

The Coordination of Primary and Oncology Specialty Care at the End of Life

Paul K. J. Han, Daniel Rayson

Correspondence to: Paul K. J. Han, MD, MA, MPH, Center for Outcomes Research and Evaluation, Maine Medical Center, 39 Forest Ave., Portland, ME 04101 (e-mail: hanp@mmc.org).

The end of life is a time in which both the intensity of cancer patients' needs and the complexity of care increase, heightening the need for effective care coordination between oncology and primary care physicians. However, little is known about the extent to which such coordination occurs or the ways in which it is achieved. We review existing evidence on current practice patterns, patient and physician preferences regarding involvement of oncology and primary care physicians in end-of-life care, and the potential impact of care coordination on the quality of care and health outcomes. Data are lacking on the extent to which end-of-life care is coordinated between oncology and primary care physicians. Patients appear to prefer the continued involvement of both types of physicians, and preliminary evidence suggests that coordinated care improves health outcomes. However, more work needs to be done to corroborate these findings, and many unanswered questions remain.

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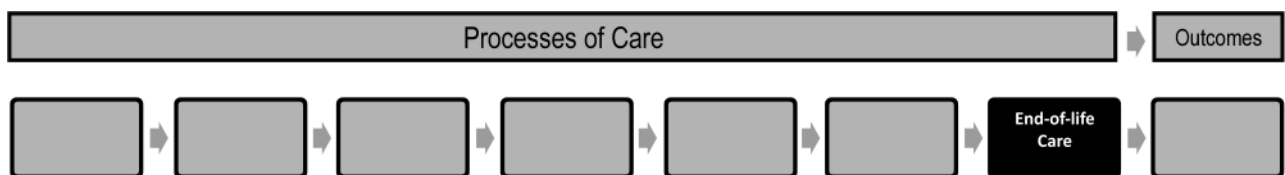


Figure 1. Types and transitions in care that constitute the process of care across the cancer continuum. Hx = history.

The end of life, the final stage in the cancer care continuum, poses unique challenges for the coordination of care between oncology and primary care physicians. At this stage, perhaps more than at any other, patients' needs for physical, emotional, and existential support become especially great, as symptoms often intensify and death becomes imminent (1). Communication between clinicians, patients, and family members—a vital endeavor at all stages of medical care—takes on added importance and difficulty under these circumstances.

Health-care delivery also becomes more complex at the end of life as the number of involved clinicians often increases and their care responsibilities change in fundamental ways. At earlier points on the disease continuum, care is delivered primarily by one or two sets of physicians: primary care physicians providing the bulk of care related to prevention, screening, and initial diagnosis, and oncologists providing care related to curative or palliative cancer treatments. The end of life, however, often involves additional clinical personnel, including hospice and palliative medicine physicians and nurses, as well as other allied health and supportive care professionals, such as social workers and clergy. The involvement of these various clinical professionals adds complexity to the care delivered to cancer patients and may alter the roles, responsibilities, and levels of engagement of primary care and oncology physicians. At the same time, the settings in which health care is delivered often change and become more varied at the end of life, moving outside of hospitals and clinics and into

skilled nursing facilities, inpatient hospice units, and/or the family home.

As both the complexity of care delivery and the intensity of patients' and families' needs increase at the end of life, the risks of fragmented and ineffective care become greater, and the coordination of care among various providers becomes an ever more critical task. A major aspect of this task is the coordination of care between primary care physicians and oncology specialists, who each have integral patient care responsibilities and roles. Despite this, surprisingly little is currently known about the coordination of care delivered by these two types of physicians and many unanswered questions exist. To what extent do oncology and primary care physicians assume various end-of-life care responsibilities, such as pain and symptom management, psychosocial and existential supportive care, communication regarding end-of-life goal setting and care priorities, and overall coordination of symptomatic and supportive care? How does the transition from active treatment or cancer survivorship to end-of-life care occur, and how are oncology and primary care specialists involved in these transitions? What are patients' and physicians' preferences regarding the involvement of different specialists in end-of-life care? And finally, how does the presence or lack of multidisciplinary care affect the quality of care delivery, and do best practices aiming to maximize care quality exist? In this article, we review existing literature in search of answers to these key questions, discuss

issues raised by past work, and attempt to identify critical areas in which further research is needed to move the field forward.

To begin to address these questions, some operational assumptions are needed. First, we define “oncologist” as any physician who has primary responsibility for patients’ cancer treatment; this includes medical and radiation oncologists, hematologists, and various surgical subspecialists (eg, ENT and gynecologic surgeons). We chose this inclusive definition because of our main interest in issues surrounding the coordination of care with primary care physicians; however, we recognize that these issues may differ depending on the oncology subspecialists involved. Second, we define “end of life” as the stage of care that occurs in the context of progressive disease and begins when the primary goal of treatment shifts from potential cure or significant prolongation of symptom-free survival to active palliation in the setting of treatment-refractory or clinically life-threatening disease. This shift to end-of-life care has profound medical, psychological, and existential implications, and the timing of this transition for any given patient varies as a function of numerous factors. We recognize that the onset of this stage, furthermore, is often difficult to identify prospectively and may not always be explicitly acknowledged by either clinicians or patients. We also recognize that in certain clinical situations, the timeline to “end of life” may be particularly long and that with the advent of novel targeted cancer therapies, the future holds promise for further prolongation of this timeline. This can add to the difficulty of delineating transition points between active oncological and “end of life” care. This difficulty, furthermore, makes the measurement of the quality of end-of-life care problematic (2–4).

For our purposes, however, we assume it is possible to define this stage with sufficient specificity and in a sufficient proportion of patients to make an analysis of end-of-life care coordination worthwhile. We also distinguish between end-of-life and palliative care, which refers to care directed at maximizing patients’ quality of life along multiple dimensions. The two are closely related both conceptually and practically because of the overlapping goal of maximizing quality of life through both symptom control and psychosocial support. The integration of palliative and oncological care across the cancer continuum is an important clinical and research problem in its own right and has attracted growing attention (5,6). Our focus in this article, however, is on end-of-life care, although we will often touch on palliative care to the extent that its goals are conceptually and practically related. We did not restrict our review to studies from any particular country or geographic region, although studies from Canada turned out to be particularly prominent, possibly because of health-care system attributes that have made the coordination of primary and specialty care an especially salient issue in Canada, compared with countries like the United States. These include potential differences in the overall utilization of primary care physicians in different countries.

Challenges at the Interface of Primary and Specialty Care: Current Practice Patterns in End-of-Life Care

A major challenge confronting primary care and oncology physicians is to determine their respective care responsibilities with

respect to one another, and this challenge is arguably the most problematic at the end of life. At earlier stages in the cancer care continuum (ie, screening, diagnosis, primary treatment, and adjuvant therapy administration) (Figure 1), responsibilities for patient care lie more clearly with one group of physicians or the other. During the phase of cancer survivorship, the boundaries of care responsibilities become more difficult to delineate because the main tasks at hand, such as surveillance for recurrent disease and the late or long-term effects of cancer or its treatment, potentially fall within the expertise and interest of both oncologists and primary care physicians. Care coordination issues at this stage, the subject of the article by Grunfeld and Earle (7) in this supplement, have thus become the subject of active research with evolving evidence regarding best practices and ongoing refinement of key conceptual issues (8–10).

End-of-life care poses even more ambiguity regarding the responsibilities of primary care and oncology specialists because the clinical tasks involved at this stage—including both technical aspects of care as well as communication and care coordination—may fall legitimately within each specialty’s domain of expertise and interest. As well, the heightened emotional and psychodynamic tensions at this stage in the disease process can exacerbate confusion and tensions about goals, expectations, and responsibilities of care. Exactly who assumes responsibility for what aspects of end-of-life cancer care has not been fully explored. Most previous studies related to this question have focused on the integration of palliative and oncological care and on the transition from curative to palliative goals of care in this setting. The available evidence from this line of work suggests that palliative care is often not optimally integrated in oncological care and that the transition to end-of-life care often occurs very close to death.

For example, a significant minority of cancer patients experience multiple emergency room visits and intensive care unit admissions during their last months of life. Past studies have shown that 8%–27% of patients with metastatic cancer make one or more visits to emergency room facilities, and 5.4%–12% of these patients are admitted to intensive care units in their last months of life (11–13). This suggests that for many dying cancer patients, the transition of care goals from active treatment to end-of-life care is suboptimal. As a result, these patients end up in medical environments poorly suited to the goals of end-of-life care, with consequent escalation of unnecessary, costly, and futile interventions.

Although oncologists may provide the bulk of clinical services for cancer patients at the end of life, it is conceivable that primary care physicians may become more involved as cancers progress and the goals of care shift from active oncological care to end-of-life care. However, the role and influence of primary care physicians in this process is not clear. Curiously lacking from the literature is an examination of exactly how the services of primary care physicians are coordinated and integrated in the care of dying cancer patients. To our knowledge, few studies have explored the extent, nature, and timing of primary care physicians’ involvement in the end-of-life care of cancer patients.

One study by Barnes et al. (14) examined cancer patients’ perceptions of the extent to which their family physicians were involved in their cancer care. In a review of 365 consecutive patients with metastatic cancer presenting for urgent palliative

radiotherapy to the Rapid Response Radiotherapy Program at the Toronto Sunnybrook Hospital, 98% had a family physician on record, but only 43% felt that their primary care provider was involved in their cancer care. In multivariate analyses, several factors predicted greater perception of family physician involvement, including overall satisfaction with this provider, shorter time since last family physician visit, visiting with the family physician since the cancer diagnosis, and provision of after-hours emergency services by the family physician. Overall, the findings suggested a relatively low and variable level of involvement of primary care physicians in the end-of-life care of cancer patients.

Further research is needed not only to better describe the patterns and impact of care delivered by primary care and oncology physicians but also to identify other potential reasons for variation in practice. For example, some researchers have asserted that the transition to end-of-life care for cancer patients is often marked by confusion—on the part of both patients and physicians—regarding the roles and responsibilities of primary care, oncology, and palliative care specialists (6,15). Delivery of active systemic therapy toward the end of life may further serve to marginalize the role of primary care providers by focusing care on active disease management rather than symptomatic and supportive care. In a population-based study from the Ontario Cancer Registry, Barbera et al. (12) observed that 16% of patients dying with cancer received chemotherapy in the past 2 weeks of life. The difficulties of communicating about potential changes in the goals of care in patients receiving active systemic therapy have been reviewed (16) and may diminish the role of primary care providers in patient care. Empirical evidence on the extent and outcomes of such role limitation and confusion in end-of-life care is scant; however, it stands to reason that it could impair care coordination and lead to poorer health outcomes (17).

Involvement of Primary Care and Oncology Physicians in End-of-Life Care: Patient and Physician Preferences

Irrespective of current practice patterns, an important issue in the coordination of end-of-life care is the question of what patients and physicians prefer regarding the involvement, roles, and responsibilities of primary care and oncology specialists. These preferences may ultimately influence patients' experiences with care at the end of life and thus represent a critical area of research.

Much of the existing research related to this issue has focused on general patient preferences regarding the role of different physicians in providing palliative care services. For example, a small number of studies have suggested that cancer patients value the involvement of their primary care physicians as a means of addressing needs related to quality of life. Sisler et al. (18) surveyed patient attitudes regarding family physician involvement in cancer care in a random sample of Canadian patients within the first year of a cancer diagnosis. In this study, 38.9% of patients reported that their oncologist and family physician were involved in the care of their cancer, 44.4% reported that their oncologist cared for all cancer-related problems, whereas their family physician cared for other problems, and 10.0% reported that specialists cared for all

their medical needs and that they rarely saw a family physician. Furthermore, approximately 75% of patients reported that the level of involvement of their family physicians in both treatment and follow-up care was “about right,” with the remainder expressing a desire for greater involvement of their family physicians. Patients reporting greater involvement of their family physicians had higher health-related quality-of-life scores as measured by the Functional Assessment of Cancer Therapy-general scale (FACT-G). Specific aspects of the care seen as provided by the family physician—discussing feelings of patients and family members, helping with noncancer problems, and answering questions about cancer and cancer treatment—also were associated with higher FACT-G scores.

These findings provide preliminary evidence that the continued involvement of primary care physicians in cancer care is valued by patients, may influence care experiences and outcomes, and serves identifiable functions specifically related to care at the end of life—in particular, meeting patients' needs for communication and emotional support. These findings have been corroborated by qualitative studies in both Canada (19) and the United Kingdom (20), which also suggest that cancer patients value primary care physicians for providing key information about their disease and treatment, as well as emotional support to themselves and their families. A key question raised by these findings is whether primary care physicians are willing and able to remain involved in the care process, particularly in nonintegrated health-care delivery systems, such as those in the United States, where numerous barriers—including lack of time and financial incentives—may discourage them from maintaining care continuity with their cancer patients.

To the extent that communication and emotional support represent key domains of palliative care, these studies provide preliminary insight into cancer patients' perceptions and preferences regarding physician roles at the end of life. Preferences regarding different physicians' roles in other specific supportive care domains, such as pain and symptom management, have not been explored. Furthermore, it is not clear whether patients actually prefer receiving information and psychosocial support from primary care physicians as opposed to oncology physicians or palliative medicine specialists or simply view primary care physicians as satisfying current unmet medical and/or situational needs.

Research on patient preferences regarding the provision of palliative care services provides suggestive, but indirect, evidence on preferences for the involvement of primary care and oncology physicians in end-of-life care. One relevant line of research has focused on patient perceptions regarding continuity of care, which has been identified as a core value underlying patient preferences for physician involvement in end-of-life care. Several qualitative studies (21–23) have shown that terminally ill patients, family members, and health professionals all place great value on the ideal of continuity of care at the end of life. Michiels et al. (23) interviewed end-stage cancer patients in Belgium and distinguished between two types of continuity that were important to patients: 1) “relational continuity”—having an ongoing relationship with the same physician over time and 2) “informational continuity”—the use by physicians of information on past events and personal circumstances of their patients. The value of both types of continuity was reflected in patients' expressed expectations and preferences

for the ongoing involvement of their primary care physicians in end-of-life care and for sharing of care responsibilities between primary care and oncology specialists.

Patient preferences for physician continuity of care at the end of life have been identified in some quantitative studies (24,25), but more work needs to be done to understand how general preferences for continuity of care relate to preferences concerning the specific roles and responsibilities of primary care and oncology physicians—both of whom may have meaningful longitudinal relationships with their patients. Further research also is needed to understand the factors that influence patient perceptions and preferences regarding physicians' care responsibilities at the end of life. de Vogel-Voogt et al. (26) conducted a qualitative study in the Netherlands of 128 patients with incurable cancer and found that satisfaction with primary care at the end of life varied according to patient education level, with those having lower education being more satisfied with their primary care providers. These findings need to be replicated, and more work needs to be done to identify additional factors that may be influential. Cancer patients' preferences regarding the role of palliative medicine specialists is another important area for future research. The recent expansion in the availability and involvement of palliative medicine specialists poses new challenges to the coordination of care between primary care and oncology physicians and may even threaten continuity of care at the end of life, depending on the extent and manner in which primary care responsibilities are transferred to palliative medicine physicians. Some cancer patients may feel abandoned during these care transitions (27), irrespective of whether oncologists or primary care physicians are involved.

These issues call for greater understanding of not only patients' but physicians' preferences and expectations regarding their respective roles in palliative and end-of-life care. Data on this issue also are limited, although Cherny and Catane (28) surveyed 895 European medical oncologists on their attitudes toward palliative care for patients with advanced and incurable cancer. In this survey, 88.4% of oncologists agreed that medical oncologists should coordinate the care of cancer patients at all stages of disease, including the end of life. However, only 52.8% reported receiving good training in palliative care, and approximately 35% believed that a palliative care specialist was the best person to coordinate the palliative care of advanced cancer patients and preferred having another physician look after their patients who were dying. These beliefs were reflected in self-reported practices: Only 43.2% of oncologists reported that they directly provided end-of-life care to their dying patients, and less than 40% indicated that they often collaborated with home hospice palliative care teams, palliative medicine physicians, or nurses. Similar data have not been collected in the United States, with the exception of a 1998 survey conducted by the American Society of Clinical Oncology (ASCO), in which pediatric oncologists reported using referrals to pain or palliative care specialists about half of the time, and maintaining primary responsibility for providing end-of-life care 75%–100% of the time (29).

These findings shed light on end-of-life care continuity between oncologists and palliative medicine specialists and suggest areas for future research. One conspicuous omission from these studies, however, were physicians' preferences and expectations

regarding the role of primary care physicians in end-of-life cancer care. This represents an important direction for future work, which might further examine the concordance of physician and patient preferences regarding the respective roles of primary care physicians, oncologists, and palliative medicine specialists in end-of-life care. Such work would allow an examination of how patient and physician preferences—and the concordance between these preferences—relate to patterns of care, care processes, and important patient-centered outcomes, including communication and patient satisfaction.

Quality of End-of-Life Care for Cancer Patients: Relationship to Care Coordination Between Primary Care and Oncology Physicians

In the final analysis, the coordination of end-of-life care between primary care physicians and oncologists is an important issue only insofar as it affects the quality of care that is delivered. As evidenced by recent literature syntheses (4,30) and a report by the Institute of Medicine (1), experts widely agree that coordination of care—conceived broadly—is a key factor influencing the quality of palliative and end-of-life care for cancer patients. However, as noted by the Institute of Medicine (1), no widely accepted indicators or measures of care coordination currently exist, and only a small number of studies have provided weak evidence that interventions to improve care coordination improve care outcomes for cancer patients at the end of life (4,30).

Data are particularly lacking on the nature and outcomes of care coordination occurring specifically between primary care physicians and oncologists. Limited data suggest only indirectly that care coordination affects important patient outcomes. For example, Jones et al. (31) observed a statistically significant lower risk of death among 329 patients with lung cancer if they had one or more primary care visits in the first 6 months after cancer diagnosis compared with those who did not use primary care. This study observed median survival times of 3.7 vs 7.5, 13.9, and 13.8 months for those with zero, one, two, and three primary care contacts, respectively ($P < .0001$). However, these primary care visits may have been devoted to addressing problems that had little or nothing to do with patients' cancer or the coordination of cancer care. The study did not examine key variables including the extent of care coordination between primary care and oncology specialists. Furthermore, although a few outcomes studies have examined “coordination” and “continuity” with respect to the provision of particular services (eg, home care, hospice, and nursing support) or information to cancer patients at the end of life (30,32), care coordination specifically between primary care and oncology physicians has not been examined. This is a critical gap in our knowledge, given that each of these physicians might legitimately “lay claim” to care responsibilities in these domains, and differences in their perspectives and skills may influence the quality of care provided.

In this respect, the few data that are available do shed light on potential ways in which the coordination of care between primary care physicians and oncologists might affect the quality of end-of-life care in cancer patients. In an observational study of advanced breast cancer patients tracked by the Surveillance, Epidemiology, and

and End Results (SEER)-Medicare database, Keating et al. (33) examined predictors of hospice use and enrollment at the end of life. In multivariate analyses adjusting for patient characteristics, hospice referral rates differed significantly according to the physicians seen by the patient: 41% for patients seeing both a cancer specialist and a primary care physician, 38% for patients seeing a cancer specialist and no primary care physician, and 30% among those seeing a primary care physician and no cancer specialist. The finding of higher rates of hospice referral for oncology specialists than for primary care physicians is consistent with another study by Keating et al. (34) and may suggest a greater propensity or capacity of oncologists to use palliative and end-of-life care services or to recognize the appropriateness of such services (33). However, some studies have shown no specialty-specific differences in hospice referral rates (35), and others have shown longer survival time for hospice patients referred by primary care vs oncology physicians (36). Other studies have identified specialty-specific attitudinal differences that may moderate the effect of physician specialty on hospice referral patterns, including more favorable attitudes toward hospice care (37), longer lead-time preference for hospice referral (38), and more pessimistic estimates of prognosis (39) for primary care than for oncology physicians.

Important unmeasured variables in all of these studies include the nature and extent of interaction between primary care and oncology physicians. Primary care physicians may bring different preferences and skills to bear in end-of-life care, and their concurrent involvement may have interactive effects on care quality. In this regard, the finding by Keating et al. (33) that patients seeing both an oncologist and a primary care physician had the highest hospice referral rate is intriguing and may suggest some beneficial influence of care coordination or of the involvement of greater numbers of physicians in decision making at the end of life.

Similarly, it is possible that coordination and continuity of care may affect utilization of other important clinical services at the end of life. Burge et al. (40) examined correlates of continuity of end-of-life care for metastatic cancer patients provided by family physicians in Nova Scotia, Canada, an area in which the bulk of such care is provided by family physicians. In this retrospective population-based study, continuity of care (operationalized in terms of the proportion of patient visits to a single vs multiple providers) was strongly associated with lower emergency department utilization at the end of life. The relationship between care continuity and intensive care unit utilization was examined by Sharma et al. (41), who used the SEER-Medicare database to study end-of-life hospital care received by advanced lung cancer patients in the United States. In this study, continuity of care—operationalized in terms of whether patients were seen by their usual care provider during their final recorded hospitalization—was associated with a 25% reduced odds of entering the intensive care unit. The potential influence of care continuity on end-of-life health services utilization was also examined by Barbera et al. (12) in Canada. Their study found that patients who received home care within 6 months of death, or a palliative care assessment or family physician home visit within 2 weeks of death, had a significant reduction in the odds of receiving poor quality of care at the end of life—indicated by a reduction in intensive care admissions, emergency department visits, and receipt of chemotherapy.

Although these findings may be difficult to generalize to other care settings, they suggest that continuity of care may have important effects on the use of important health services at the end of life.

COMMENTARY

Cancer care in the nursing home setting is an informational black hole. No good data exist. Quality of care measures in traditional care and nursing home care don't match. Many cancers are diagnosed after admittance to a nursing home. Everything is different in the nursing home setting: no primary care providers, no multidisciplinary care teams. Care is provided by the nursing home staff, and 50 percent of nursing homes currently have unfilled medical director positions.

From a Supplement Author

Some important unanswered questions, however, are whether these same potential effects apply equally to continuity of care provided by oncologists and primary care physicians in other settings, and how “discontinuity” posed by concurrent visits to both oncologists and primary care physicians in other settings might also influence the use of various health services.

A few other small studies have compared primary care and oncology physicians in terms of specific end-of-life care practices, such as pain management. Older studies of care delivered in home hospice settings have suggested that oncologists are more aggressive than primary care physicians in prescribing opioids for pain control (42,43). Corroborating the generalizability of these findings, a survey of French oncology and primary care physicians found that primary care physicians were less satisfied with their ability to manage pain and more reluctant to prescribe morphine for pain control (44). A more recent survey (45), however, found that although French primary care physicians were more likely than oncologists to equate high-dose morphine therapy with euthanasia, they did not report lower morphine prescribing in general. These types of studies have not been replicated in Canada or the United States, where the rate of opioid prescribing in general and by primary care physicians has been increasing recently (46), but they raise the possibility that involvement of oncology physicians may foster greater use of opioids for pain control in cancer patients at the end of life. These trends further heighten the need for care coordination and communication because opioids are legally controlled substances requiring careful monitoring and management and for which individual physicians typically assume prescribing responsibility.

Clearly, much remains unknown about the determinants and outcomes of care coordination and continuity in end-of-life care. Further research examining best practices, communication tools, patient experiences with care, cost effectiveness, and health-related quality of life in relation to the integration of primary and oncology care will be required to meet escalating demands for quality end-of-life care for patients with advanced cancer.

Future Needs and Potential Solutions

Expert consensus and emerging empirical evidence suggests that the effective coordination of health care at the end of life is a major need for cancer patients and that the interaction between oncology

and primary care physicians is a critical aspect of this coordination. The end of life is a period characterized by added diversity and intensity of patient and caregiver needs, and potentially dramatic, existentially challenging transitions in care goals, providers, and settings. Under these circumstances, oncologists and primary care physicians may assume a variety of roles and care responsibilities, but these have not been fully characterized. We also lack data about whether these roles and responsibilities vary when different oncology subspecialists are involved in patient care. Patients appear to prefer the continued involvement of both oncology and primary care physicians in end-of-life care, but these preferences have only begun to be defined, and it is unclear whether physicians share those preferences. Similarly, we know little about how the concurrent involvement and interaction of primary care and oncology physicians affects patient outcomes and care quality at the end of life, although preliminary evidence suggests that shared care leads to improved outcomes.

The primary need going forward is for more empirical research to address these many incompletely answered questions. Several specific issues require further attention:

1. Defining the time period at which end-of-life care begins.
2. Assessing the patterns and specific components of end-of-life care as provided by different types of oncologists and primary care physicians.
3. Understanding patient and caregiver preferences for the relative involvement of oncology vs primary care medical specialists at the end of life.
4. Designing appropriate and validated assessment tools to further understand how end-of-life care should best be managed.
5. Evaluating the impact, in terms of quality of care and other end-points, of different models of end-of-life care and understanding how these different models might be implemented in different health-care delivery systems.
6. Ascertaining best practices and methodologies for integrating primary and oncology specialty care in patients dying of advanced cancer.

Adequately addressing these questions is a particular challenge, given the general lack of research support that continues to exist in palliative medicine and that limits research on the role of the primary care medical team in caring for dying cancer patients (47).

The field also may benefit from further theoretical work to conceptualize the problem of care coordination as it applies to the involvement of primary care and oncology physicians in end-of-life care. Implicit in research examining the coordination of services by these different physicians are questions related to the relative value of different models of care and the assessment of best practices and barriers to shared coordinated care. An underlying assumption is that some sort of shared care or “collaborative” (6) model may be preferable to patients and more effective in achieving desired outcomes, in contrast to models in which care occurs in a sequential (involving the transfer of primary care responsibilities to different providers over time) or parallel (involving the provision of care by two or more physicians acting independently) fashion (19). Further theoretical work examining these alternative models and concepts and their meaning for end-of-life care would be useful to orient future empirical research.

The ultimate goal of research is to inform the design of interventions to improve the coordination—and thus the quality—of end-of-life care. One promising approach toward this goal may be to apply interventions that have been developed to improve communication between primary care and oncology specialists at earlier stages of the cancer care continuum. For example, Jefford and Moore (48) conducted a small randomized controlled trial evaluating the outcomes of providing primary care physicians with tailored specific information regarding the treatment regimens of their cancer patients receiving chemotherapy. This trial demonstrated a statistically significant improvement in confidence and satisfaction with care delivery. Although the study did not specifically focus on end-of-life care, it does suggest a promising strategy for enhancing communication between oncology and primary care medical specialties at all stages of the cancer care continuum, including end-of-life care. Further work to develop and evaluate interventions to coordinate cancer care at the end of life are clearly needed to further knowledge and move the integration of primary and oncology care from anecdote and accident to best practice and to improve the quality end-of-life care for all cancer patients.

References

1. Institute of Medicine. *Improving Palliative Care for Cancer*. Washington, DC: National Academies Press; 2001.
2. Earle CC, Ayanian JZ. Looking back from death: the value of retrospective studies of end-of-life care. *J Clin Oncol*. 2006;24(6):838–840.
3. Earle CC, Landrum MB, Souza JM, Neville BA, Weeks JC, Ayanian JZ. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol*. 2008;26(23):3860–3866.
4. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med*. 2008;148(2):147–159.
5. Rayson D, McIntyre P. Transitions to palliation: two solitudes or inevitable integration? *Curr Oncol Rep*. 2007;9(4):285–289.
6. Davis MP. Integrating palliative medicine into an oncology practice. *Am J Hosp Palliat Care*. 2005;22(6):447–456.
7. Grunfeld E, Earle CC. The interface between primary and oncology specialty care: treatment through survivorship. *J Natl Cancer Inst Monogr*. 2010;40:25–30.
8. Grunfeld E, Fitzpatrick R, Mant D, et al. Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial. *Br J Gen Pract*. 1999;49(446):705–710.
9. Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol*. 2006;24(6):848–855.
10. Institute of Medicine. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.
11. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol*. 2003;21(6):1133–1138.
12. Barbera L, Paszat L, Chartist C. Indicators of poor quality end-of-life cancer care in Ontario. *J Palliat Care*. 2006;22(1):12–17.
13. Grunfeld E, Lethbridge L, Dewar R, et al. Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. *Palliat Med*. 2006;20(8):769–777.
14. Barnes EA, Fan G, Harris K, et al. Involvement of family physicians in the care of cancer patients seen in the palliative Rapid Response Radiotherapy Program. *J Clin Oncol*. 2007;25(36):5758–5762.
15. Steinberg SM, Block SD. Caring for patients at the end of life in an HMO. *J Palliat Med*. 1998;1(4):387–399.
16. Harrington SE, Smith TJ. The role of chemotherapy at the end of life: “when is enough, enough?” *JAMA*. 2008;299(22):2667–2678.

17. Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. *BMJ*. 1990;301(6746):277–281.
18. Sisler JJ, Brown JB, Stewart M. Family physicians' roles in cancer care. Survey of patients on a provincial cancer registry. *Can Fam Physician*. 2004;50(6):889–896.
19. Norman A, Sisler J, Hack T, Harlos M. Family physicians and cancer care. Palliative care patients' perspectives. *Can Fam Physician*. 2001;47(10):2009–2012, 2015–2016.
20. Kendall M, Boyd K, Campbell C, et al. How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Fam Pract*. 2006;23(6):644–650.
21. Borgsteede SD, Graafland-Riedstra C, Deliëns L, Francke AL, van Eijk JT, Willems DL. Good end-of-life care according to patients and their GPs. *Br J Gen Pract*. 2006;56(522):20–26.
22. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozny DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. *J Gen Intern Med*. 2001;16(1):41–49.
23. Michiels E, Deschepper R, Van Der Kelen G, et al. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliat Med*. 2007; 21(5):409–415.
24. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19): 2476–2482.
25. Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ*. 2006;174(5):627–633.
26. de Vogel-Voogt E, van der Heide A, van Leeuwen AF, Visser A, van der Rijt CC, van der Maas PJ. Patient evaluation of end-of-life care. *Palliat Med*. 2007;21(3):243–248.
27. Han PK, Arnold RM. Palliative care services, patient abandonment, and the scope of physicians' responsibilities in end-of-life care. *J Palliat Med*. 2005;8(6):1238–1245.
28. Cherny NI, Catane R. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. *Cancer*. 2003;98(11):2502–2510.
29. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol*. 2001; 19(1):205–212.
30. Gysels M, Higginson I. *Improving Supportive and Palliative Care for Adults with Cancer: Research Evidence*. London, UK: National Institute for Clinical Excellence; 2004.
31. Jones LE, Doebbeling CC. Beyond the traditional prognostic indicators: the impact of primary care utilization on cancer survival. *J Clin Oncol*. 2007;25(36):5793–5799.
32. Addington-Hall JM, MacDonald LD, Anderson HR, et al. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ*. 1992;305(6865):1317–1322.
33. Keating NL, Landrum MB, Guadagnoli E, Winer EP, Ayanian JZ. Care in the months before death and hospice enrollment among older women with advanced breast cancer. *J Gen Intern Med*. 2008;23(1):11–18.
34. Keating NL, Herrinton LJ, Zaslavsky AM, Liu L, Ayanian JZ. Variations in hospice use among cancer patients. *J Natl Cancer Inst*. 2006;98(15): 1053–1059.
35. Stillman MJ, Syrjala KL. Differences in physician access patterns to hospice care. *J Pain Symptom Manage*. 1999;17(3):157–163.
36. Lamont EB, Christakis NA. Physician factors in the timing of cancer patient referral to hospice palliative care. *Cancer*. 2002;94(10):2733–2737.
37. Bradley EH, Cramer LD, Bogardus ST Jr, Kasl SV, Johnson-Hurzel R, Horwitz SM. Physicians' ratings of their knowledge, attitudes, and end-of-life-care practices. *Acad Med*. 2002;77(4):305–311.
38. Iwashyna TJ, Christakis NA. Attitude and self-reported practice regarding hospice referral in a national sample of internists. *J Palliat Med*. 1998;1(3):241–248.
39. Rose JH, O'Toole EE, Dawson NV, et al. Generalists and oncologists show similar care practices and outcomes for hospitalized late-stage cancer patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks for Treatment. *Med Care*. 2000;38(11):1103–1118.
40. Burge F, Lawson B, Johnston G. Family physician continuity of care and emergency department use in end-of-life cancer care. *Med Care*. 2003;41(8):992–1001.
41. Sharma G, Freeman J, Zhang D, Goodwin JS. Continuity of care and intensive care unit use at the end of life. *Arch Intern Med*. 2009; 169(1):81–86.
42. Nowels D, Lee JT. Cancer pain management in home hospice settings: a comparison of primary care and oncologic physicians. *J Palliat Care*. 1999;15(3):5–9.
43. Ramsay A. Care of cancer patients in a home-based hospice program: a comparison of oncologists and primary care physicians. *J Fam Pract*. 1992;34(2):170–174.
44. Larue F, Colleau SM, Fontaine A, Brasseur L. Oncologists and primary care physicians' attitudes toward pain control and morphine prescribing in France. *Cancer*. 1995;76(11):2375–2382.
45. Peretti-Watel P, Bendiane MK, Obadia Y, Favre R, Lapiana JM, Moatti JP. The prescription of opioid analgesics to terminal cancer patients: impact of physicians' general attitudes and contextual factors. *Palliat Support Care*. 2003;1(4):345–352.
46. Olsen Y, Daumit GL, Ford DE. Opioid prescriptions by U.S. primary care physicians from 1992 to 2001. *J Pain*. 2006;7(4):225–235.
47. Gelfman LP, Morrison RS. Research funding for palliative medicine. *J Palliat Med*. 2008;11(1):36–43.
48. Jefford M, Moore R. Improvement of informed consent and the quality of consent documents. *Lancet Oncol*. 2008;9(5):485–493.

Affiliations of authors: Center for Outcomes Research and Evaluation, Maine Medical Center, 39 Forest Ave, Portland, ME 04101 (PKJH); Division of Medical Oncology, Department of Medicine, Dalhousie University, Halifax, NS, Canada (DR).