⁴ We sought transferability of our results, clarification of areas of disagreement/agreement, and any missing elements through several established strategies: discussion of findings with primary care researchers during research meetings, presentation of early results to a group of palliative care clinicians, presentation as a poster at a national primary care research meeting, and presenting at palliative care research meeting "works in progress" sessions with palliative care researchers.³⁵

Results

Participants/Practices

We interviewed 20 participants; their characteristics are described in Table 1. These clinicians had practiced a range of 1 to 37 years and averaged about 15 years in their current practice. They practiced in a variety of settings (eg, urban, rural, academic). The median number of their patients who had died in the previous year was 8 (range, 0–50). Participants responded that they would not be surprised if an average of 4.9% (range, 1–17.5%) of their patients died in the following year.

Themes

We identified 3 main thematic areas in these data: (1) recognizing patients' palliative needs, (2) the primary care physician's response to identified palliative needs, and (3) strategies to improve the delivery of a basic palliative approach in a primary care environment.

Table 1. Characteristics of Respondents and Their Practice Locations

Provider type	
Physician (DO/MD)*	18
PA	1
NP	1
Practice characteristics	
Community, single specialty	8 (2 hospital owned)
Academic-affiliated, single specialty residency	8
Large, multidisciplinary, public health safety net and large academic medical center	4
Practice location	
Suburban	8
Rural (rural/community health center)	7
Urban	5
Year respondents completed training	
Range	1978–2015
Median	1998
Time in current location (years)	
Range	0.75–37
Mean	14.6
Median	14
Patients who died in the past year (n)	
Range	0–50
Mean	11.8
Median	8
Physicians would not be surprised if this proportion of patients died in the next year	
Range	1–17.5
Mean	4.9
Median	5

*Practicing in Family Medicine, Internal Medicine, or Internal Medicine/Pediatrics.

Recognizing Patients' Palliative Needs

Participants felt that palliative care should be provided when patients are terminally ill, and some indicated that palliative care can also be provided in preterminal stages along with all other chronic illness care. Participants discussed that palliative care helps patients receive care aimed at providing comfort and that patients, and their loved ones, also receive support: “More that they will have support services, but they can still be treated for their chronic illness, to the extent they want.”

Patients with chronic illness described by these participants were typically viewed as being in a stable to gradually declining state, with some being more fragile and later in their disease trajectory. Even for patients in stable stages of illness, respondents saw these patients as often having unmet needs across multiple dimensions. Symptoms, most commonly pain, shortness of breath, nausea, and fatigue, were causes for them to seek care and come to the attention of the practice. These patients are

also considered to have other numerous and diverse unmet needs in social, emotional, and practical aspects of daily living; functional problems; financial issues; and health literacy and knowledge dimensions.

Participants became aware of these patient problems through their usual practice of primary care. They viewed themselves and their practice as having a responsibility to manage patients' overall health needs by coming to know their patients as individuals and learning about the social aspects of the patients' lives in the context of an ongoing relationship. In more rural areas, participants commented that they would see patients in nonhealth settings, such as at the grocery store, and learn more about their needs that way: “. . . I see these patients not only in the clinic, but I see them in the grocery store, in church, at ball games. That sort of thing. So the emotional/social/family issues, those all tend to run together for us down here [rural area].”

Primary Care Physician Response to Identified Palliative Needs

Participants all responded as best they could to the medical and health care needs of their chronically ill patients. Specifically, they reported addressing the management of physical and emotional symptoms, support for family and other social issues, at least some components of advance care planning, and attempts to coordinate care in the community. A few participants did a brief spiritual assessment, but most did not; some expressed concerns about engaging in such a role. Goals of care discussions in the context of advancing illness were performed by participants from each practice setting. Most saw these conversations as challenging at times, usually because of a patient's or family's resistance in acknowledging the realities of declining disease trajectories and sometimes because of the positive interpretations patients took from conversations with medical specialists. A significant minority described active management in the terminal phase of care of their patients, but most felt that the active management of death was outside their scope of care. All agreed that primary care practice should assess and manage most palliative needs: ". . . goal setting and the advance care planning . . . we have the discussion with the patient as far as . . . say the goal is to never be in the hospital . . . some of that stuff we already talk about. Symptom management . . . is pain control. You know, they still have other issues that come along with their disease . . . we always try to address it."

Participants often stated that they were the ones in their practices who performed the assessments and managed the care for these identified needs. However, a team-based approach had developed in practices with higher PCMH-level certification. Several practices used care managers and/or social workers to coordinate care, enhance communication with patients and families, and identify community resources. Even in those practices, however, our participants reported that if they personally did not pursue conversations with patients about goals in relation to illness and care planning, such conversations rarely happened. They described a lack of comfort and experience with having such conversations among other practice clinicians: "I have a partner who is a younger physician. A very compassionate guy . . . [he is] relatively inexperienced and tend[s] to hand off

more of these end of life discussions. . . . I think it is more [a lack of] experience."

Participants did not typically view themselves as delivering *palliative care*, as that term was seen to imply specialty services. They uniformly preferred the term *supportive care* in referring to the palliative services they provide. Several commented that *supportive care* would be more palatable to their patients because the term *palliative care* is associated with terminal care: "And I think it [*supportive care*] would be a great term to use. Well, it just does not sound like *palliative*—like you are dying tomorrow, or maybe not tomorrow, but it is kind of a death sentence."

When participants were then asked about the interaction between their practice and specialist palliative care, many urban-based providers indicated that patients were referred to community palliative care services. A few participants identified frustrations with hospital-based palliative care specialists; they had experienced the palliative specialist creating care plans in which the primary care clinician was not included, creating a silo effect. When this occurred it was viewed as redundant and devaluing. More identified the potential for, rather than the actual occurrence of, this dynamic. Overall, more participants described hospice availability but no community palliative care. Neither was available for some in rural practices.

Interestingly, several participants from different geographic areas reported barriers to referring some patients for hospice care because of perceived regulatory and "paperwork" burdens related to admission criteria for terminal illness: ". . . we have hospice, however we are not able to use it much. Because of all the regulations from [Centers for Medicare & Medicaid Services]." Our participants described using home care or long-term care services for such patients, with the participants managing symptoms in a comfort-focused care plan. This approach was thought to be easier than managing hospice administrative requirements.

Strategies to Improve the Delivery of a Basic Palliative Approach

Nearly all participants felt that the routine and systematic integration of a basic palliative approach to care was appropriately within the scope of primary care and important for patients and families. When asked what practices could use to support basic palliative care integration, they identified 5

components: a patient registry, a multidimensional needs assessment, a care management approach that includes goal setting, team-based care, and decision aids including a guideline.

“One of the things you need to do . . . is set up a registry.”

“Some form of moderately comprehensive checklist. Because I think if you start to go through needs, they are pretty extensive. Everything from functional status to spiritual needs and then everything in between.”

“I think the way it should work is, for one thing to routinize it, so it does not depend on the physician making the call. We know the right thing to do so we make it automatic. So I think the way we would do it is, you know, have a person whose job it is to . . . see every single person who is identified by whatever mechanism . . . they go in and have the task of assessing those need[s] . . . our team would include this person who is there to assess these issues [including goal setting] and then provide support as needed.”

“Demands are huge to see patients . . . and the way you do it is not by loading more work onto the provider, but by enlarging the team.”

“So I think guidelines . . . giving people some resources or helping . . . physicians to know how to do that. I think that would be good.”

In addition, participants identified that their practices would need help during their transition toward this model of delivering basic palliative care. They identified 3 essential elements to help the practice with this transition: education, practice coaching, and prioritization. Participants felt that education addressing knowledge and application of palliative interventions should target both providers and others who work in the practice. Several of the practices had previously used practice coaches and found them to be important in facilitating integration activities.

“Because you know, the primary care level education in palliative care, I haven’t seen too much of that. . . .”

“We did the initial PCMH, so having a coach has been crucial. And none of the changes would have happened without coaching.”

The most important factor identified as facilitating the integration of basic palliative care is that it is valued, prioritized, and supported financially. Participants noted that specific disease management activities are encouraged and that practices are incentivized financially to collect disease-focused quality measures. As a result, practices commit many resources to developing workflow and capturing certain national disease quality measures, which creates a competing demand situation for practice resources. Most practices reported insufficient “bandwidth” to do any other practice improvement activities, even if those activities better meet patient needs.

“So you know it is not even necessarily time and money . . . we are so overburdened with things that, I say this laughingly but it is totally true and I am not really joking: If I accept anything else on my docs’ plates I will have to quit my job [practice manager]. They would come after me. There would be torches and pitchforks, man!”

“So we could implement . . . the best palliative care ever . . . and . . . really help people a ton and it will not be measured by the people who evaluate us. It would be nice to do it just because it is the right thing to do . . . but there are so many right things to do that you cannot choose them all. And it is largely going to be payer driven. A better way to do this is to convince Medicaid that they need to look at this.”

“So we sort of have to go with topics that are chosen for us a lot of the time. Like for example ACOs [accountable care organizations], they haven’t chosen a palliative care guideline. They have chosen well-child checks . . . but we have to do it because that is what we are going to get measured on.”

Discussion

The primary care participants interviewed in our study care for chronically ill people with progressive illnesses and multiple morbidities throughout the trajectory of those illnesses. They identify many unmet needs across multiple dimensions in this patient population. The unmet needs they identify are consistent with the broad literature about the needs of people with chronic, progressive illness

well before the terminal phase.^{36–40} Addressing these unmet needs is a significant issue in primary care practice since people with chronic progressive illness are cared for more in primary care than in any other setting.⁴¹

Key components of palliative care services were identified by our participants, who strive to meet basic palliative needs from within their practice when possible and through various ways of engaging community services. However, participants found themselves responding to patient- and family-identified needs rather than proactively engaging in systematic efforts to identify unmet needs, help patients to identify and prioritize their goals, and plan care to meet those needs within the framework of the patient's goals. Successful evidence-based strategies in the care management of patients who have complex needs include a systematic approach to identifying needs.^{42–44}

Our findings express the views of a wide range of primary care providers from diverse practices. We used procedures that are ensured to enhance the validity and reliability of our data.³⁵ We achieved saturation in the main findings presented, and there is consistency across practice settings and participant type. Our approach provided in-depth exploration and analysis in a highly focused area using rich, descriptive data.

Our participants could envision that the integration of basic palliative approach may allow their practices to address unmet needs in patients with complex illness. They specified that the structures and processes used by effective PCMH practices to improve disease management (eg, patient registry, needs assessment, care planning, team-based approach, clinician education) could be used to facilitate the changes required for their practices to deliver a basic palliative/supportive approach for such patients. Some of the structures and processes identified focus on care management (eg, needs assessment, care planning), whereas others focus on practice change management (eg, team-based approach). The Conceptual Model of Practice Improvement described by Solberg⁴⁵ identifies care management and change management as necessary elements for practices to change and improve. The model also identifies the need to prioritize in order to overcome barriers and achieve successful and sustained practice change. Our participants believe that there is not enough prioritization in the current regulatory and reimbursement environments

to implement proactive and systematic integration of basic palliative/supportive care, even in highly transformed PCMH primary care practices.

We were able to test our hypotheses in a small demonstration project. Three disparate primary care practices used structures and processes they had previously developed (when creating practice changes used to qualify for PCMH level III certification) to implement components of basic palliative/supportive care. The practices received education and practice coach support. The project evaluation revealed that practices could successfully implement components of a palliative approach using a rapid-cycle quality improvement approach and that practices chose 1 component to work on initially. (This report is available from the primary author (DN) upon request.) Implementation of a comprehensive basic palliative care program would require ongoing support and focus over time, something the participants in this study felt would require prioritization and appropriate reimbursement.

The current reimbursement environment rewards quality as measured mainly through disease-focused metrics. Decontextualized disease-based measures are likely to have less relevance and are potentially harmful in the context of health care for patients with multimorbidity or advancing illness.^{46,47} The next major development in the evolution of the transformed primary care PCMH model needs to be a focus on evaluating and addressing the needs of patients with complex problems and their families.^{48,49}

Evolution of the PCMH model to caring for complex patients and their families will be key to solidifying the model's value.⁵⁰ Careful attention should be paid to the multidimensional, patient-focused, specialist palliative approach during this evolution. Adapting that approach and implementing it systematically in primary care practices to provide basic supportive care alongside appropriate disease management may better meet the triple aim. We do not yet know which features of a basic supportive approach to incentivize and implement systematically in primary care practice. From a research perspective, identifying patients likely to have unmet palliative needs (regardless of where they are perceived to be in their disease trajectory) and evaluating those needs seems a worthy next step. Several approaches to this issue have been

developed in Europe,^{51,52} but none in the United States using our coding systems.

References

- Noël PH, Frueh BC, Larme AC, Pugh JA. Collaborative care needs and preferences of primary care patients with multimorbidity. *Health Expect* 2005;8:54–63.
- Fortin M, Soubhi H, Hudon C, Bayliss EA, van den Akker M. Multimorbidity's many challenges. *BMJ*. 2007;334:1016–7.
- Gerteis J, Izrael D, Deitz D, et al. Multiple chronic conditions chartbook. 2010 Medical Expenditure Panel Survey data. Rockville, MD: Agency for Healthcare Research and Quality; 2014.
- Ward BW, Schiller JS, Goodman RA. Multiple chronic conditions among US adults: a 2012 update. *Prev Chronic Dis* 2014;11:E62.
- LeRoy L, Bayliss E, Domino M, et al. The Agency for Healthcare Research and Quality Multiple Chronic Conditions Research Network: overview of research contributions and future priorities. *Med Care*. 2014;52:S15–22.
- Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care—translating data in oncology into practice. *N Engl J Med* 2013;369:2347–51.
- Smith TJ, Hillner BE. Bending the cost curve in cancer care. *N Engl J Med* 2011;364:2060–5.
- Bernabeo E, Holmboe ES. Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Aff (Millwood)* 2013;32:250–8.
- Phillips RL, Bazemore AW. Primary care and why it matters for U.S. health system reform. *Health Aff (Millwood)* 2010;29:806–10.
- Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. Washington, DC: National Academies Press; 2015.
- Constance D, ed. Clinical practice guidelines for quality palliative care. Third ed. Pittsburgh: National Consensus Project for Quality Palliative Care; 2013.
- Lupu D; American Academy of Hospice and Palliative Medicine Workforce Task Group. Estimate of current hospice and palliative medicine workforce shortage. *J Pain Symptom Manage* 2010;40:899–911.
- von Gunten CFS. Secondary and tertiary palliative care in us hospitals. *JAMA* 2002;287:875–81.
- Murray SA, Boyd K, Sheikh A, Thomas K, Higginson IJ. Developing primary palliative care. *BMJ* 2004;329:1056–7.
- von Gunten CF. Who should palliative medicine be asked to see? *J Palliat Med* 2011;14:2–3.
- Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 2013;368:1173–5.
- World Health Organization. Strengthening of palliative care as a component of integrated treatment throughout the life course. *J Pain Palliat Care Pharmacother* 2014;28:130–4.
- Pattison M, Romer AL. Improving care through the end of life: launching a primary care clinic-based program. *J Palliat Med* 2001;4:249–54.
- Wallenstein DJ. Palliative care in the patient-centered medical home. *Prim Care* 2012;39:627–31.
- Green LA, Graham R, Bagley B, et al. Task Force 1. Report of the task force on patient expectations, core values, reintegration, and the new model of family medicine. *Ann Fam Med* 2014;(2 Suppl):S33–49.
- Nielsen M, Buelte L, Patel K, Nichols L. The patient-centered medical home's impact on cost and quality: annual review of evidence, 2014–2015. Washington, DC: Patient-Centered Primary Care Collaborative; 2016. Available from: <https://www.pcpc.org/resource/patient-centered-medical-homes-impact-cost-and-quality-2014-2015>. Accessed August 20, 2016.
- Sandelowski M. Focus on research methods—what happened to qualitative description? *Res Nurs Health* 2000;23:334–40.
- Lindbloom EJ, Ewigman BG, Hickner JM. Practice-based research networks: the laboratories of primary care research. *Med Care* 2004;42:III-45–9.
- Patton M. Qualitative research & evaluation methods. Thousand Oaks, CA: Sage; 2002.
- Novick G. Is there a bias against telephone interviews in qualitative research? *Res Nurs Health* 2008; 31:391–8.
- Block E, Ershine L. Interviewing by telephone: specific considerations, opportunities, and challenges. *Int J Qual Methods* 2012;11:428–45.
- BIGHORN: Building Investigative Practices for Better Health Outcomes Research Network [homepage]. Available from: <http://www.ucdenver.edu/academics/colleges/medschool/departments/familymed/research/PBRN/BIGHORN/Pages/BIGHORN.aspx>. Accessed August 20, 2016.
- CaReNet: Colorado Research Network [homepage]. Available from: <http://www.ucdenver.edu/academics/colleges/medschool/departments/familymed/research/PBRN/CaReNet/Pages/CaReNet.aspx>. Accessed August 20, 2016.
- ACORN [homepage]. Available from: <http://www.familymedicine.vcu.edu/research/fmresearch/acorn/>. Accessed August 20, 2016.
- HealthTeamWorks. Palliative care guideline. 2011. Available from: https://www.colorado.gov/pacific/sites/default/files/HTW_Palliative-Care-Guideline_07-13-2011.pdf. Accessed August 20, 2016.
- Bodenheimer T, Ghorob A, Willard-Grace R, Grumbach K. The 10 building blocks of high-performing primary care. *Ann Fam Med* 2014;12:166–71.
- Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval* 2006; 27:237–46.

33. Saldana J. The coding manual. Thousand Oaks, CA: Sage; 2012.
34. Guest G, MacQueen KM. Handbook for team-based qualitative research. Lanham, MD: AltaMira, Rowman & Littlefield; 2007.
35. Creswell JW. Qualitative inquiry and research design: choosing among five approaches. Thousand Oaks, CA: Sage; 2012.
36. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer* 2009;17:1117–28.
37. Murray SA, Kendall M, Grant E, Boyd K, Barclay S, Sheikh A. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *J Pain Symptom Manage* 2007;34:393–402.
38. Pinnock H, Kendall M, Murray SA, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ* 2011;342:d142.
39. Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. *Palliat Support Care* 2004;2:371–8.
40. Smith SM, Soubhi H, Fortin M, Hudon C, O’Dowd T. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ*. 2012;345:e5205.
41. Sharma MA, Cheng N, Moore M, Coffman M, Bazemore AW. Patients with high-cost chronic conditions rely heavily on primary care physicians. *J Am Board Fam Med* 2014;27:11–2.
42. McCarthy D, Ryan J, Klein S. Models of care for high-need, high-cost patients: an evidence synthesis. Issue brief (Commonwealth Fund) 2015;31:1–19.
43. Tracy CS, Bell SH, Nickell LA, Charles J, Upshur RE. The IMPACT clinic innovative model of inter-professional primary care for elderly patients with complex health care needs. *Can Fam Physician* 2013;59:e148–55.
44. Berry-Millett R, Bodenheimer T. Care management of patients with complex health care needs. *Synth Proj Res Synth Rep* 2009;(19). pii: 52372. Available from: http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2009/rwjf49853. Accessed August 20, 2016.
45. Solberg LI. Improving medical practice: a conceptual framework. *Ann Fam Med* 2007;5:251–6.
46. Reuben DB, Tinetti ME. Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med* 2012;366:777–9.
47. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition—multimorbidity. *JAMA* 2012;307:2493–4.
48. Rich EC, Lipson D, Libersky J, Peikes DN, Parchman ML. Organizing care for complex patients in the patient-centered medical home. *Ann Fam Med* 2012;10:60–2.
49. Bayliss EA, Balasubramanian BA, Gill JM, Stange KC. Perspectives in primary care: implementing patient-centered care coordination for individuals with multiple chronic medical conditions. *Ann Fam Med* 2014;12:500–3.
50. Flottemesch TJ, Anderson LH, Solberg LI, Fontaine P, Asche SE. Patient-centered medical home cost reductions limited to complex patients. *Am J Manag Care* 2012;18:677–86.
51. Mason B, Boyd K, Murray SA, et al. Developing a computerised search to help UK general practices identify more patients for palliative care planning: a feasibility study. *BMC Fam Pract* 2015;16:99.
52. Gómez-Batiste X, Martínez-Muñoz M, Blay C, Espinoza J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. 2012. *Curr Opin Support Palliat Care* 2012;6:371–8.

Appendix
Primary Care Provider Perspectives of Palliative Care

Date of Interview: ___/___/___
 Interview number: ___
 Interviewer: _____
 Start Time: ___ : ___

Telephone Interview Guide for Primary Care Providers

Introduction. Thank you for agreeing to talk with me today. I am going to ask you some questions about your experiences in providing palliative care to your patients. Our hope is to learn your perspectives about palliative care and its relationship to primary care practice. We expect this discussion to take 30 to 45 minutes.

Before we start, I need to make sure you are aware of the following:

- Your participation is voluntary; you do not have to answer any question that makes you uncomfortable, and you may stop at anytime.
- Your responses will be recorded in a manner that will maintain your anonymity and confidentiality.
- If you have any concerns about this study, you may contact the primary investigator, David Nowels (303-724-9733) or COMIRB (303-724-0155).
- [Obtain verbal consent (if phone interview)]: Do you consent to go ahead with the interview? **__ Yes __ No**

- [If no:] Thank you for your time.
- [If yes:] Do you have any questions before we begin?

Begin Recording. Let us begin with a few questions about your practice.

1. What type of clinician are you (physician, NP, PA) _____
2. What is your specialty? _____
3. When did you complete your training? **Year:** _____
4. How long have you been working at your current location? _____ **years**
5. Would you describe your clinic location as rural, urban, suburban? _____
6. Would you describe your practice as private, academic, other? (Describe) _____
7. Can you give me an estimate of the number of your patients who have died within the past year? _____
8. What is your estimate of the percentage of your patients whom you would not be surprised if they died in the next year? _____ %

Let me now ask you a few general questions regarding how you provide care for your patients with serious or advanced illness.

9. Thinking back over the past year, can you describe a “typical” patient who has chronic illness that you provided care for?

Probes: One or more illness? Any particular illnesses? What other problems do they have?

10. When someone uses the term *palliative care*, what comes to mind for you?

Probes: What does the term mean to you? Who provides palliative care services? In your mind, what kinds of patients would benefit from palliative care services? At what point in a patient’s illness trajectory do you think it would be helpful? Does the term *supportive care* mean anything different to you?

11. What do you see as the **elements** of “palliative care services” for patients with chronic illness?

Probes: Goal setting? Advance care planning? Evaluating and managing symptoms (which ones)? Evaluating and managing emotional issues (which)? Evaluating and managing social issues (what)? Evaluating and managing spiritual issues? Supporting family and caregivers? End-of-life care? Hospice?

12. I want to do a little shift here and ask you to think about patients with chronic illness who may

not be approaching the end of their lives. Do you think about them the same way or differently? What are your thoughts about whether those patients need the elements of palliative care services that we just discussed? Which elements?

13. Some practices are able to assess patients’ needs for these elements of palliative-oriented services and provide these elements at the practice level directly, whereas others are not.

Do you perform an assessment of palliative/supportive-oriented needs for your patients with serious or advancing illness?

Can you tell me which of these palliative elements your practice provides and which you refer?

Probes: Difficult conversations, assisting patients with goal setting, end-of-life services, caregiver support, advance care planning, physical symptoms, emotional symptoms, spiritual issues, social concerns: provide directly or refer? Does your practice ability to assess or provide these vary based on diagnosis (cancer vs noncancer)?

How is your practice structured to provide these? Are you providing these yourself? Who else is involved? How are they involved? Team approach?

14. What specialty palliative services are you able to refer these patients to? What about their caregivers and families?

Probe: Hospice: Inpatient or Outpatient? Outpatient Palliative care services? Other?

15. What else would you like to provide these patients/caregivers/families that is not available in your location?

Probe: Barriers to what practice can provide; barriers in the community.

16. If a guideline were available to help you to integrate palliative services into usual care for patients with chronic illness, what do you imagine would make it most helpful?

Probes: Visual model? Text? All-in-one or online support? How to access it? What content should it include? Which providers/clinicians in your practice should be using it?

I now would like to show you a proposed guideline from HealthTeamWorks, a nonprofit organization in Colorado (etc., describe HealthTeamWorks). Do you have the guideline I sent you so can you pull it up electronically? Please look it over for a minute if you have not yet.

17. In general, what do you think about this guideline?

Probes:

- What do you like/not like about it?
- What is missing, if anything?
- How do you think it might work in your practice?
- What barriers do you see in using it in your practice?
- What advice would you give to improve it?

18. If your practice were to engage in a practice improvement/transformation project (similar to what happens in some patient-centered medical home projects), would you be more likely to select 1 focused on a specific disease like diabetes care, or palliative care?

Probes: Why? What would make primary care providers choose the palliative care project first?

19. If your practice were to engage in a palliative/supportive care practice improvement project, what would help the practice do the project?

Probes: Motivation? People? Tools: patient identification strategies (registry)? Practice support/education/outside expertise?

20. Can you imagine how you might manage issues such as: Evaluation of palliative issues? Difficult conversations? Assisting patients with goal setting? Advance care planning? Managing symptoms? Caregiver support? Providing end-

of-life care? Offering emotional support? Offering spiritual support?

21. Have I missed anything? That is, is there anything else that is important for me to understand about your approach to palliative care?

Would you be willing to serve as a reviewer for a summary of our findings once we've completed our data collection? As part of our analytic process, we conduct a "member check," where we ask participants who are willing to review a summary and give us feedback on the degree to which the findings fit with their own clinical practice. We will use the feedback to revise our results before dissemination and/or future studies of the topic. Would you be willing/able to help us with this part of our study? **__ Yes __ No**

(If yes:) Thank you so much. It will likely be months before you will hear from us for the member check.

(If no:) Well thank you for considering this request. We understand that not everyone is able to commit to the member check.

Thank you for your participation today. We're grateful to learn from your experiences. Please do not hesitate to contact us if you have any questions.

Thanks again for your help!

End Time: __ __: __ __