

## Directly Observed Patient–Physician Discussions in Palliative and End-of-Life Care: A Systematic Review of the Literature

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### Abstract

**Objectives:** To review studies that used direct observation (i.e., videotaping or audiotaping) methods in palliative/end-of-life care communication research.

**Design:** Descriptive thematic analysis.

**Setting:** Multinational studies were conducted in both the outpatient and inpatient setting.

**Measurements:** Extensive bibliographic searches (January 1, 1998 to July 31, 2009) of English-language literature involving physician–patient (or physician–family) interactions were conducted and augmented by reviews of reference listings. Three investigators independently abstracted key information from each article.

**Results:** Of the 20 retained articles, most enrolled young-old participants (mean age, 60 years) who were white and had a cancer diagnosis. Patient/family participation rates ranged from 68% to 89% demonstrating feasibility of this approach when studying palliative/end-of-life care communication issues. Four common themes were identified: (1) physicians focus on medical/technical and avoid emotional/quality of life issues; (2) sensitive topics are perceived by physicians to take longer to discuss and often do take longer to discuss; (3) physicians dominate discussions; and (4) patient/family satisfaction is associated with supportive physician behaviors.

**Conclusions:** This study demonstrates that direct observation methods can be feasibly used when studying physician–patient/physician–family communication in palliative/end-of-life care, but few investigations have utilized this approach. This article highlights areas that need improvement, including physicians' ability to address patient/family emotional issues and provide what patients and families find most satisfying (participation and support). A particular focus on older patients and patients with end-stage or late-stage chronic (noncancer) illness, the adaptation/application of existing communication measurement tools to capture palliative care communication issues, and development of corresponding outcome measures to assess impact is now needed.

### Introduction

PALLIATIVE CARE involves multiple dimensions of care directed at relieving symptoms and improving quality of life for patients with chronic and/or life-threatening illness across the spectrum of disease severity. Key elements include effective management of pain and other symptoms, treating the patient as an individual, family inclusion, delivering care consistent with patient and family goals and values, taking a multidisciplinary approach with attention to coordination of care and ensuring continuity of providers.<sup>1</sup> Effective communication between physicians and patients/patients' families (including nonrelated significant others) constitutes the foundation for many of these tasks.<sup>2–5</sup>

Prior research in communication and palliative care has focused mainly on communicating prognosis to patients with cancer, breaking bad news, the elements of care necessary to ensure a good death, and physician and patient communication around advanced care planning preferences. In general, patients with cancer desire specific estimates about their life expectancy, whereas physicians voice difficulty providing precise estimates.<sup>6</sup> Research on communication at the end of life suggests that it is important to elicit patients' preferences, which can include preparing for death, minimizing pain and other debilitating symptoms, and avoiding inappropriate prolongation of the dying process. Patients prefer initiation of advance directive discussions early in their disease course by their primary care physician.<sup>7</sup> Despite this, many patients

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Accepted January 19, 2010.

report they have not discussed advanced directives with their physician and physicians do not know their patients end-of-life preferences.<sup>2</sup> Even when patients have documented end-of-life preferences, these are often not recognized once they are hospitalized with a serious condition.<sup>8</sup>

The studies described above gathered data almost exclusively via focus groups, expert panels, as well as patient, caregiver, and/or physician surveys. Direct observation methods, i.e., recording actual physician–patient interactions, constitute a complementary approach to studying communication issues in palliative care. Directly observed discussions capture actual interactions and allow for an analysis of the process of communication. Utilizing this approach avoids problems with recall and can accurately capture both quantitative aspects of communication (e.g., length of time of discussion), as well as qualitative aspects of the interactions (e.g., style of speech). Although these approaches have been previously used in both primary care and oncology settings<sup>9,10</sup> the extent to (and ways in) which this approach has been used in palliative care communication research have not been previously defined.

Accordingly, we conducted a systematic review of palliative care studies that employed direct observation methods involving actual conversations between physicians and patients/families. We specifically sought to: (1) quantify the number and types of studies that employed direct observation methods; (2) identify common themes in these studies; (3) identify gaps in the literature that could help to inform future research initiatives in the field of communication in palliative care; and (4) offer clinicians practical strategies to improve communication with patients and families in the palliative care setting.

## Methods

### Search strategy and selection criteria

We searched the Ovid/MEDLINE, PubMed, EMBASE, CINAHL, Pre-CINAHL, and Social Gerontology databases (January 1, 1998 to July 31, 2009) to identify pertinent articles for review. MeSH terms included palliative care, terminally ill, and communication. Other keywords included palliative care, palliative therapy, terminal disease, terminal care, dying, end of life, communication, discussion, videotape, audiotape, videodisc, and recording. Citation abstracts identified in the initial search were independently reviewed to determine their suitability for inclusion in the review. If eligibility could not be determined from the abstract, the full text of the article was reviewed.

Articles were included if they: (1) used direct observation methods when studying physician–patient or patient family interaction via audiotape or videotape recordings; (2) were published in English; and (3) focused on adult (versus pediatric) populations. (The focus on adult populations was due to the fact that three of the four authors were geriatricians.) The search linking the above keywords with “videotape” or “audiotape” produced 265 citations. Articles were excluded because they focused on pediatric populations ( $n = 156$ ), used audiotaping as a means of recording survey interviews with patients and not actual patient–physician interactions ( $n = 39$ ), did not focus on a communication issue in palliative or end-of-life care ( $n = 37$ ), or were not written in English ( $n = 16$ ). Seventeen articles met the above criteria and were

retained for review. Three additional studies were included after reviewing the reference lists of the retained articles resulting in a final sample of 20 articles.

### Data extraction and synthesis

Three investigators independently abstracted information on study articles. Information regarding study design, setting, methodology, participants along with study outcomes was extracted. Frequently appearing themes and key findings were characterized and enumerated. The authors conducted a descriptive thematic analysis. All coding discrepancies were resolved by discussion.

## Results

### Descriptive characteristics of sample

One study generating nearly half of the articles took place in the medical intensive care unit.<sup>11</sup> The rest of the studies were conducted in outpatient clinics, most were oncology clinics (70%). Patient/family participation rates ranged from 68% to 89% with a median value of 74%. All the articles evaluated physician language and communication, while over half also evaluated patient or family member language and communication. The median number of physicians observed in the studies was 35 (range, 3–56), whereas the median number of patients was 56 (range, 6–1832). All but one study used audiotaping as the recording medium. The studies were multinational with over half conducted outside the United States.

### Study design and focus

Studies were organized by design to include descriptive, quantitative, both descriptive and quantitative, as well as interventional investigations. Each study is briefly described below.

**Descriptive studies ( $n = 10$ ).** One investigation<sup>11</sup> identified the content and styles of physician communication employed during intensive care unit (ICU) family meetings involving withholding/withdrawing life support or breaking bad news. Using the same audiotaped conversations, other investigators described physician (and family) expressions of patient nonabandonment,<sup>12</sup> missed opportunities for physicians to express family support,<sup>13</sup> tensions arising during the course of the meetings (e.g., disagreements around honoring the patient’s wishes versus the family’s wishes) and communication strategies physicians used in response to these tensions,<sup>14</sup> as well as alterations that occurred when medical interpreters were present for conversations with non-English-speaking families.<sup>15</sup> Two investigations<sup>16,17</sup> described communication content that occurred between physicians and patients/families in the context of delivering palliative cancer care. Another investigation<sup>18</sup> characterized the process of communication between physicians and patients discussing the option of palliative chemotherapy. One article<sup>19</sup> sought to characterize the extent to which physicians provided information regarding prognosis to advanced cancer patients during an initial visit and whether the topic of death was discussed (and the methods of doing so). Finally, one study<sup>20</sup> determined how physicians discuss advance directives with patients during routine office visits.

**Quantitative studies ( $n = 2$ ).** Two articles examined potential associations between specific physician communication strategies and outcomes. Using data from the ICU physician–family conference study described above, investigators demonstrated that the amount of time families (versus physicians) talked<sup>21</sup> and the degree of emotional support provided by physicians to families during these meetings<sup>22</sup> were both independently associated with increased family satisfaction.

**Descriptive and quantitative studies ( $n = 6$ ).** Two investigations<sup>23,24</sup> characterized the content of physician communication around health-related quality of life issues when delivering palliative chemotherapy to patients with cancer. Another study<sup>25</sup> focused on the types of information provided to patients with advanced cancer during an initial consultation. Using the ICU physician–family meeting data, investigators described the types of prognostic information<sup>26</sup> and the extent to which shared decision-making occurred during the conversations.<sup>27</sup> Patient and physician characteristics associated with these outcomes were examined in the above studies. The sixth investigation<sup>28</sup> described communication strategies used by physicians deemed to be experts in bioethics/end-of-life care during advance directive discussions and compared the specific types of strategies used by this group to those used by general practitioners.

**Interventional studies ( $n = 2$ ).** Two articles<sup>29,30</sup> examined the efficacy of interventions designed to facilitate patient–physician communication. Providing patients receiving palliative chemotherapy with a standardized health-related quality of life assessment tool prior to a routine office visit with their oncologist was found to increase both physician discussion of and awareness of patients' quality of life issues.<sup>29</sup> Similarly, use of a question prompt list administered to patients with advanced cancer prior to a routine office visit increased patient–physician communication around prognosis/end-of-life care issues.<sup>30</sup>

### Common themes

Despite the varied topics and study settings, four common themes emerged and are described below:

1. Physicians focus on medical/technical issues and avoid emotional issues ( $n = 9$ ): Nine articles<sup>16–18,20,23–25,28,29</sup> found that medical and technical (procedures and treatments) issues were discussed more and were more likely to be brought up by physicians than quality of life and emotional issues during medical encounters. For example, one randomized controlled trial<sup>29</sup> sought to determine whether a standardized health-related quality of life could facilitate discussion (and increase physician awareness) of quality of life issues during outpatient oncology visits. Although the intervention improved physicians' ability to identify and discuss quality of life issues, physicians still focused on medical/technical issues three times as much as quality of life and emotional issues. However, this finding was still true when several of the quality of life issues were reported as "severe."<sup>23</sup> Another study<sup>16</sup> found that physicians initiated discussions mostly
2. Sensitive topics are perceived by physicians to (and often do) take longer to discuss ( $n = 4$ ): One study<sup>23</sup> found that perceived time pressures, measured by how long after the scheduled appointment time the encounter actually started (e.g., patient scheduled to be seen at 3:30 PM but the encounter did not begin until 4:15 PM), decreased the time physicians devoted to emotional issues. In one of the randomized controlled trials,<sup>29</sup> where intervention patients were administered a standardized health-related quality of life questionnaire that was then given to physicians as a means of facilitating quality of life discussions, mean visit time was 7.3 minutes longer than in the control group. Similarly, another study<sup>19</sup> found that experts' discussions regarding advanced directives lasted 6.6 minutes longer than nonexperts' discussions. Finally, another study<sup>26</sup> found that providing information regarding ICU patient prognosis was associated with longer physician–family conferences.
3. Physicians dominate conversations ( $n = 9$ ): Five studies<sup>16,17,20,21,28</sup> reported that physicians use approximately 60%–70% of the discursive space (the amount of spoken words) during these discussions. Physicians guide discussions in several ways including topic choice and depth each topic is explored. This communication approach is particularly problematic because many physicians avoid discussion of quality of life and emotional issues. One study<sup>18</sup> illustrated this point by showing how physicians reframed rather than validated patients' experiences to lessen the emotional intensity of the encounter.
4. Patient and family satisfaction is associated with supportive physician behaviors and greater patient/family participation ( $n = 5$ ): Increased family satisfaction was associated with more frequent clinician statements about not abandoning the patient at the end of life, ensuring patient's comfort, and supporting family's decision about end-of-life decisions.<sup>22</sup> Satisfaction was positively correlated with increased family speech time irrespective of conference length<sup>21</sup> and negatively correlated with number of missed opportunities to clarify, offer support or acknowledge emotion in ICU family conferences.<sup>13</sup> Finally, higher levels of shared decision-making were associated with greater family satisfaction.<sup>27</sup>

around treatment issues, whereas patients typically initiated discussions about quality of life issues and what is to come in the future. Similarly, one study<sup>17</sup> reported that psychosocial topics were raised about ten times more by patients and their families as compared to physicians. Another investigation<sup>25</sup> found that the impact of palliative chemotherapy on work, sexual, and social aspects of life was rarely discussed and the emotional impact of treatment was never discussed. Finally, one study<sup>18</sup> characterized the types of interactions between patients and physicians finding that two of the three main ways physicians respond to patients involve down-playing or avoiding further discussion about patients' emotional experiences related to their disease. Physicians responded by "toning down" the level of emotion by assigning possible medical explanations

TABLE 1. CHARACTERISTICS OF STUDY SAMPLE

<i>Author, Year</i>	<i>Purpose</i>	<i>Setting</i>	<i>n (Physicians)</i>	<i>n (Patients/ family members)</i>	<i>Location</i>	<i>Method of analysis</i>	<i>Key concepts</i>
<b>Descriptive Studies</b>							
Curtis, 2002 <sup>11</sup>	To identify content styles of communication used by ICU physicians in ICU family meetings	ICU	36	0/163	Seattle, WA	Qualitative using grounded theory	Coded communication into "content" and "style and support" categories.
West, 2005 <sup>12</sup>	To identify expressions of nonabandonment during ICU family meetings	ICU	35	51/169	Seattle, WA	Qualitative using grounded theory; ATLAS-TI employed to help with data organization	Implicit statements of nonabandonment were used more frequently by both physicians and families. Physicians expressed nonabandonment by ensuring comfort, accessibility to staff and by valuing family's decisions.
Curtis, 2005 <sup>13</sup>	To identify missed opportunities to provide family support during ICU family meetings	ICU	35	51/169	Seattle, WA	Qualitative using grounded theory	Approximately 30% of conferences had missed opportunities to offer support or information to families. Conferences with more missed opportunities were associated with lower family satisfaction.
Hsieh, 2006 <sup>14</sup>	To identify tensions arising during the course of ICU family meetings and communication strategies employed by physicians in response to these tensions	ICU	36	51/169	Seattle, WA	Qualitative with dialectical perspective	Information-seeking strategies worked better than decision-centered strategies when dealing with contradictions between families and physicians.
Pham, 2008 <sup>15</sup>	To identify frequency of interpretation errors occurring during ICU family meetings requiring presence of a language interpreter	ICU	9	0/70	Seattle, WA	Qualitative using grounded theory and previously validated framework for coding of errors	Alterations occurred in 55% of all interpreted speech passages. Seventy-seven percent of alterations could have potentially changed goals of care—93% in a negative way, 7% in a positive way.
Ohlen, 2008 <sup>16</sup>	To describe content of communication between palliative care specialists and advanced cancer patients	Oncology outpatient clinic	3	6/0	Sweden	Qualitative with deductive analysis	Physicians usually initiated medical topics associated with studies and treatments. Patients usually initiated topics about living with a life-threatening illness, care at the end-of-life or the future.
Timmermans 2005 <sup>17</sup>	To describe types and amount of patient/proxy participation occurring during initial consultation with radiation oncologist and to quantify strategies physicians employ to stimulate patient/proxy participation	Radiation oncology outpatient clinic	8	54/0	Nijmegen, The Netherlands	Roter Interaction Analysis System (RIAS)	Patients talked mostly about their experiences and life circumstances whereas physicians provided medical/technical information during the encounter.

Lidén, 2009 <sup>18</sup>	To describe how the interaction between patient and physician shapes the discussion about changing prognosis in an outpatient oncology clinic	Oncology outpatient clinic	3	6/0	Sweden	Qualitative	Two frames of conversation were characterized: person-person frame and person-professional frame. Person-professional frames included 3 patterns: (1) patients emphasizing his/her emotional experience of illness and physician responding using “toning down” strategies, (2) patients asking direct questions and receiving direct answers from physicians and (3) patients avoiding topics about their health.
Rodriguez, 2007 <sup>19</sup>	To describe how physicians—implicitly or explicitly—discuss death	Oncology outpatient clinic	6	29/0	Australia	Qualitative	80% of visits included discussion about prognoses, always with implicit talk of death and only half the time with explicit talk of death.
Tulsky, 1998 <sup>20</sup>	To describe types of information conveyed when physicians engage in advance directive discussions	Primary medicine clinic	56	56/0	Durham, NC and Pittsburgh, PA	Qualitative; Unix Text Analyzer	Less than 1/3 of advance directive (AD) discussions touched on emotional concerns. Most posed hypothetical scenarios that were very dire and discussed treatment possibilities, while 71% of the discussions touched on values/goals/reasons for ADs.
<b>Quantitative Studies</b>							
McDonagh, 2004 <sup>21</sup>	To determine whether increased amounts of family speech during ICU meetings are associated with greater family satisfaction	ICU	35	51/169	Seattle, WA	Amount of time spent talking quantitated by the investigators	Increased family satisfaction was associated with more family speech time. Family satisfaction was not correlated with total duration of conference. More tension was negatively associated with family speech time.
Stapleton, 2006 <sup>22</sup>	To assess for associations between physician communication behaviors conveying support and family satisfaction	ICU	35	51/169	Seattle, WA	Qualitative using grounded theory	Three clinician statements were associated with greater family satisfaction: 1) nonabandonment, 2) assuring patient comfort, and 3) supporting family's end-of-life decisions.
<b>Descriptive and Quantitative Studies</b>							
Detmar, 2001 <sup>23</sup>	To describe physicians' communication of HRQL issues with patients receiving palliative care	Oncology outpatient clinic	10	240/0	The Netherlands	Roter Interaction Analysis System (RIAS)	Emotional functioning and fatigue issues were not addressed half the time, even among patients who ranked them as severely problematic. Physician perceived time pressure associated with less time devoted to emotional concerns.
Rodriguez, 2009 <sup>24</sup>	To describe the content and frequency of communication about HRQL issues during outpatient encounters between oncologists and advanced cancer patients	Oncology outpatient clinic	37	70/0	Durham, NC and Pittsburgh, PA	Qualitative using content analysis	HRQL issues discussed, but communication remained mostly about treatment and symptoms even in patients with very advanced disease. Psychological, social and spiritual issues were the least frequently discussed.

(continued)

TABLE 1. CONTINUED

<i>Author, Year</i>	<i>Purpose</i>	<i>Setting</i>	<i>n (Physicians)</i>	<i>n (Patients/ family members)</i>	<i>Location</i>	<i>Method of analysis</i>	<i>Key concepts</i>
Koedoot, 2004 <sup>25</sup>	To describe the content and amount of information conveyed when proposing palliative chemo treatment and to identify patient and physician factors associated with this outcome	Oncology outpatient clinic	33	95/0	Amsterdam The Netherlands	Qualitative	Watchful-waiting mentioned in half of all encounters with a more detailed explanation in less than one third of these. Work related, sexual, social effects of chemotherapy mentioned seldomly and emotional side effects never mentioned. Less than half of patients received information on disease-related symptoms, prognosis or treatment side effects.
White, 2007 <sup>26</sup>	To determine the types of prognostic information communicated during ICU family meetings and physician/family factors associated with increased provider levels of prognostic information	ICU	35	51/169	Seattle, WA	Qualitative using grounded theory; ATLAS-TI employed to help with data organization	Increased number of prognostic statements were associated with (1) longer conference duration, (2) increased conflict about withholding/drawing life support, (3) white physicians, and 4) family members with higher education.
White, 2007 <sup>27</sup>	To characterize the extent to which shared decision making occurs during ICU family meetings and predictors of shared decision making	ICU	35	51/169	Seattle, WA	Previously validated tool employed to identify dimensions of shared decision making	Two percent of discussions met all 10 criteria for shared decision making, physicians scored higher on information-giving than process of decision making.
Roter, 2000 <sup>28</sup>	To describe and compare communication content during advanced directive discussions of bioethical experts vs. general practitioners	University and VA medicine clinics	18 "experts" 56 "nonexperts"	48/0 with "experts"; 56/0 with "nonexperts"	Durham, NC and Pittsburgh, PA	Roter Interaction Analysis System (RIAS) and content analysis	Experts devoted one visit to ADs, let their patients talk more, did more relationship building, addressed more socioemotional topics and scored higher on content-specific AD skills than nonexperts. Differences diminished when controlling for time differences.
<b>Interventional Studies</b> Detmar, 2002 <sup>29</sup>	To determine whether a standardized HRQL instrument can facilitate physician communication around QOL issues	Oncology outpatient clinic	10	214/0	The Netherlands	Stepwise linear regression analyses	In the intervention group, QOL issues discussed more and physicians better able to identify moderate-to-severe health problems. Satisfaction higher only for degree of perceived emotional support.
Clayton, 2007 <sup>30</sup>	To determine the impact of employing a standardized patient question prompt list on discussion of end-of-life care topics	Palliative care outpatient clinic	15	174/0	Australia	Standardized coding procedures employed to assess MD response to questions prompted by the intervention	Providing a question prompt list to patients/families prior to the encounter increased the number of questions asked and promoted discussion about prognosis and end-of-life issues.

ICU, intensive care unit; AD, advance directives, HRQL, health-related quality of life.

## Discussion

Our review identifies areas that need significant improvement in both the content and process of physician communication and offers techniques to improve physician–patient communication. The specific techniques are described below.

### **Ask why**

Physicians have particular difficulty initiating and exploring emotional issues and allowing more participation in discussion by patients and families. Given that most of the studies enrolled patients with life-threatening disease, these considerations likely trump the more procedural oriented conversation most physicians feel comfortable discussing. Patients often offer comments about how they feel emotionally. At those moments heavy with expectation it is helpful to ask “Why do you feel that way?” or “Why do you think that?” and be prepared to listen to the response.

### **Reprioritize emotional and quality of life issues**

The amount of time spent talking to patients and families is another important consideration. Several studies<sup>28,29</sup> noted a 6- to 7-minute increase in discussion duration during outpatient medical encounters when more of these topics were addressed or were explored in further detail. It is also likely that the anticipated time required to address these topics and associated emotional burden contribute to physicians’ avoidance in initiating such discussions.<sup>23,29</sup> One could argue that there is not enough time to address all the “important” issues in any kind of medical encounter. Reprioritizing emotional and quality of life issues so these patient-raised issues take precedence in a visit may avoid the conflict in agenda that often occurs between physicians and patients.<sup>31</sup>

### **Expand your role as a communicator**

Discussing death and dying with patients and families can bring up feelings of uncertainty and inadequacy, because most providers feel it is their role to provide definite answers and treatment options rather than admit to an uncertain future and that perhaps the best option is to manage symptoms only. Several factors seem to influence physicians’ exploration of these issues: (1) both of the intervention studies in our sample<sup>29,30</sup> found improved topic coverage when discussion prompts were utilized and (2) physicians who felt it was their responsibility to discuss these issues did so more frequently. A growing number of educational opportunities exist for clinicians who would like to expand their ability to engage in these types of discussions. In addition, physicians can employ existing prompt tools to better ascertain patient and family concerns during medical encounters.<sup>29,30</sup> From a research perspective, it will be important to better explore physician perceptions about their responsibilities with regard to their role in palliative and end-of-life care.

### **Enlist the help of other health professionals**

Physicians may feel overwhelmed by the range and extent of psychological and social issues that often arise when delivering palliative or end-of-life care. It may be particularly valuable to obtain assistance from collaborative disciplines such as chaplaincy, social work, psychiatry, and palliative

care. Professionals from these disciplines can help to address many issues such as complex family dynamics, bereavement, spiritual concerns, and eliciting and clarifying goals of care.

### **Speak less, listen more**

A physician’s perceived role as an information and recommendation giver also guides discussion. The common finding of physician dominance in nearly all of the recorded conversations may speak to physicians’ attempts to fulfill the above role. Experts at discussing advanced directives spoke significantly less than their nonexpert counterparts.<sup>20</sup> When contradictions arose between patients’ families and physicians surrounding end-of-life decisions an information-seeking style, rather than a decision-based (arguing for or against a decision) approach improved the likelihood of coming to an agreement.<sup>14</sup> Not surprisingly, these data suggest that allowing patients and families increased participation improves patient and family perceptions of these discussions.

### **Offer support and emotional validation**

Finally, patient and family satisfaction was higher when physicians used supportive statements to acknowledge patients’ and families’ feelings.<sup>22</sup> Statements like “We respect your decision” help validate patients’ and families’ decisions. “Whatever you choose we won’t stop taking care of you,” can alleviate concerns about abandonment.

The common themes found in these disparate studies speak to inadequacies in medical training (and medical practice as most medical trainees learn from observing attending physicians) and in the health care system itself. Medical trainees need more instruction on how to initiate and interact during conversations about prognosis and goals of care, how to process the myriad of emotions that these conversations raise, and how to effectively collaborate with other disciplines. Communication skills training should emphasize (1) patient and family engagement, (2) supportive/validating comments, (3) initiating discussion on quality of life and emotional issues, and (4) using the information learned to offer appropriate management of symptoms including watchful waiting. Health care reforms that could facilitate effective communication include appropriate reimbursement for often time-intensive “patient-centered” discussions.

Our review also identified many knowledge gaps regarding patient/family-physician communication in palliative care. The studies included patients who were relatively young (mean age, 60 years). A large, rapidly growing subset of the population (i.e., those ages 70 and above) receiving palliative care, therefore, remains unstudied with direct observation methods. The only investigations to include patients with varying diagnoses were the advanced directive<sup>20,28</sup> and ICU<sup>7</sup> studies, leaving out the broad spectrum of patients with advanced or advancing chronic illness. More focus is needed on older patients with late-stage or end-stage chronic disease given that most health care dollars are spent on this patient population. Finally, although there are validated coding systems to measure the content and structure of directly observed communication,<sup>9,10,32,33</sup> their adaptation to palliative care outside the realm of oncology has been limited.<sup>10</sup>

This systematic review reveals that direct observation methods can be feasibly employed to study communication issues in palliative care. Nearly 80% of those asked to

participate in the outpatient (and 74% in the inpatient) setting agreed to do so. Directly observed methods offer glimpses into physician–patient interaction that are often difficult (if not impossible) to capture with other data collection methods. In one descriptive study, discussion of prognosis was examined in terms of implicit vs. explicit references to death (finding that most references were implicit, possibly leading to confusion). It would be difficult and likely inaccurate to gain information about possibly ambiguous terminology by self-report methods. Our review further highlights the fact that few investigators have used direct observation approaches when examining communication issues in palliative and end-of-life care research.

The methodology of directly observed interaction among patients, their families, and their physicians (as well as other health care professionals) holds great promise for investigating communication in palliative and end of life care. More widespread application of this approach can potentially lead to a better understanding of the content, process, and language of these types of interactions. Studying successful and unsuccessful examples of physician and nonphysician provider (e.g., hospice nurses) communication may help investigators develop evidence-based approaches to communicating with patients and families concurrent with the application/development of appropriate tools for measuring outcomes of these interactions (e.g., health-related quality of life measures, symptom relief measures). The development of evidence-based communication strategies would be particularly helpful to practicing clinicians. In addition, investigating low literacy patients and the responsiveness of their physicians, utilization of translators in palliative/end-of-life discussions and physician communication with terminally ill patients with varied diagnoses and their caregivers are ripe areas for research. It is critical that such communication studies include patients of diverse cultures, ethnicities and practice settings.

Our study has several limitations. Our search criteria may not have captured every study that used directly observed methods to study palliative/end-of-life care communication issues. The studies were few, had small samples, included varied outcome measures and were mostly descriptive, so the conclusions contained in this article should be considered preliminary in nature. In addition, all of the studies employed cross-sectional designs (i.e., recorded interactions at a single point in time) and therefore would not have included prior important interactions that could have influenced physicians', patients', and/or families' interactions during the recorded encounters.

In conclusion, this article demonstrates areas that need improvement in what physicians discuss in palliative and end-of-life care communication (emotional issues, prognosis) and offers ways to do so. It highlights what patients and families find most satisfying (participation and support). This article also illustrates the gaps in directly observed research in palliative care: focus on older patients and patients with end-stage or late-stage chronic illness, the adaptation/application of existing communication measurement tools to specifically capture palliative care discussions, and the utilization of varied outcome measures.

### Acknowledgments

This work was supported by a John A. Harford Foundation Center of Excellence in Geriatric Medicine Award.

This work was also supported by the Cornell-Columbia Translational Research Institute on Pain in Later Life (TRIPLL) is funded through an Edward R. Roybal Center for Translational Research on Aging Award (P30AG22845-02) provided by the National Institute on Aging.

Drs. Fine, Reid, and Adelman contributed to study concept, design, analysis, and interpretation of data and preparation of the manuscript. Dr. Shengelia contributed to interpretation and preparation of the manuscript.

### Author Disclosure Statement

No competing financial interests exist.

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