Literature Review of "Communication"
for the
The Irish Hospice Foundation's
Hospice Friendly Hospitals Programme

Hospice *friendly* Hospitals PROGRAMME

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INTRODUCTION

The Irish Hospice Foundation (IHF) *Hospice Friendly Hospitals Programme* (HFH) is being developed to promote the integration of mainstream hospice principles into hospital practice. This innovative approach is aimed at improving the lived experience of dying patients and their families as they navigate through hospital systems. Because hospitals are currently oriented towards cure and aggressive treatment interventions, the programme is advancing a shift in hospital orientation that would address the needs of dying patients and their families. The changes proposed by the programme are intended to improve conditions specifically from the perspective of such patients and families.

The Hospice Friendly Hospitals Programme is oriented around the four key themes of Integrated Care, Communication, Dignity & Design, and Patient Autonomy. Per the request of the IHF, the following is a literature review for the theme of Communication. The review covers a widely-defined perspective of communication within the hospital context and thus should be viewed as a structured broad overview of the literature.

Aims and scope of the review

The aim of this review is to explore, identify and present the literature on the topic of Communication. The review should be viewed as a scoping document that highlights the major areas of the literature, rather than covers them in-depth. Because the HFH Programme aims to address the patient and family experience from the time of admission to the hospital, through the duration of the hospital stay, and into the post-death period

which includes autopsy procedures and bereavement services, there are many elements of

communication that may be considered. The information we sought focused on the

overarching question of what is known about communication in the hospital setting that

may inform how to enhance and optimize the experience of patients and families facing

dying, death and bereavement.

For the purposes of this review, components of communication we have aimed to

examine include:

- Interpersonal communication among patients, family members and
  healthcare providers

- Systems of communication between groups, such as clinical teams and
  departments

- Training and education on communication skills

- Communication technologies

- Written communication in the form of information resources such as
  brochures and written documents

The vast nature of the communication literature required that we strategically approach

the review in such a way that will capture as much of the relevant literature and as little

of the irrelevant literature.

METHODS

The term communication is used broadly in academic literature, thus covering

many areas of information which would not be pertinent to this particular review. The

challenge in reviewing such a topic is to remain sufficiently broad in order to capture the

full range of relevant literature while being specific enough to exclude extensive amounts of unrelated literature. Electronic databases were used to search for academic journal articles on the subject of communication as it relates to the parameters of the Hospice Friendly Hospitals programme. Databases were chosen based on their relevance to the topic and limited overlap with each other.

We identified 6 electronic databases for the academic literature review. These include Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), CareSearch (an Australian online resource for palliative care information), Cumulative Index to Nursing & Allied Health Literature (CINAHL), the Cochrane Database of Systematic Reviews, and PubMed [a service of the United States National Library of Medicine (NLM) and National Institutes of Health (NIH); it includes MEDLINE]. We searched each database with a number of terms and term combinations (see Appendix 1).

The searches included a limitation on timeframe of publication between 1990 and 2007 (May). Searches were defined by both inclusion and exclusion criteria to capture as much of the relevant literature as possible while trying to exclude extraneous material. Once the initial searches were conducted, we conducted several review steps to identify a number of journal abstracts/articles to examine more closely. The steps included a determination of duplication in abstracts across databases and a review of article titles for relevance. The detailed exclusion criteria included the following:

- Manual removal of duplicates not found by EndNote (referencing software).
- All papers of no relevance to communication OR broad health field.

- All papers where 'communication' refers to the paper itself (e.g. 'a communication between…') or the transmission of disease (e.g. 'HIV communication in…') and has no relevance to broad topic.
- All papers where 'communication' refers to the biomedical investigation of specific communication/speech-related illnesses (e.g. aphasia) and has no relevance to broad topic.
- All papers from a pragmatics/conversation analysis/discourse analysis tradition that have no direct relevance and no policy-orientation.

Appendix 2 presents the numerical citation results of the searches. Following the identification of potentially relevant titles, a review of abstracts was conducted, and finally, a subset of abstracts and articles was chosen for more in-depth review. Some abstracts were further deleted because of their status as editorial letters or short commentaries, their lack of substantial contribution to the literature, or the vague nature of the abstract. A subset of articles was chosen for in-depth review. These articles included review articles as well as other articles that seemed, from the abstracts, to have especially pertinent information for this review.

RESULTS

The breadth of the literature on communication lends itself to various ways of organizing and presenting its content. The majority of the literature centers on the ways in which people communicate with each other, especially when, what and how they communicate. Closely related to these considerations are ethical issues that influence these processes. Topics that are less evident but mentioned in this literature include institutional systems of communication and communication education.

The first section of the results touches on the significance of communication in palliative and end of life care and on using the trajectory of illness (from advance care planning through to bereavement care) as one framework for thinking about the subject. The second and largest section examines communication within and among patients, family members, and professional care providers. Much of the discussion focuses on information and recommendations about when, what and how communication occurs. Some structured models of communication are presented. Further particular focus is given to cultural and language considerations, specific populations, and specific settings within the hospital. The third section of the review looks at the intersection of ethics with many of the issues noted in sections one and two. Then, the review presents literature on structured strategies for communication within the hospital setting. The results conclude with highlights from several literature reviews on communication, as a way of recapitulating the topics that have been discussed.

There is tremendous overlap in the material among the themes in this literature, reflecting the complexity of communication as a topic in palliative and end of life care. Some topics appear under multiple headings and others that are mentioned only once could easily fit under a variety of headings. The material has been organized to be informative to the needs of the Hospital Friendly Hospices programme.

Considering communication in palliative and end of life care

The need for better communication in the care of dying patients and families is frequently mentioned in the literature and appeared repeatedly in the previous literature review on Integrated Care (Baker, Wuk, Teno, Kreling, Damiono, Rubin, Roach,

Wenger, Phillips, Desbiens, Connors, Knaus, & Lynn, 2000; Edmonds & Rogers, 2003;

Heyland, Groll, Rocker, Dodek, Gafni, Tranmer, Pichora, Lazar, Kutsogiannis, Shortt, &

Lam, 2005; Hodges, London & Lundestedt, 2006; Irvine, 1993; Pincombe, Brown, &

McCutcheon, 2003). A study of communication in the last week of life in the United

Kingdom, Ireland and Italy suggests that communication is a moderate to severe problem

for 30-40% of patients with cancer (Higginson & Costantini, 2002). However, positive

outcomes in cancer care, including patient quality of life, satisfaction with care, and

medical outcomes, can be influenced by effective and empathic communication with

patients and families (Baile & Aaron, 2005). Additional literature suggests that effective

communication can improve palliative care by alleviating anxieties, encouraging

situational control and promoting quality of life for patients (Wallace, 2001). As such,

communication has an important role in the provision of care to those facing palliative

and end of life care.

Communication across the trajectory of illness

        One framework for looking at communication in palliative and end of life care is

the trajectory of illness. Using a broad approach to this trajectory, it may begin with

advance care planning and progress through bereavement services. Some may question

the inclusion of advance care planning in this trajectory, since it may occur before or after

there is a diagnosis of life-limiting illness. It is included here because of its frequently

mentioned role in palliative and end of life care. Looking at the literature through this

framework brings focus both to the different phases of the trajectory and to the significant

processes of transition between phases.

Advance care planning may be understood as the process of contemplation and

communication about preferences for care towards the end of life, including the exchange

of information between patients, those close to them, and their health care providers.

Such planning can help guide care decisions across settings, including the hospital.

Although there is a literature on this topic, few references specific to it appear in the

search for this review. Rather, advance care planning is noted in numerous articles that

generally discuss issues of communication in palliative and end of life care.

Curtis and colleagues (2005) highlight the importance of advance care planning in

their discussion of physician-patient communication for patients with chronic obstructive

pulmonary disease (COPD), a leading cause of death. Another article addresses

communication about advance care planning with hospitalized elderly patients, indicating

it is a cumulative process often facilitated by a social worker. The process has several

elements, including initiation of the discussion, exchange of information, identification of

a surrogate decision-maker, addressing of treatment options, elicitation of patient values,

interaction with family members, and collaboration with a multidisciplinary array of

health care professionals (Black, 2004). Additional considerations in advance care

planning not evident in the results of this literature search include variations in advance

care planning across cultures and countries, documentation used in advance care

planning, and issues of capacity/competency in such planning. These aspects reflect the

essence of advance care planning as a method for facilitating communication among

people and across settings of care.

When examining the trajectory of illness, especially from the perspective of the

patient, several articles offer ideas about the phases along the trajectory and the processes

of transition between them. One article with specific recommendations about communication between physicians and terminally ill cancer patients organizes the information by four situations: diagnosis, relapse, progression of disease and terminal illness (Stiefel & Razavi, 2006). Detailed report of the recommendations is beyond the scope of this overview, but the article in mention may be helpful for considering differing elements of communication for specific types of discussion along the continuum of palliative care. Another overview of communication between oncologists and patients focused on the context of transitions, such as the time of diagnosis, disease progression, or treatment shifts (Evans, Tulsky, Back, & Arnold, 2006). Another article targets recommendations towards the broader multidisciplinary team, offering interventions that improve communication specifically at time of diagnosis and during progressive disease (Blum & Blum, 1991). Clearly diagnosis and disease progression are key points along the trajectory, and they will be discussed in addition to other points.

Diagnosis. The literature on communication at the time of diagnosis is extensive and is noted both here and in the next section of the review. Examination of first-time discussions between oncologists and patients with incurable disease diagnoses revealed that 79.3% of visits included mention of prognostic treatment-related and disease-related outcomes, with 52.2% of these mentions utilizing explicit language about death (Rodriguez, Gambino, Butow, Hagerty, & Arnold, 2007). All of the visits contained implicit language for discussing death, including mention of anticipated life span, estimated time frame, or projected survival. However, a study about communication between staff and 130 adult patients with advanced malignancy who were admitted to the

hospital, 25% of patients indicated that the diagnosis was not disclosed in a clear or caring manner while a third of patients had an incomplete understanding of their prognosis (Chan & Woodruff, 1997). Overall, the literature on diagnosis focuses on the questions of whether the information is provided, what information is provided, to whom, when and how.

Disease progression. In the setting of communication about disease progression, patients and health professionals note the importance of conveying hope, checking the patient's preferences for information prior to discussing prognosis, matching prognostic information with patient goals, checking patient understanding, discussing practical and emotional issues, and having clear and consistent communication with members of the multidisciplinary care team and the family (R. D. Hagerty, S M; Butow, P, 2000). Overall, patients with metastatic cancer want to negotiate the amount, format and timing of prognostic information they receive from their doctors (R. G. Hagerty et al., 2004). Similar to the time of diagnosis, themes of what information is provided, to whom, when and how are central regarding disease progression.

Nearing the end of life. The time close to the end of life is identified as a distinct phase in the trajectory of illness. Barriers to discussion of end of life issues between physicians and family caregivers at the time of hospice enrolment were identified as both the physicians' lack of information provision and discussion, as well as the family caregivers' difficulty and ambivalence about hearing the news (Cherlin et al., 2005).

Barriers to nurses' communication of prognosis and hospice referral to hospitalized terminally ill patients were identified as unwillingness of the patient or family to accept information about prognosis and/or hospice, the sudden death or non-communicative status of the patient, perception of physicians' hesitance, nurses' discomfort, and nurses' desire to maintain hope among patients and their families (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Recommendations for communication during this phase of care are mentioned in the section on patient-family-staff communication.

Some phases of the illness trajectory are more associated with the surviving family of the patient. Family should be understood in broad terms to mean those people close and important to the patient, not necessarily biologically or legally related to the patient. These phases of the illness experience have unique communication demands.

Organ donation and autopsy. Patients and families navigating the very end of life may face sensitive decisions about organ donation and autopsy. Communication about these topics may be especially difficult for families if there has been no previous discussion with the patient about their wishes. Furthermore, it is a challenging topic for health care staff to approach. In a survey of surgeons, while more than half of the survey participants felt at least competent in seven of the ten interactional skills investigated, 56.6% and 48.9% felt a lack of competence in gaining consent for organ donation and autopsy, respectively (Girgis, Sanson-Fisher, & McCarthy, 1997).

Grief and Bereavement. Grief and bereavement are an integral part of facing loss at the end of life. Losses from varied circumstances may require equally varied responses in services. For example, a hospital may develop a specific bereavement program for parents who have lost a baby (Chambers, 2003; Tom-Johnson, 1990). Under other circumstances, special attention is required for child survivors of parental suicide (Mitchell et al., 2006). Modes of expression such as drawing and drama therapy have been suggested for helping bereaved children (Clements, Benasutti, & Henry, 2001; A. M. Curtis, 1999). A study of families in which a child had died concluded there are two family cultures: open family, where language is used to comfort and inform the surviving parents and children, and less open families that use language to promote avoidance of emotion and confronting of the death (Silverman, Weiner, & El Ad, 1995). Examining a different aspect of bereavement, one program found that an intensive parent guidance intervention for helping parents to communicate with adolescents who have experienced the sudden death of a sibling was beneficial (Horsley & Patterson, 2006). The literature brings to light the need to consider a variety of populations who may need tailored bereavement services, and the importance of utilizing varied approaches within these services. It is important to mention that in addition to the grief and bereavement of patients and families, consideration should be given to the grief and bereavement needs of staff.

While some of the literature discusses points along the trajectory of illness, some authors frame these times as processes of transitions. A Swedish study on communication between nurses and physicians about patients' transition from curative to

palliative focus of care found that most wanted more communication among the staff and

a more individualized approach to decision-making regarding the shift in approach to

care (Lofmark, Nilstun, & Bolmsjo, 2005). A desire was expressed for uniform

documentation of the decision to shift to palliative care. The transition from cure-

oriented to palliative-focused care, especially in the dramatic setting of life support

removal, holds numerous communication needs for families that have been identified as

needing improvement. These needs include timely information, honesty, clarity,

informed health care providers and listening (Norton, Tilden, Tolle, Nelson, & Eggman,

2003). Some emphasize that oncologists have opportunities at times of transition to help

patients with the adjustment to possible losses and the need to redefine hope. The

communication activities at these times include giving biomedical information,

expressing care and understanding for patients as people, and balancing the discussion

with both honest realism and hope. Recommendations for conducting these activities

include elicit patients' concerns, express empathy (both verbally and nonverbally),

balance hope and realism, and demonstrate sensitivity when giving information (Evans et

al., 2006). Such recommendations arise frequently in the literature on patient-family-

staff communication.

Patient-family-staff communication

Using the framework of the illness trajectory is just one approach to organizing

thinking about communication in the setting of palliative and end of life care. Another

approach clusters topics within the broad realm of patient-family-staff communication.

These topics examine aspects of interpersonal communication, specific populations, and specific settings of communication.

Discussion of preferences

Conclusions from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) included that physicians and patients' surrogate decision makers often lacked awareness of the patients' preferences. In addition, patients often received care inconsistent with their preferences (Covinsky et al., 2000). An interview study with 20 seriously ill patients found that patients considered it natural to talk about the topic of limiting life support and were not upset by discussing the topic (Lofmark & Nilstun, 2000). Many of the patients wanted a family member and sometimes a staff person to participate in the conversation. Assisting patients with coming to terms with impending death was viewed by nurses as a high moral priority in their work role (May, 1995).

A study on patient-physician communication about terminal care in Japan found that although 80% of patients preferred to have honest information about diagnosis and prognosis about their illness, regardless of its nature, physicians assessed this preference correctly only in about half the patients (Kai et al., 1993). Similarly, although 70% of patients indicated a preference to die at home, physicians estimated this preference correctly in less than half of the patients. Finally, the study reports that two-thirds of the patients expressed a preference for pain control over life prolongation, and physicians estimated this preference correctly approximately half of the time. Another paper also reported substantial underestimation of pain by hospital medical officers (Chan &

Woodruff, 1997). These results reinforce the importance of patient-physician communication about preferences and experiences, given the substantial potential for mis-estimation when communication has not occurred.

A particular point of focus in the literature is that of cardiopulmonary resuscitation (CPR). The SUPPORT research revealed that only 23% of the study's seriously ill patients had discussed preferences for resuscitation with their physicians (Hofmann et al., 1997). Although the majority (58%) of those who had not discussed the topic did not wish to do so, that leaves 42% who would have wanted to discuss resuscitation. Significantly, 25% of those who did not want to discuss the topic also did not want resuscitation, highlighting that the lack of communication about the topic could lead to unwanted interventions for those patients. Communication about CPR did not occur frequently after hospital admission for a serious illness, even among patients who did not wish to be resuscitated and those whose quality of life was declining (Golin et al., 2000). Reid and Jeffrey (2002) note that discussions about resuscitation should be part of a wider discussion about treatment goals, and they offer a framework for clarifying the decision making. Other literature also offers practical guidelines for communication at the end of life, applicable for discussing palliative care topics such as advance care planning, resuscitation, and hydration/nutrition (Chopra, 2001).

This body of literature highlights the presence or absence of communication about preferences and care. It demonstrates that the most basic aspect of communication, whether or not it has happened, is still one that is not consistently practiced in the care of those facing serious illness and end of life.

How communication happens

While having communication is viewed as a basic need in care, how that communication takes place is more complicated. An interview study with patients and physicians notes that the communication interaction around discussion of death and dying is bidirectional, whereby patients are influenced by how physicians deliver the information and physicians' delivery is influenced by how patients respond (Lutfey & Maynard, 1998). Paternalistic and informative models of communication tend to dominate in interactions with family caregivers of patients with terminal cancer, but both patients and caregivers report they prefer an interactive model that considers both medical facts and individual family values equally (C. P. Grbich, Deborah; Maddocks, Ian, 2000). Health care providers' wishes to "protect" patients and families from difficult news may lead them to provide ambiguous or misleading information throughout serious illness, from the process of diagnosis to end of life. However, such less-than-honest approaches may be more hurtful than helpful to patients and families (Fallowfield, Jenkins, & Beveridge, 2002). Consideration of the need for interdisciplinary collaboration in end of life care led to a study of attitudes and beliefs among physicians and nurses in the region of French-speaking Switzerland, Belgium and France (Levorato, Stiefel, Mazzocato, & Bruera, 2001). Results suggested overall agreement between the professions on topics such as patients' need for information, "do not resuscitate" orders, and ethical principles in decision making processes.

Husebo (1997) points out the importance of conveying respect and hope in communication with seriously ill patients and their families. Similarly, the importance of language choices in communication about end of life is noted in the literature (Limerick,

2002). In exploring the conveyance of hope in situations of cancer patients with incurable disease, a survey study found that a majority of patients reported the following factors as not facilitative of hope: the doctor appearing nervous or uncomfortable, giving the prognosis to the family first, or using euphemisms (R. G. Hagerty et al., 2005). By contrast, doctors' having the most updated treatment information, being highly informed about the patient's cancer, and saying that pain will be controlled were all reported as behaviours that give hope. The theme of hope is emphasized in many parts of the literature.

A study involving family members, nurses and physicians concluded that several communication strategies may be used to facilitate end of life decision making in the care of elderly patients and their families. These strategies include being clear, avoiding euphemisms, clearly discussing goals and expectations of treatment, using words such as "death" and "dying", and being specific in the use of words such as "hope" and "better" (Norton & Talerico, 2000). High levels of distress reported by families in Japan who are learning about the ending of cure-oriented treatment to their loved one was reported by researchers who suggest the following strategies to improve communication in such situations: having physicians avoid saying they can do nothing for the patient but rather that they will do their best to achieve specified goals, carefully providing information with consideration of the family's readiness and patient's condition, exploring families' emotions and providing emotional support, and creating a relaxing setting that enables families to ask questions (Morita et al., 2004). Research has found that end of life care decisions being made too close to death cause unnecessary stress for both patient and

families (C. Grbich et al., 2006). The themes of honesty, clarity, language choices and timing seem to appear in the literature time and time again.

There are topics that are less frequently noted but are worthy of mention due to their direct relevance to patient care. The first is discussion of non-conventional treatment. Communication between oncologists and patients about the use of Complementary and Alternative Medicine (CAM) during or after conventional medical treatment is infrequent and primarily initiated by patients (Roberts et al., 2005). However, 84% of patients indicated using at least one type of therapy, and physicians were generally enthusiastic and supportive of patients' use. Notably, both patients and physicians reported that their relationship is enhanced when the topic is discussed.

The second rarely discussed topic in palliative care is that of sexuality and body image. A palliative care conference presentation highlights this topic, providing an overview of a communication skills training program for health care professionals that combines information on sexuality, psycho-oncology, adult education and communication in health care settings (Sundquist, 2003). Another publication offers recommendations for the multidisciplinary team about discussing pain, sexual functioning, and financial problems (Blum & Blum, 1991). These portions of the literature are an important reminder of neglected topics within the already limited and sensitive realm of palliative and end of life communication.

The Family

The discussion of family in this review has used the term in a broad sense to mean those people close and important to the patient, though family may be understood in a

variety of ways (Sheldon & Oliviere, 2005). It may be helpful to note that much of the literature that mentions family in regard to palliative and end of life care does not specify how the term is being used. For nurses, communicating with families of hospitalized patients with advanced cancer was identified as a difficult task (Davis, Kristjanson, & Blight, 2003).

In the context of British care, most patients want their wishes, rather than those of their families, to guide physicians. In most cases, patients supported close family receiving information about the patient, with the patient's consent (Benson & Britten, 1996). End of life decisions invite the use of negotiation and mediation in the process of communication (Bowman, 2000). These processes are sometimes employed in meetings with the family. The family conference, a meeting attended by family members and several health care staff, is a method that may serve to improve communication in the setting of end of life care (J. R. Curtis et al., 2001). Family conferences in the intensive care unit (ICU) setting were found to have 5 main pairings of themes: killing or allowing to die, death as a burden or benefit, prioritizing patient's or family's wishes, considering contradictory versions of the patient's wishes, and identifying one family or the whole family as the unit of decision making (Hsieh, Shannon, & Curtis, 2006). An intervention study using family conferences and a written brochure in situations of patients dying in the ICU found that families receiving the intervention of a proactive end of life family conference and brochure (versus a standard end of life conference) had longer family conferences and spent more of the time speaking in the conferences (Lautrette et al., 2007). Furthermore, family members receiving the intervention reported significantly lower post-traumatic stress symptoms, and lower depression and anxiety symptoms

during their bereavement. Such work suggests that family conferences may be a valuable

tool for communication with families.

Structured models for end of life discussions

Although much of the literature regarding patient-family-staff communication

revolves around the interpersonal considerations and nuances such as what, how, and

when communication should take place, some authors offer structured models for

approaching communication in palliative and end of life care. This section includes a few

examples of these models.

The first is the Ask-Tell-Ask method in which the oncologist asks clarifying

questions that bracket the provision of information. This approach enables the oncologist

to gauge the extent and type of information desired, as well as whether the information

provided was sufficient and helpful (Evans et al., 2006).

The second approach is the Hope for the Best, Prepare for the Worst method

which supports realism and hope during the provision of difficult information. Such an

approach highlights the importance of health care providers being able to help people re-

orient to focusing on hopes other than cure (Evans et al., 2006).

A third model, well known in medicine, is the SPIKES protocol specifically

offered for breaking bad news (Buckman, 2001). According to Moss (2001), advantages

of Buckman's model include strengthening of the physician-patient relationship, offering

a positive approach to engaging the patient and family in shared decision making,

fostering collaboration among the physician, patient and family, allowing the patient and

family to cope with the reality of the situation and make plans.

A fourth model is a 7-step approach that Von Gunten, Ferris, and Emanuel(2000) recommend for patient-physician communication about end of life issues. These steps include preparing for discussions, establishing what the patient and family know, determining at the beginning of the relationship how information is to be handled, delivering the information in a sensitive but open manner, responding to emotions, establishing care goals and treatment priorities, and determining an overall plan.

In a fifth approach, Balaban (2000) offers physicians a 4-step process for discussing end of life care with patients and families. The process components include initiating discussion, clarifying prognosis, identifying end-of-life goals, and developing a treatment plan. The author suggests that using this process will enhance communication and offer benefits of allying fears, minimizing pain and suffering, and resolving most issues without conflict.

Although many of the models share elements, each has a slightly different approach to communication. It is important to recognize that these models have been developed primarily for and by physicians. Other professions may offer different approaches that do not appear in this literature search.

Cultural and language considerations

Discussion of patient-family-staff communication must take into consideration issues of culture and language. These have tremendous impact on the processes that have been mentioned up to this point in the review. Some of the discussion focuses on the practicalities of language. For example, the literature states the need for using professional interpreters when communicating with patients who are not fluent in English

(Chan & Woodruff, 1997). Although this may seem obvious, patients and families have found themselves as translators and interpreters, a problematic and potentially harmful practice. Professional medical interpreters recommend that physicians and interpreters meet prior to joint discussions with patients about bad news and end of life care (Norris et al., 2005). The recommendation includes that clinicians express their preferences for whether the interpreter serves as strict interpreter or cultural broker in the discussion. One neonatal intensive care unit took the approach of using illustrated cards with translations of phrases commonly used in that setting (Dye, 2001). Such an intervention would not substitute for interpreters but enable another avenue for communication between families and staff.

Culture is seen as a major factor in ethical decision making. A study of palliative care specialists from South America, French-speaking Europe, and Canada showed wide regional variations in physicians' estimates of patients' desires to be told of a terminal diagnosis, families' desires to know this information, and patients' knowledge of their terminal status and stage of illness (Bruera, Neumann, Mazzocato, Stiefel, & Sala, 2000). Furthermore, the physicians emphasized differing ethical principles in their approaches to this topic.

Examination of relationships between physicians and patients revealed varied expectations based on cultural affiliation. Physicians' attitudes about communication with seriously ill patients in Saudi Arabia reveal that 47% provide information about diagnosis and prognosis at all times, and 75% prefer to discuss information with close family members rather than patients (Mobeireek, al-Kassimi, al-Majid, & al-Shimemry, 1996). Whereby European American patients expected an equal relationship with the

physician, patients with other ethnic backgrounds (such as Hispanic, Eastern European, African, or Arab) expected a more paternalistic relationship with the physician but one in which the physician could be viewed as a family member and would allow the patient to tell their story (Torres, 2005). More effective interactions between patients and physicians, meaning interactions in which both participants achieve their goals, were characterized by a negotiation between the patient and physician about preferences regarding the medical approach, type of relationship, and communication style. Ineffective interactions were characterized by the physician imposing preferences without taking the patient's preferences into consideration.

A study of communication preferences about cancer diagnosis in Japan reported that advanced patient age, female sex, non-English speaking, and palliative care aim were all factors significantly associated with non-disclosure of the cancer diagnosis to the patient (Fujimori et al., 2005). The patient's autonomy was promoted by asking the patient about their preferences regarding disclosure to them and permission to include family members as decision makers. Within the United Kingdom, palliative care services for ethnic minorities, and specifically South Asian populations, were generally viewed by patients as valuable and satisfactory (Randhawa, Owens, Fitches, & Khan, 2003). However, areas for improvement of these services were identified as informing people of the availability of palliative care and improving communication between patients and service providers.

The literature on language and culture serves to reinforce the nuanced nature of communication and the importance of supporting communication that is pertinent and fitting to its users. Issues of culture and language are integral to who is part of

conversations about care and decision making, how much and what type of information is conveyed, the style of relationship between the provider and patient/family, and the effectiveness of the interaction.

Specific populations

The literature on communication in the setting of palliative and end of life care includes mention of populations that may have specific needs. These groups are mentioned here.

Children and adolescents

An international study exploring communication with children with cancer concluded that children respond similarly to the cancer experience, regardless of ethnicity and culture. The utilization of drawing as a mode of communication with children enhanced communication through direct visual expression and/or related verbal expression (Rollins, 2005). Another approach to communicating with children with cancer is outlined by Beale and colleagues (2005; Chambers, 2003). The approach emphasizes the importance of having rapport and a trusting relationship with the child prior to having discussions about the illness and its implications. With that in place, the authors suggest a 6 component approach: establish an agreement about communication preferences, engage the child a the appropriate time, explore with the child needs and desires regarding information, explain medical information in ways that are age and need appropriate, empathize with emotional reactions, and encourage the child by providing reassurance that you will listen and support. Other sources also provide

recommendations for communication in paediatric palliative care, emphasizing elements such as caring, compassion, cohesive functioning of the health care team, and relationship building with parents (Browning, 2002; Chesterfield, 1992). Paediatric pain also benefits from good communication, showing that maintaining child-centred communication and behaviour during painful procedures may result in less distress and discomfort for the child (Naber, Halstead, Broome, & Rehwaldt, 1995).

Communication between health care providers, children with serious illness and the parents of these children is especially important in paediatrics where the family is as involved in the situation as the patient (Huddleston & Alexander, 1999). It is suggested that good communication between the team and family is a central element for prevention or resolution of conflicts, as well as promotion of satisfaction with care (Johnson & Mattson, 1992; Wanzer, Booth-Butterfield, & Gruber, 2004). Since the emotional state of the parents influences their capacity to comprehend and retain information at the time of child's diagnosis, and then communicate about it with their ill child, repetition and clarification of information may be helpful strategies for health care providers to use with parents (Eden, Black, MacKinlay, & Emery, 1994).

Particularly pertinent in paediatric care are issues of assent, consent, decision-making and control of the flow of information to children (Kunin, 1997; Levetown, 2002; Rushforth, 1999). Communication decisions are underpinned by people's understanding of what children understand (Pettle & Britten, 1995; Watts, 1993), as well as what parents see as their roles as parents (Young, Dixon-Woods, Windridge, & Heney, 2003). These issues vary across the age of the children but need additional consideration in caring for adolescents for whom issues of control, autonomy and a sense of belonging are perhaps

especially important (Pazola & Gerberg, 1990; Young et al., 2003). There is much

variation among parents as to whether they acknowledge and discuss death with their

children who are diagnosed with cancer (Goldman & Christie, 1993), but research with

parents whose child had died from cancer revealed that no parent who had talked with

child about death regretted having done so while 27% of those had had not discussed it

with their children did regret that choice (Kreicbergs, Valdimarsdottir, Onelov, Henter, &

Steineck, 2004).

Communication between parents and children about a parent's illness is another

challenging topic for many parents. Research with mothers with breast cancer noted

variations in if, when, and how parents discussed the diagnosis with children (Barnes et

al., 2000). Mothers in this study indicated that the following would have been helpful to

them: knowledge of children development and age-appropriate strategies, space and

consideration for children in the hospital, and preparation (for the children) for the

experience. Attention to patient's potential needs in their role as ill parents would be an

important component of any system that aims to enhance care of people with life-

threatening illness.

<u>Elderly people</u>

The review has already noted research relevant to elderly people, but additional

articles reinforce this population group as one that needs consideration. Articles by

Clarke and Ross (2006) and Coe and Miller (2000) note that older adults facing end of

life have a set of special issues to consider. A survey study conducted using interviews of

patients 60 years and older residing in the community concluded that there are seven

primary points of advice for medical providers regarding how to communicate with patients about end of life care. The seven suggestions include "engage in strategies to ensure patient understanding, communicate honestly and truthfully, develop a compassionate bedside manner, treat others as you would want to be treated, provide empathic care, take the time needed to communicate, and determine patient information and decision-making preferences" (Rodriguez & Young, 2005, p. 534). The vast literature on care of geriatric patients is minimally visible in this literature search, but it is clearly one that requires further exploration given that the aging of the population.

Gay and lesbian people

A sector of the population that may be viewed as vulnerable in the health care setting, and certainly in that of end of life, is that of people who are gay, lesbian or bisexual. The literature suggests that clinician-patient communication with gay and lesbian patients faces barriers that include clinician attitudes, medical training, clinician level of skill/confidence in discussing sexuality with patients, and mistaken clinical assumptions (Bonvicini & Perlin, 2003). Practice implications and recommendations include (a) strategies for eliciting accurate sexual orientation and relationship status of patients, (b) strategies to communicate a safe and welcoming practice environment, and (c) strategies to communicate consideration of partner and family relationship. For (b), specific suggestions include to discuss practice policy on confidentiality, evaluate what is communicated through waiting room materials, role model sensitive and inclusive behaviour to colleagues and staff, and circulate important findings related to gay and lesbian health. For (c), specific suggestions include inquire about significant relationships

and family structure, present a positive accepting attitude, acknowledge and encourage

inclusion of partner or significant other in health care, encourage patients to express

concerns, and extend the system appropriately, with referral sources that are gay-family

sensitive. The authors further recommend that clinicians be aware of legal issues that

affect visitation and a partner's ability to make medical-decisions for patients, noting that

clinicians should explore surrogate preferences of the patient before the need arises

(Bonvicini & Perlin, 2003).

People with limited capacity

A small section of the literature brings attention to a population that may have

limitations in mental capacity or capacity to communicate verbally. There is a

recommendation for use of non-verbal communication (NVC) in nursing, especially for

use with people who have a learning disability (Chambers, 2003). Utilization of music

therapy is an alternative method for communicating with brain-impaired patients

receiving palliative care (O'Callaghan, 1993). Since music is primarily a right-hemisphere

brain activity, while language is primarily based in the left-hemisphere, combining the

two activities enhances avenues for communication. These brief suggestions highlight

the importance of exploring non-verbal and alternatives modes of communication to suit

the needs of patients and family members. Since some trajectories of illness are well-

known to lead to limited capacity for communication and decision making,

communication systems within the care setting should include attention towards planning

forward for such eventualities in order to maximize discussions with patients while they

still have mental and physical capacity to communicate.

Specific hospital settings

When designing the care of seriously ill and dying patients and their families in the hospital setting, one should consider that various departments or wards across the hospital may be involved with the person's care over the span of illness and dying. Although there is little literature about palliative care communication in relation to most hospital departments, the few mentions of these in the literature are included here.

Emergency department

The emergency department (also called and emergency room or accident and emergency) is a common point of entry into the hospital. It is a place of triage and fast-response, often plagued by time and staff limitations. Yet, it can be one of the key entry points for dying patients and their families into the hospital system, sometimes for the first (or last) time. Communication in an emergency department of an urban academic medical centre has numerous challenges. On study showed that discussions were characterized by brevity, clinician interruption of the patient's report, infrequent invitation for patients to ask questions, no confirmation by clinicians that patients understood information provided, and limited information about diagnosis, course of illness, self-care, medications, symptoms and follow-up (Rhodes et al., 2004). Physician disclosure of a new life-threatening diagnosis in the emergency department setting is challenged by limited time with the patient, limited resources in the busy context of the emergency department, and the restricted ability to make definitive diagnosis based on the information available during the emergency evaluation of the patient (Takayesu &

Hutson, 2004). According to the authors, a patient-and family-centred approach to disclosure of such information includes essential roles for additional professionals who can assist patients and families with various concerns, promoting a smooth transition from the emergency setting to further inpatient or outpatient care. This point may useful to consider when designing systems that promote the transmission of communication across the transition.

Intensive Care Unit (ICU)

The intensive care unit (ICU) setting is one where death and dying are perhaps more familiar than in other parts of the hospital. Communication is identified as a very important factor in end of life care in ICUs. Like other ICU skills, it requires training, practice, planning, preparation and supervision (J. R. Curtis, 2004). Various strategies may be used to proactively improve communication in this setting: family meetings, daily team consensus strategies, palliative care team case finding, and ethics consultations (Boyle, Miller, & Forbes-Thompson, 2005).

It may not be surprising that nurses in the ICU have more verbal communication with verbally responsive patients than unconscious patients (Alasad & Ahmad, 2005). A non-experimental descriptive observational and interview study of ICU nurses found that on average they spend 5% of their time verbally communicating with unconscious patients, primarily regarding immediate procedural matters or statements of reassurance. Nurses consider this communication very important. Elements influencing the communication include patient's level of consciousness, amount of physical care given and presence of relatives (Baker & Melby, 1996). Patients on mechanical ventilation in

the ICU may use gestures, head nods, writing and mouthing of words to communicate

with staff and family members (Happ, Tuite, Dobbin, DiVirgilio-Thomas, & Kitutu,

2004). Even situations of short-term oral intubation, such as surgical critical care, require

attention to methods and opportunities for communication. Patients reported feeling

discomfort, fear and frustration as they wished to communicate about their experience

(i.e., pain, breathing) and care (i.e., suctioning) during intubation (Fowler, 1997). This

literature brings to focus the importance of utilizing varied modes of communication,

taking into account people's unusual circumstances. Furthermore, it brings forward the

importance of continuing to treat unconscious patients as people, recognizing the

uncertainty of what people may or may not hear or absorb.

An examination of 17 ICUs in 17 European countries reported that 95% of

patients lacked decision making capacity at the time that end of life decisions needed to

be made in the ICU (Cohen et al., 2005). Thus, the role of the family in the ICU setting

becomes potentially critical. End of life decisions were discussed with the family 68% of

the time, with 88% of families being told these decisions and 38% being asked about the

decisions (Cohen et al., 2005). Different research showed that family members of

critically ill patients in the ICU showed a significant relationship between decreased

satisfaction with communication frequency as time progressed in the ICU (LeClaire,

Oakes, & Weinert, 2005). Thus, the longer length of stay in the ICU was a factor in the

family's communication expectations and needs.

In addition to the strategies briefly mentioned earlier in this section, some studies

have examined specific interventions with families in the ICU. A structured

communication system for families was implemented to include a discussion with the

nurse approximately 24 hours after the patient's admission, an information pamphlet at the time of the discussion, and a daily telephone call from the caring-taking nurse. These interventions significantly increased family members' satisfaction with care, their perceptions of how well their information needs were met, and significantly lowered the number of phone calls from family members to the ICU (Medland & Ferrans, 1998). Another ICU incorporated family members into daily team rounds, finding that this improved relationships between families and the team, reduced stress and hostility, and reduced occurrences of dysfunction (Schiller & Anderson, 2003). These interventions offer examples of the types of approaches to improving patient and family communication in the ICU setting.

Radiology

One department that may not be considered in relation to palliative and end of life care is radiology. This may be especially true for diagnostic radiology as opposed to interventional radiology. Diagnostic radiologists may have stressful interactions with oncology patients, but they tend not to relieve this stress (Murray & Stanton, 1998). Thus, patients/families may have communication needs that are not addressed in this potentially high-distress setting where people are having tests to determine if they are seriously ill, if disease has progressed, or the extent of a disease. This finding highlights a potential need for education and support with this professional group regarding communication with seriously ill patients.

<u>Surgery</u>

Surgeons are another professional sub-group in the hospital setting that is not often associated with communication about serious illness and dying. A survey with 143 surgeons identified several communication skills that surgeons consider important or very important for being a good surgeon. These include breaking bad news, preparing patients for procedures, educating patients about diagnosis and treatment, including increasing the likelihood that they will remember what they have been told, detecting anxiety and depression in patients, encouraging patients to express these emotions, and listening to their anxieties (Girgis et al., 1997). While most surgeons felt at least competent in many of these, approximately half identified organ donation and autopsy as areas in which they lacked communication competence. Specific attention to communication between surgeons, patients and families may be valuable to consider given the intense and sensitive nature of the information that may be exchanged, before and after surgery.

Ethics and communication: a close partnership

Breakdown in communication is frequently a factor in requests for an ethics consultation in the health care setting (Stagno, Zhukovsky, & Walsh, 2000). An analysis of the cases brought to the clinical ethics committee at a hospital in Norway revealed that of 31 cases, 19 related to the treatment of children, 20 pertained to the withholding or withdrawing of treatment, and 25 involved aspects of information/communication (Forde & Vandvik, 2005). This brief analysis suggests the importance of communication, and difficulties with it, in the hospital setting. It reinforces the recognized intersection of communication and ethics in the arena of end of life care (Addington & Wegescheide-

Harris, 1995). This intersection includes numerous topics, some of which are disclosure

of life-limiting diagnosis, futility, euthanasia, assisted suicide and issues of culture

(Gregory & Cotler, 1994; Kaufert & Putsch, 1997; Stagno et al., 2000).

The topic of disclosing a life-limiting diagnosis has long been a challenging one

in the communication between health care providers (primarily physicians), patients, and

families. However, it has been suggested that perceived conflicts between the principles

of nonmaleficence/beneficence and autonomy in the arena of communication in palliative

care may not be as conflicting as they appear (Taboada & Bruera, 2001). An article

describing a communication dilemma for a Japanese woman and her family highlights the

dynamics of disclosing diagnostic information to family members, separately from the

patient, and respecting the wishes of a patient who expresses a preference not to be told

of a diagnosis of cancer (Akabayashi, Fetters, & Elwyn, 1999). The authors discuss their

perspective on understanding autonomy in diagnostic settings, supporting the approach of

ethicist Edmund Pellegrino.

Annunziata (1997) discusses the ethics of relationship as they apply in Italy to the

patient-doctor relationship, and specifically the question of whether physicians should

inform cancer patients of their diagnosis. The emphasis on the ethics of relationship is a

respect for guidelines in the relationship, understanding that these guidelines may shift

and adjust as the relationship changes. In application to the patient-doctor relationship,

this approach includes a view of the patient as a person whose emotions, needs and

values must be considered; a doctor who recognizes him/herself as having a personal

history, emotions and values, distinct from the patient; and a balanced form of

communication, in the form of conversation. This approach suggests that accurate and

adequate information would be conveyed between the patient and doctor, but according to the guidelines of the relationship between the two.

Paediatric care for children with life-threatening illness is an additional setting for the intersection of ethics and communication. Specifically, topics of information exchange, communication, participation in decision making, assent, consent, patient autonomy, and parental responsibility often come to bear on the process of care (Kunin, 1997). Furthermore, it is suggested that the relationship between the health care team and the paediatric patient's family is critical to the avoidance or resolution of ethical conflicts.

Barriers to communication

Some literature on communication identifies barriers that influence improving this element of patient care. For example, perceptions of intensive care nurses studied in Brazil identified barriers in their communication with dying patients as including their own ill preparation for the discussion and the inability to deal with their own feelings regarding imminent death (Trovo de Araujo & Paes da Silva, 2004). Nurses' communication with patients and families was negatively affected by an increase in the nurses' own death anxiety, but positively affected by exposure to communication education (Deffner & Bell, 2005). Regarding oncology training programs, challenges include finding motivated faculty to teach communication and interpersonal skills and incorporating these topics into the time and structure of curriculum (Baile & Aaron, 2005). These examples highlight personal and structural barriers on the side of professional providers.

A broad range of barriers to optimal communication was discussed in a dedicated issue of the American Behavioral Scientist to the topic of end of life care (Hickman, 2002). Social barriers such as culture, medical culture, and health care systems were identified and noted as amenable to change through public and professional education, changes in models of care, and coalition building. Individual barriers such as health care providers' beliefs and patient characteristics were thought to be subject to change through education, advance care planning, individualization of care, and inclusion of families in care.

Structured strategies for communication in the hospital

A portion of literature describes structured strategies that have been attempted to improve communication in the hospital setting. Although strategies have mentioned throughout the review, this sections focuses on a few structured models. A communication system implemented on a hospital unit in Canada included a multi-strand approach using a patient-family orientation brochure, an interdisciplinary kardex, and an interdisciplinary patient goal sheet (Escaf, 1995). Benefits from the system are reported as improved staff access to current assessment information, improved ability to establish and document integrated patient goals, improved communication among team members, and increased patient and family satisfaction. The intervention attended to communication between and among the patient, family and staff.

A ward at a specialist paediatric hospital in Australia implemented an interdisciplinary morning meeting as an effort to enhance communication. The results of a qualitative evaluation they conducted revealed four major areas of impact of instituting

these team meetings (Aston, Shi, Bullot, Galway, & Crisp, 2005). These areas were

predictability, seen as a valuable contributor to a sense of structure and certainty to the

work day; *knowledge and perspectives*, described as the benefit of learning from the

discussions in a setting that promotes sharing and growth; *relationships and support*,

discussed as the opportunity to become familiar with members of the team and build

rapport; and *desired outcomes*, which were seen as improved communication within the

team, positive impact on patients' families (primarily parents) as they experienced

positive interactions among staff, and improved continuity of care for patients. A related

pre- and post-intervention study on 100 patient records revealed that benefits of

instituting the interdisciplinary morning meetings included significantly greater

likelihood that children would b reviewed regularly by medical staff, and in the morning;

children would have discharge plans documented regularly throughout their hospital

admission; and admission summary sheets would be completed at the time of discharge

(Aston, Shi, Bullot, Galway, & Crisp, 2006). Two varied research approaches to

understanding the impact of the strategy seemed to show it as beneficial.

Written forms of communication may be used for various types of information

exchange. A problem checklist was proposed as a mechanism for facilitating

interdisciplinary communication and continuity of care in the hospital and in the

community for patients with advanced disease (Walsh & Zhukovsky, 2004). The

checklist was found to be a useful communication tool for conveying information about

complex situations for both patients with cancer and non-cancer diagnoses, allowing for

better patient care. In a different setting, the use of written information on general

medical and elderly care hospital wards showed that basic written information about

cardiopulmonary resuscitation (CPR) provided in the patient room (in a folder or posted

on the wall) did not result in distress to patients or families, but the availability of detailed

information leaflets about CPR was rarely utilized by patients and families (Sivakumar et

al., 2004). These examples of attempts at improving communication demonstrate the

variety of approaches that may be used to do so. As one may expect, different strategies

may be more effective for certain settings than others.

Literature reviews: common themes in the communication literature

A few literature reviews on communication in palliative care do exist. Rather

than presenting them at the outset of this document, we include them here as means to

refresh the reader of select topics that have come to light in the literature search

conducted. One review mentioned a number of themes. A broad need for attention to

communication education for health care providers was noted, along with the need to care

for carers, and the need for interdisciplinary communication. More specific topics that

were noted included the importance of relationship building in palliative care

communication, the consideration of cultural factors in information giving, and the

tendency of health care providers to avoid communication about emotions and overlook

existential distress of patients and families (de Haes & Teunissen, 2005). A literature

review examining the transition from curative to palliative care in cancer treatment

brought to light several recommendations for improving communication around this

process (Schofield, Carey, Love, Nehill, & Wein, 2006). These include attention to

timing, preparing, initiating and concluding the discussion; the environment and

circumstances for the discussion; identifying information to provide and introducing

palliative care services; responding to emotional reactions and family concerns;

recognizing cultural and linguistic diversity, and promoting continuity of care.

Siegler and colleagues (2000) review the literature on communication between

physicians and older patient at the end of life, highlighting the topics of physician-patient

discussions, decision-making, advance directives and cultural factors.

Greater and greater numbers of cancer patients wish to be fully informed and involved in

decision making, and effective physician communication is high on cancer patients'

priorities for care. Clinicians themselves view communication as difficult and have it

contribute to their stress. Simultaneously, patients do not understand much of what they

are told, and often physicians are unaware of the lack of or mis-understanding. One of the

problems is that most physicians are deficient in communication skills, and especially at

discussing bad or sad news, despite programs to improve these skills. Expert opinion on

diagnosis consultation varies in the literature quite a bit in relation to such elements as

how the communication should happen and who should be there. Overall, more evidence

and research are needed to understand the impact of communication on health outcomes

(Butow & et al., 1995).

Finally, we include here the major points from an article that is not itself a review

but offers a thoughtful set of recommendations that reiterate or complement many of the

topics that have appeared in our review. The article comes from the Committee on

Bioethical Issues of the Medical Society of the State of New York and discusses several

recommendations for communication in caring for terminally ill patients (Berger, Rosner,

Potash, Kark, & Bennett, 2000). Although the concepts are summarized here, their

discussion in the article may be valuable for readers. They include the following:

- *Attending to isolation in dying*: actively engage dying patients in discussion about their dying, recognizing and responding to patients' emotions, assisting patients in finding meaning in their dying. There is a need for educational initiatives for physicians to learn empathetic communication.

- *Overcoming barriers to communication*: physicians should confront their fears, anxiety and stigmas about death and dying; discussions with patients about their fears would be helpful; using open ended questions, attending to psychological concerns, articulating feelings of empathy, and using humour are all recommended.

- *Disclosing and discussing health information*: inquire of patients regarding their understanding of their condition; create an atmosphere of dialogue and partnering, information sharing, support, and dialogue, strengthen the trust relationship, and facilitate consistency between diagnosis and medical responses. Attention to cultural needs that might mediate how much and to whom information is disclosed and discussed is important.

- Recognize that ill and dying patients are vulnerable, recognize the use of different coping mechanisms in patients; offer only medically appropriate interventions, and exclude treatments not medically indicated (and explain these exclusions)

- Physician's orientation has great impact on patients' choices for end of life interventions

- *Family considerations*: respect and promote interpersonal relationships, recognizing that stress of illness can cause distress that leads to dysfunctional

coping behaviours; emphasize goals shared with the family, sharing information, respect for family and the patient's important relationships.

- *Barriers*: there is little formal instruction for physicians; there is significant discomfort by physicians; social barriers such as culture, religion, language and literacy are factors; system barriers include complexity of medical care, fragmented health care delivery and financing.

- *Overall recommendation*: Promote an individualized plan of care with attainable and individualized goals

DISCUSSION

The topic of physician-patient communication alone has been the subject of numerous books and countless journal articles over many decades. The recent attention to the importance of interpersonal communication among patients, family members, and all members of the healthcare team (not just the physician) has led to a great expansion in the literature. As the reader can see, the majority of articles in the review reflect this focus of the literature. Yet even the many articles on these aspects of communication represent only one sub-category of communication targeted for this review. Several of the other aspects of communication that we sought to review yielded either few articles or mere mention within other articles. These results may reflect a number of factors. Firstly, the narrowing strategies used to restrict the literature may have eliminated some of the literature that would have been of interest. Although we tried to avoid this, it is likely that some literature did not get included due to lacking key words that were used in for literature identification or being so broadly written as to be unidentifiable for the

specific search. Secondly, perhaps the databases chosen for the review did not include

some of the available literature. For example, it is possible that a targeted review of

business literature or computer-systems literature would capture some of the literature we

did not see in this search. Thirdly, there may be little to no literature on some of the

important aspects of communication that are relevant to the goal of improving the

experiences of dying patients and their families.

There are a number of topics within communication that were not mentioned in

the literature but may be worth noting for future exploration and discussion. These topics

are not exhaustive but are rather intended to promote thought and discussion. First of all,

there are formal systems of communication. These may include the major area of

medical records and medical charts. These written and visual forms of communication

play central roles in the care of patients. Closely related to them are the computer

systems in the hospital setting. The Information Technology (IT) element of

communication in the hospital setting is a tremendous topic. While some literature

alluded to using such systems for improving communication (mostly between health care

providers), there is potentially a wide range of strategies that IT systems could offer for

advancing continuity of communication as patients transition across departments,

providers, institutions, and phases of care. This would include providing opportunity for

improved communication between and among health care professionals using these

technologies.

A second category of communication that did not appear much in the literature

involved systems of communication for advising and improving care. These might

involve mechanism for eliciting and handling patient/family suggestions and complaints,

as well as staff suggestions and complaints. They may cover designing systems for

directing and overseeing integrated care across the hospital. In addition, they may inform

systems related to advisory boards and panels that may be used to provide feedback and

recommendations for care design. Finally, they might include research systems that are

integrated into the programme of care to enable smoother and more thorough capacity to

study the many layers of care and communication in the trajectories of patients and

families.

A third and final topic of communication that we will highlight here is

communication education. Although the literature alludes to the importance of this

education for professionals, the vast literature on educating health care professionals

(physicians, nurses, and social workers especially but not exclusively) in the area of

palliative and end of life care was not apparent in this review. This is logical in that

much of that literature would focus on formal education systems and the area of academic

education, rather than hospital-based or hospital-oriented education. Communication

education may need to be addressed in many different forms within a hospital. Some

education may be generically offered across a diverse portion of the hospital staff, while

some education would be most effective is designed for a specific audience such as one

department (i.e., surgery) or professional group (i.e., nutritionists). Furthermore,

education has to also be considered for nonprofessional staff, many of whom have

numerous and critical interactions with patients and families. Again, such education may

be generic for certain purposes and more specifically designed for certain groups (i.e.,

receptionists; janitorial staff).

Although this review of the literature has clear and recognized limitations, we hope that it serves as a valuable source of information. For those unfamiliar with the field, it offers an immediate orientation to the complexity and intricacy of this casually used word, communication. Perhaps most importantly, we hope it reinforces the critical nature of excellent and effective communication in having the potential to improve the lived experiences of patients and families facing serious illness, dying and death. And, it has additional potential, if done well, also to improve the work lives and personal experiences of the health care staff, professional and non-professional, who work with patients and families in the hospital environment. There is no doubt that communication does matter.

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Appendix 1: Search terms used for electronic databases

Name of Database	Terms searched
Applied Social Sciences Index and Abstracts (ASSIA)	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative
British Nursing Index (BNI)	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative Exclusion criteria: Pre-1994 publication. (Journal only available 1994 onward)
CareSearch (an Australian online resource for palliative care information)	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative
Cumulative Index to Nursing & Allied Health Literature (CINAHL)	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative
Cochrane Database	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative
PubMed	Search terms in <u>Title</u>: communicat* OR talk* AND Search terms in <u>Abstract</u>: bereave* OR death OR dying OR hosp* OR diagnos* OR mortality OR terminal* OR incurab* OR inoperab* OR untreatab* OR fatal* OR palliative

*Using an asterisk in searches allows for multiple endings to the search term.

Appendix 2: Number of academic journal abstracts/articles identified and included

Name of database	Number of citations in original search	Number of titles after duplicates removed	Number of abstracts for review	Number of abstracts to review in depth	Number of abstracts included	Number of full articles
ASSIA	478					
BNI	133					
CareSearch	14					
CINAHL	861					
Cochrane	18					
Subtotal	1510	1367	386			
PubMed	5309	4403	367			
Total:	**8323**	**5770**	**753**	**236**	**135**	**34**

Note: ASSIA, BNI, CareSearch, CINAHL, and Cochrane databases were searched simultaneously in one electronic search.

Exclusion criteria for title list:

1. Manual removal of duplicates not found by EndNote (referencing software).

2. All papers of no relevance to communication OR broad health field.

3. All papers where 'communication' refers to the paper itself (e.g. 'a communication between..') or the transmission of disease (e.g. 'HIV communication in…') and has no relevance to broad topic.

4. All papers where 'communication' refers to the biomedical investigation of specific communication/speech-related illnesses (e.g. aphasia) and has no relevance to broad topic.

5. All papers from a pragmatics/conversation analysis/discourse analysis tradition that have no direct relevance and no policy-orientation.