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## Communication in End-Stage Cancer: Review of the Literature and Future Research

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### Abstract

Concerns have been raised about the quality of life and healthcare received by cancer patients at the end-of-life (EOL). Many patients die with pain and other distressing symptoms inadequately controlled, receiving burdensome, aggressive care that worsens quality of life and limits patient exposure to palliative care, such as hospice. Patient-physician communication is likely a very important determinate of EOL care. EOL discussions with physicians are associated with an increased likelihood of: 1. acknowledgement of terminal illness, 2. preferences for comfort care over life-extension, and 3. receipt of less intensive, life-prolonging and more palliative EOL care; while this appears to hold for white patients, it is less clear for black, advanced cancer patients. These results highlight the importance of communication in determining EOL cancer care and suggest that communication disparities may contribute to black-white differences in the EOL care. We review the pertinent literature and discuss areas for future research.

### Introduction

Over 565,000 cancer deaths are expected to occur in 2008, with 1500 cancer patients dying each day (ACS, 2008). Because there is usually an identifiable terminal phase (McCarthy, Phillips, Zhong, Drews, & Lynn, 2000), cancer deaths offer an opportunity to achieve a “good death,” defined by the Institute of Medicine’s Committee on Care at the End of Life as one “free from avoidable distress and suffering for patients, families and caregivers; in general accord with the patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards. A bad death, in turn, is one that is characterized by needless suffering, dishonoring of patient and family wishes or values, and a sense among participants or observers that norms of decency have been offended. Bad deaths include those resulting from or accompanied by neglect, violence, or unwanted and senseless medical treatments (IOM, 2001, p. 24).” Former *British Medical Journal* editor, Richard Smith, proposed 12 principles of a good death (Smith, 2000), which included: knowing when death was coming, retaining control, having a choice over where death occurs, access to spiritual or emotional support, control over whom is present, having time to say goodbye, and not to have life prolonged pointlessly.

However, underlying the principles of achieving a good death are the basic assumptions that patients want to know, are told, and accept that death is coming. Unfortunately, for oncologists and patients alike there remains uncertainty regarding how to avoid distress, suffering and the dishonoring of patient wishes while participating in communication of diagnosis, prognosis and during the transition from active treatment to end of life care (Butow, Dowsett, Hagerty & Tattersall, 2002). As a recent review of this literature concluded, “prognosis is an issue that most physicians and patients describe as difficult to discuss and the best way to present information to optimize patient understanding, psychological adjustment and decision-making is uncertain.” (Glare, et al., 2003, p.1005.)

Specifically questions remain regarding: 1. what information individual patients truly want (Hack, Degner & Parker, 2005; Leydon, et al., 2000; Thorne, Kuo, Armstrong, McPherson, Harris & Hislop, 2005), 2. when (Hack, et al., 2005; Leydon, et al., 2000;) 3. how best to convey that information (Hack, et al., 2005; Leydon, et al., 2000; Thorne, et al., 2005) 4. how patient preferences may change over time (Hack, et al., 2005; Leydon, et al., 2000), 5. how to provide medical information while avoiding or reducing distress and maintaining hope (Hack, et al., 2005; Leydon, et al., 2000; Stiefel & Razvi, 2006; Thorne, et al., 2005;), 6. how to effectively and efficiently translate information exchange into patient and clinician decision-making that honors patient choice and avoids unwanted or inappropriate outcomes (Thorne, Bultz & Baile, 2005) and 7. finally, how the above questions are best approached at EOL in minority populations. The following article briefly reviews end-of-life (EOL) communication between oncologists and advanced cancer patients, highlighting differences by race and ethnicity, and the EOL outcomes associated with this communication. It concludes by recommending future directions for research.

### Communication in End-Stage Cancer

After hundreds of years of physicians and patients facing the specter of cancer, it seems reasonable to expect oncologists are well-trained, experienced and confident in their EOL conversations and care. However, studies repeatedly suggest that EOL communication is lacking (Thorne & Bultz, 2005) likely due to what Baile quoted as the mistaken belief that patient communication is an, “innate skill of minor importance when compared with the technical aspects of care.” (Baile & Aaron, 2005, p. 331.) In addition, some authors note that the unequal power differential, involuntary nature of the relationship, fear, stigma, complexity, and uncertainty of cancer likely adds greater emotional weight to the patient-oncologist relationship than the general physician-patient relationship (Arora, 2003; Ong, DeHaes, Hoos, & Lammes, 1995; Parker, Davison, Tishelman & Brundage, 2005), making good communication even more critical.

Studies suggest that the majority of patients do want prognostic information (Arora, 2003; Butow, McLean, Dunn, Tattersall & Boyer, 1997; Hagerty, Butow, Ellis, Lob, Pendlebury & Leighl, 2005; Christakis & Lamont, 2000; Levinson, Kao, Kuby & Thisted, 2005; Leydon, et al., 2000; Thorne & Kuo, 2005; Parkes, 1972; Vigano, Dorgan, Buckingham, Bruera, & Suarez-Alzamor, 2005) and shared decision-making (Hack, et al., 2005). When discussing prognosis patients’ communication preferences include, but are not limited to: 1. realistic, complete information (Arora, 2003; Hagerty, et al., 2005) 2. an opportunity to ask questions (Hagerty, et al., 2005), 3. to be treated as an individual (Hagerty, et al., 2005), 4. to trust the competence of the physician (Hagerty, et al., 2005; Leydon, et al., 2000), 5. reassurance of sufficient pain control (Hagerty, et al., 2005), and 6. to maintain hope (Butow, et al., 2002; Christakis, 1999; Kutner, et al., 1999; Leydon, et al., 2000;). Despite this, there is also evidence for relative independence between the patient’s desire for information and his or her preference for participation in decision making (Arora, 2003; Hack, et al., 2005; Ong, et al., 1995; Thorne & Kuo, 2005;). Furthermore, patient satisfaction, emotional health and regret may be related to congruence between preferred and actual participation but

physicians often have difficulty determining what patients want (Hack, et al., 2005; Ong, et al., 1995; Parker, 2005). Finally, within oncology, maintaining hope while articulating prognosis truthfully has been the subject of numerous articles and studies and continues to prove a thorny issue in daily practice (Christakis, 1999; Helft, 2005; Mack, Wolfe, Cook Grier, Clearly & Weeks, 2007; The, Koeter, van Der Wal, 2000;).

As suggested above, the goals of the patient-oncologist communication equation are to create a therapeutic alliance, exchange information, and involve patients in decision-making. (Ong, et al., 1995) However, how these goals are achieved and the relationships of one goal to another are complex. For the sake of simplicity we have separated the discussion of the communication literature into the following broad categories: 1. What is said, 2. What is heard, 3. Differences by racial or ethnic status, 4. EOL communication outcomes and 5. Future research.

**What is Said**—Physicians spend the majority of the consultation time talking, typically discussing medical or technical issues (Detmar, Muller, Wever, Schornagel, & Aaronson, 2001; Hack, et al., 2005; Ong, et al., 1995), or asking close-ended questions (Ong, et al., 1995). While providing technically important information, physicians often appear to misunderstand the type of information that is valuable to patients (i.e., specifics of how treatment will affect patient quality of life) or have difficulty assessing symptoms and needs completely (Hack, et al., 2005; Ong, et al., 1995). With respect to psychosocial issues, what physicians and patients are willing to discuss, and who initiates that discussion, depends upon the topic, the physician's attitude toward discussing psychosocial aspects of care, time constraints, and patient-related factors (e.g. age, gender) (Detmar, Aaronson, Wever, Muller & Schornagel, 2000; Detmar, et al., 2001; Hack, et al., 2005).

Authors suggest oncologists may not provide complete information or may actively withhold information due to: discomfort with their own EOL communication skills or knowledge (Ong, et al., 1995; Stiefel, 2006), clinical uncertainty (Christakis, 1999), a sense of failing the dying patient or facing the patient's (unrealistic) expectations (Stiefel, 2006), fear of creating or worsening patient or caregiver distress (Helft, 2005; Ong, et al., 1995; Stiefel, 2006;), time constraints (Hack, et al., 2005), and patient characteristics and communication style (Street, 1991). Some authors cite collusion between physicians and patients, preferring not to discuss or to delay discussion of diagnosis, prognosis or EOL options either due to patient preference, cultural norms, a paternalistic sense of what is best for the patient, personal discomfort, or concerns of patient distress (Helft, 2005; Mack, et al., 2007; The, et al., 2000).

Empirical results suggest that physicians often do not disclose the terminal prognosis to their patients or do not do so in a manner that facilitates patient acceptance (Chan & Woodruff 1997; Cherlin, et al., 2005; Glare, et al., 2003; Hagerty, et al., 2005). In the Coping with Cancer (CwC) study, approximately 30% of patients reported being given their prognosis by their physician at baseline, despite study entry criteria that included metastatic disease, failure of first-line chemotherapy and life expectancy of six months or less (Wright, et al., 2008). In the Connecticut Hospice study less than half of the bereaved caregivers reported being told the patient's life expectancy despite the patient being enrolled in hospice (Cherlin, et al., 2005).

Studies also show that when physicians forecast prognoses they tend to be overly optimistic, with survival estimates approximately 3 times longer than the patient's actual survival (Chan & Woodruff, 1997; Cherlin, et al., 2005; Glare, et al., 2003; Hagerty, et al., 2005; Parkes, 1972). And physicians tend to communicate more optimistic life estimates to patients and family members than they formulate privately. A study of physicians referring patients to

hospice found that the median survival they communicated to patients was 90 days, their median formulated survival was 75 days, and the median observed survival was 24 days (Parkes, 1972). Oncologists may also inadvertently mislead patients regarding their prognosis when attempting to offer hope; for example, addendums to the prognostic discussion such as mentioning why the patient might “beat the odds” if they are younger than the typical patient with the same prognosis may effectively discount or negate the relevance of the prognostic information given (Prigerson, 1992).

Finally oncologist-specific factors likely play a role in determining what is communicated; for example, oncologists at academic medical centers appear to disclose prognoses to their patients less often than community-based oncologists (Prigerson, 1992; Wright et al. 2008). Although this may be due to physician characteristics alone (such as discomfort, fear of failing the patient or hope regarding clinical trial participation), it may also be the result of interactions between physician and patient characteristics or perceptions of patient expectations on the part of physicians (e.g. patients’ hope for cure when receiving care at an academic medical center). Further research is necessary to understand how physician characteristics determine and interact with patient characteristics resulting in observed EOL communication and outcomes.

**What is Heard**—Most studies suggest that patients either do not understand or do not recall a significant amount of information provided in a medical visit and cancer patients are particularly vulnerable after receiving bad news (Hack, et al., 2005; Ong, et al., 1995). Our finding that 33% of patients reported having had EOL discussions (Wright, et al., 2008) is similar to the rate reported by patients in the Lehmann study but different than the 72% of oncologists recorded as having EOL discussions when audio-taped (Lehmann, Shaykevich & Weeks, 2007). This supports the idea that patients who report an EOL discussion may be a select group and that many patients may not hear or understand the message when prognostic information is shared. In our study, patients who reported an EOL discussion were also more likely to want their physician to tell them their life-expectancy (Wright, et al., 2008), suggesting that physicians may selectively disclose the prognosis to those patients whom they think want, and can “handle”, this information.

Consistent with this, physicians who reported sharing prognostic information “matter-of-factly” as opposed to “in general terms” were significantly more likely to care for patients who cognitively accepted their terminal condition (Prigerson, 1992). This suggests that more factual, realistic disclosures by oncologists may have a higher probability of being understood. However, mixed results have been found for giving statistics or qualitative versus quantitative information about prognosis or expressing uncertainty about the course of the cancer (Hack, et al., 2005; Hagerty, et al., 2005), while still other authors have suggested this may be a source of hope for patients (Christakis, 1999). Like physicians, patients tend to overestimate their life expectancy (Chan & Woodruff, 1997) and this overestimation predisposes them to choose aggressive interventions that may be of questionable value at the EOL (Weeks, et al., 1998).

The literature indicates that personal patient factors, rather than just physician EOL conversations, also determine factors critical to EOL outcomes and achieving a good death, including the manner of communication between doctors and patients. For example, oncologists alter their communication based on patient coping style and assertiveness (Thorne & Kuo, 2005). Studies suggest that women are less likely to say that they want and are less likely to receive prognostic disclosures (Elkin, Kim, Casper, Kissane, & Schrag, 2007). Married patients are less likely to report EOL discussions while those with more functional impairment are more likely to report EOL discussions with physicians (Wright et al., 2008). Younger, more anxious patients are more likely to want emotional support, while

those with longer life expectancy or who are English speaking are more likely to want realistic disclosure (Elkin, et al., 2007). Type of cancer may also affect desire for information (Hack, et al., 2005), possibly due to the patient's perception of the lethality of the condition.

**Acceptance and therapeutic alliance:** Our research suggests that cognitive and emotional acceptance of a terminal cancer diagnosis are two distinctly different entities that are affected by prognostic communication and in turn may affect what is heard (Ray, et al., 2006). This distinction between cognitive and emotional acceptance is important because cognitive and emotional acceptance appear to have different correlates, to affect one another, and to have unique and synergistic effects on EOL outcomes. In CWC, 17.5% of the sample met criteria for cognitive acceptance (i.e. they both acknowledged that they were terminally ill and were "peaceful"). These individuals were more likely to be in physical distress with greater symptom burden and more likely to report having had an EOL conversation and to participate in advance care planning but *less* emotionally accepting at baseline (Ray, et al., 2006).

By contrast, emotional acceptance was significantly associated with feeling less terrified, more supported by others, wanting fewer heroic measures and eventually having a better quality of life in the last week of life (Ray, et al., 2006). Emotional acceptance may be affected by several factors including: the family caregiver's emotional acceptance and the presence of dependent children (Nilsson et al., 2008). Other factors that are highly likely to be related to emotional acceptance are spirituality (Balboni, et al., 2006; Tarakeshwar, et al., 2006; McClain, Rosenfeld & Breitbart, 2003) and the patient's stage or state of grief (Maciejewski, Zhang, Block & Prigerson, 2007; Prigerson and Maciejewski, 2008).). Finally, patients who report a stronger "human connection", or therapeutic alliance, with their physicians appear much more likely to emotionally accept their illness (Mack, under review). In this way, emotional acceptance appears to be influenced by the quality of the interrelationship with the patient's oncologist and in turn, the relationship with the physician likely colors the patient's understanding of their illness (Thorne & Kuo, 2005).

Although we found no significant association in a cross-sectional analysis between patient therapeutic alliance and rates of EOL discussions (Wright, et al., 2008), it seems possible that as the relationship between oncologist and patient develops over time, the closeness of the relationship might affect the ability to discuss prognostic information. This may make it harder, rather than easier, to discuss the patient's impending death and in turn lead to increasing aggressiveness of care at the EOL rather than palliative care. Supporting this is the fact that physicians who have known the patient longer have been shown to be less accurate in their prognostic estimates than those who have known the patient a shorter period of time (Evans & McCarthy, 1985). Similarly, patients appear to prefer ACP discussions with anonymous admitting physicians to those with their family practitioner or oncologist (Lamont & Siegler, 2000). This potential confounder of the patient-physician relationship deserves further study.

**Differences by Racial or Ethnic Status**—Racial and ethnic disparities in cancer incidence, screening, diagnosis, treatment, and mortality have been known since at least the early 1990s (Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2003) and little appears to have changed in terms of the presence or magnitude of the disparities since then (Gross, Smith, Wolf & Andersen, 2008). In contrast, while minorities, particularly blacks, receive less aggressive, curative treatment upfront for their cancer, they receive more aggressive, less palliative care at EOL. For example, blacks are more likely to be admitted to the ICU (Barnato, Chang, Saynina & Garber, 2007), receive CPR (Goodlin, Zhong, Lynn, Teno, Fago & Desbiens, 1999) or other intensive interventions

(Barnato, et al., 2007), and die in the hospital (Weitzen, Teno, Fennell & Mor, 2003), and are less likely to use hospice services than whites at EOL (Greiner, Perera, & Ahluwalia, 2003). Disparities also appear to exist in minority patient-physician communication, specifically whether conversations occur, with whom (e.g. patients and family members), the quantity and quality of that communication (including question asking, eliciting further information, etc), the availability of interpreters and language-specific information, lack of understanding of cultural perceptions of health and illness, and a lack of appreciation of the heterogeneity within minority groups (Elkan, et al., 2007; Gordon, Street, Shart & Soucek, 2006; Siminoff, Graham & Gordon, 2006; Welch, Teno & Mor, 2005;).

However, definitive studies of EOL communication for minority advanced cancer patients are lacking. There is a need for research to determine whether communication disparities lead to the observed differences in EOL care and outcomes. Considering the experience of black patients specifically, much is known about the attitudes and beliefs of healthy volunteers, primary care patients, and ambulatory cancer patients regarding such topics as advance care planning, life sustaining care, hospice, and preferences for EOL communication (Blackhall, Frank, Murphy, Michel, Palmer & Azen, 1999; Elkin, et al., 2007; Gordon, et al., 2006; Gordon, Street, Sharf, Kelly, & Soucheck, 2006; Hopp & Duffy, 2000; McKinley, Garrett, Evans & Danis, 1996; Siminoff, et al., 2006; Smith, Davis, & Krakauer, 2007; Smith, et al., 2008; Welch, et al., 2005). However much less is known about communication between black, advanced cancer patients who are approaching death and oncologists, or the effect these conversations have on patient knowledge or healthcare choices, disease acceptance, therapeutic alliance and EOL outcomes,

What is known from quantitative studies of terminally ill black patients (without exclusively cancer diagnoses), is their desire for more life-sustaining care (Borum, Lynn, Zhong, 2000; Hoffmann, et al., 1997; Smith, et al., 2007). And while terminally ill blacks report wanting to discuss their EOL care choices with a physician, they often do so at a rate less than whites (Hoffmann, et al., 1997), for reasons which are unclear. In addition, patient-reported quality of the doctor-patient relationship is lower for terminally ill blacks when compared to whites and aspects of doctor-patient communication (e.g. telling bad news in a sensitive and caring manner, listening) have been implicated (Smith, et al., 2007). Of note, however, attempts to find mediators or moderators of the relationship between race/ethnicity and EOL preferences or outcomes among minority EOL patients have generally failed (Smith, et al., 2007 & 2008).

Extrapolating from communication literature, the affective quality of the physician-patient interaction is likely the most important factor in determining patient satisfaction (Bensing, 1991; Ong, et al., 1995) and may be the most important communication difference between physicians and racially and ethnically diverse patients compared to their majority counterparts (Gordon, et al., 2006; Siminoff, et al., 2006; Smith, et al., 2007). Physicians may be less empathetic and forthcoming with information and patients may be less expressive and assertive when from a minority background (Gordon, et al., 2006; Levinson, et al., 2005; Schouten & Meeuwesen, 2006; Siminoff, et al., 2006). And while there has been a great deal of discussion of the role of trust in minority patients-physician relationships in the literature, empirical results have not supported this concern (Gordon & Kelly, 2006; McKinley, et al, 1996; Smith, et al., 2007; Trice, et al., 2008). Finally, investigators have also raised questions regarding whether potential differences in outcomes and communication are the result of black cancer patients seeing a distinctly different group of physicians than their white counterparts (Bao, Fox & Escarce, 2007). Similarly, studies suggest racial concordance in cancer patient-physician interactions may affect the perception of partnership building, empathy and communication (Gordon, et al., 2006), as well as patient participation (which in turn affects the information received) (Gordon & Kelly,

2006). Together, these factors are of particular interest with respect to the potential affect on EOL outcomes, all the more so when considering evidence that black physicians prefer more aggressive EOL care when presented with hypothetical EOL scenarios, consistent with black patient preferences (Mebane, Oman, Kroonen & Goldstein, 1999). Further research is necessary to bring our knowledge of EOL communication among minority, cancer patients and physicians on par with what is known about similarly situated white, cancer patients, to eliminate disparities, and to answer how best to provide care that respects cultural differences.

**EOL Communication Outcomes**—Unfortunately, opportunities for good deaths from cancer are often missed and communication, or the lack thereof, appears to be the most likely explanation for these missed opportunities (Ashton, et al., 2003). The costs of these missed opportunities remain high (Thorne & Bultz, 2005) and the importance of prognostic disclosures, which provide information about the likely course of the patient’s illness and enables patients and families to “set appropriate goals and maximize their chances for having the kind of death that most people say they want” (Kim & Alvi, 1999, p. 195) should not be underestimated. Peacefully aware cancer patients (i.e., those who are cognitively and emotionally accepting) have lower rates of psychological distress and higher rates of advance care planning (e.g., completing do-not-resuscitate [DNR] orders) than those who are not peacefully aware (Ray, et al., 2006). Additionally, peacefully aware patients have the highest overall quality of death as reported by their caregivers in a postmortem evaluation. In turn, surviving caregivers of peacefully aware patients are more physically and mentally healthy 6 months post-loss than caregivers of patients who were “aware” but not peaceful.

There are other benefits to communication and acceptance as well. While Earle et al. (Earle, et al., 2004) has documented the increasing use of chemotherapy in cancer patients is associated with elevated rates of emergency room visits, ICU admissions, and delayed hospice admission, another study suggests patients who receive 1 or more aggressive measures in the last week of life are significantly less likely to die in their location of choice (Higginson, et al., 2003). This suggests more individuals in the future may die in institutions rather than their preferred site (home), a fate associated with higher rates of unmet needs for symptom management, physician communication, emotional support, and being treated with respect and higher rates of moderate or severe pain (Teno, et al., 2004; The SUPPORT Principal Investigators, 1995).

On the other hand, length of time in hospice for patients with caregivers who reported being told the patient’s illness was incurable was twice as long as for those who did not report being told (Wright, et al., 2008) and family members of decedents who received home hospice services are more likely to report a positive dying experience (Teno, et al., 2004). This is critically important because the average length of hospice enrollment before death has decreased in the last decade (Teno, et al., 2007), less than half of patients eligible for hospice services receive hospice care (Bradley, et al., 2000), and 30% of hospice patients die within a week of enrollment (Teno, et al., 2007).

Finally research has shown that roughly a third of Medicare expenditures go to enrollees in their final year of life (Yu, 2008). Given that the high cost of EOL care is a function of the aggressiveness of care, it follows that reductions in aggressive care in the last month(s) of life could result in cost savings. Among CwC we found that patients who reported EOL discussions with physicians received less aggressive care in the last week of life (Wright, et al., 2008). In analyses that monetized EOL health care outcomes, we found that EOL discussions reported by patients were associated with an adjusted average cost-savings of \$1070.84/patient in the last week of life. If all oncologists had EOL discussions with their

terminally ill patients, this would translate to \$374,410,301.00 saved among all US cancer deaths/year in the last week of life (Zhang, et al., 2008).

**Future Research**—Future research regarding EOL discussions should focus on who is conveying the information (eg, oncologist, nurse, or fellow) and the effect each agent has on patient acceptance and outcomes; when and how frequently in the course of the illness do EOL discussion(s) occur; what is said (e.g., how realistic the information is); how EOL information is conveyed (e.g., in a manner that encourages patient acceptance and understanding); whether prognostic disclosure causes harm at varying points in the disease trajectory and the magnitude and time span of these harms if they exist, and how the manner of conveyance affects patients' terminal illness acknowledgement, cognitive and emotional understanding of their illness, treatment preferences, care plans and care received in the last month(s) of life. Additionally research should strive to determine whether disease acceptance is more powerfully dictated by clinician behavior or personal patient factors such as ego integrity, state/stage of grief, spirituality, or the dependency of others on them. Finally, effort should also focus on differences in communication and outcomes for minority and disadvantaged, advanced cancer patients and caregivers. The goal of such research is to identify potentially modifiable factors that increase the number of good deaths among cancer patients and their caregivers for both minority and majority advanced cancer patients.

## Conclusions

In addition to the IOM report, *Approaching Death*, (IOM, 2001) that appealed for research to address deficiencies in EOL care, the NIH has called for studies to improve the quality of life of patients and families and to improve the delivery of symptom management and palliative care that also reduces health disparities. These calls to action remind us that many dying cancer patients suffer with their pain and other distressing symptoms inadequately controlled, that aggressive, burdensome care at the EOL may be becoming more common, and that the underutilization of palliative care services is ongoing. Furthermore, the experience of racial and ethnic minorities is not as well understood at the end of life, but may include disparities similar to those present earlier in the cancer care continuum. Research that uses theoretical models that incorporate potentially powerful psychosocial influences into the prediction of EOL outcomes may reveal how fundamental, potentially modifiable parameters of the oncologist-patient relationship and communication affect patients' and caregivers' recognition of, and adjustment to, their terminal prognosis and to shape the EOL care patients receive.

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