



What is it that patients at the end of life want to know? What is the best way to provide the information? A review of the scientific literature was conducted to answer these two questions. The findings suggested that, regardless of age or culture, patients at the end of life wanted information about their illness and prognosis. The expertise of the physician, his/her relationship with the patient, and the use of hopeful communication styles were important factors in how patients understood the information provided. Honest and factual communication fostered hope and quality of life at the end of life.

**Key words:** physician-patient communication, end of life, literature review, palliative care

## Effective Physician-Patient Communication at the End of Life: What Patients Want to Hear and How to Say It

Wendy Duggleby, DSN, RN, AOCN, Associate Professor, College of Nursing, University of Saskatchewan, Saskatoon, SK.

David Popkin, BSc, MD, CM, FRCSC, FSOGC, FACOG, Executive Director, Saskatoon Cancer Center; Head, Division of Oncology, College of Medicine, University of Saskatchewan; Head, Department of Oncology, Saskatoon Health Region, Saskatoon, SK.

### Introduction

Effective physician-patient communication at the end of life has a significant impact on terminally ill patients' quality of life.<sup>1</sup> It helps patients to resolve unfinished business, remember personal accomplishments, and provides them with an opportunity to say goodbye to family and friends.<sup>2</sup> Communication encompasses the content of a message as well as how the message is delivered. In a study exploring the satisfaction of palliative patients with informational sharing during their illness, the information sharing process was as important as the content.<sup>3</sup> The timing, management, and delivery of information as well as the perceived attitude of practitioners, were critical to the process. These aspects, as well as information needs for patients at the end of life, are important for practitioners to understand to improve the quality of care for this population.

Evasive or dishonest communication may add considerably to the terminally ill patient's distress and prolong adjustment processes.<sup>4</sup> It also can hinder hope.<sup>5</sup> Unfortunately, what physicians think their patients want to hear and what the patients and their families actually want are often very different.<sup>4</sup> Although there are several studies from the perspectives of health care professionals on communication needs with patients on the end of life,<sup>6-9</sup> the focus of this article is on the scientific literature exploring the patients'

perspectives. What is it that patients at the end of life want to know and what is the best way to provide the information? A review of the scientific literature specific to communication with patients at the end of life from the patients' perspective was conducted to attempt to answer these questions.

### Information Needs

Several studies have explored information needs at the end of life<sup>2,3,10,11</sup> from the patients' perspective (Table 1). These studies were qualitative or descriptive in nature, using interviews or cross-sectional survey data collection methods. Only three studies explored any age-related differences in information needs. One study suggested that older adults wanted less detail than younger (<65 years of age) adults.<sup>4</sup> Two studies suggested that there were no age-related differences in informational needs at the end of life.<sup>4,11</sup>

In spite of differing designs and sample sizes, overwhelmingly the findings of the studies suggested that, regardless of age or culture, patients at the end of life wanted information about their illness and prognosis. Information needs were disease related (such as diagnosis, prognosis, timing of death, symptoms, treatment, and side effects)<sup>2,3,10,11</sup> and illness related.<sup>2,10</sup> Illness informational needs were related to the impact of their illness on themselves and their families such as changes in their functional status, role

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changes, symptoms, stress on their families, and loss of control.

Two studies suggested that patients are conflicted in wanting to honestly know their prognosis and wanting their physicians to be optimistic.<sup>10,12</sup> This finding, however, was not supported in the other studies of informational needs from the perspective of the terminally ill patient.<sup>2-4,10,11</sup> The findings from Kirk's qualitative study of 72 palliative patients in Australia and Canada suggest that wanting honest information and wanting their physician to be optimistic is not a conflict.<sup>3</sup> Patients at the end of life want to know about two major content areas: prognosis and hope. Hope was defined by participants as the possibility for a cure or longer life, or related to short-term goals, or continued care.

Multiple definitions of hope have been described by older palliative patients in a study by Duggleby and Wright.<sup>5,13</sup> In this study, participants described the importance of receiving honest information from physicians so that they are able to transform their hope from hope for a cure to hope for a peaceful death, hope for life after death, and hope for others. Without information,

patients were unable to acknowledge what was happening to them and refocus their hope. It was difficult when they first heard that their cancer could not be cured, but later they were grateful for this information as it allowed them to "live with hope." They wanted to live with hope so that they could focus on relationships with others and have peace at the end of life.

The fear of decreasing a patient's hope has been cited as a rationale for not providing accurate information.<sup>2,4</sup> However, studies of hope with palliative patients do not support this fear.<sup>14-16</sup> In a study of 218 metastatic cancer patients, 98% wanted their doctor to be realistic, provide an opportunity to ask questions, and acknowledge them as individuals when discussing prognosis.<sup>1</sup> Terminally ill cancer patients clearly stated that if their physicians were not honest with them, their hope was decreased and they lost trust in their physicians.<sup>5</sup> However, the manner in which information was given to them was important.

### Informational Process

Informational processes were important in communicating information to

patients at the end of life. The findings related to these processes are presented in Table 2. Common findings of the studies reporting informational processes from the perspective of the patient at the end of life were a) the importance of expertise of the physician, b) patient-physician relationships, c) physician style of communication, and d) when the information was given (timing).

### Expertise

Two studies have described the importance of expertise in communication with patients at the end of life.<sup>3,17</sup> Expertise was defined as the need for prognostic information to be given by the physician who was perceived by the patient as an expert<sup>3</sup> and the physician's expertise as a communicator.<sup>17</sup> The inexperienced communicator used vague terms and appeared to lack knowledge about the patient's specific situation. In this case, the physician delivered information quickly and without warning, was blunt, and became uncertain after delivering the message. The expert communicator was an empathetic professional perceived as knowledgeable and accepting

**Table 1:** Summary of Study Findings Related to Informational Needs

Authors	Findings
Fallowfield <i>et al.</i> <sup>4</sup>	A majority wanted as much information as possible, whether good or bad, including – diagnosis, – week-by-week progress, – chances of cure, – all possible treatments, – all possible side effects, and – how treatment works.
Hagerty <i>et al.</i> <sup>11</sup>	95% wanted prognostic information but wanted to negotiate the extent, format, and timing. Patients wanted information on treatment options, side effects, and symptoms.
Kirk <i>et al.</i> <sup>3</sup>	All patients, regardless of origin, wanted information about their illness and wanted it shared with relatives. Two content areas were identified: prognosis (accuracy and time left) and hope at all stages.
Kutner <i>et al.</i> <sup>10</sup>	Patients wanted disease-related and illness-related information.
Steinhauser <i>et al.</i> <sup>2</sup>	Patients wanted to know what to expect regarding their physical condition, a plan for treatment, and the timing of death.

**Table 2:** Summary of Findings Related to Informational Processes

Author	Findings
Friedrichsen <i>et al.</i> <sup>17</sup>	Expertise in communication and relationship to the patient were key factors.
Friedrichsen <i>et al.</i> <sup>18</sup>	Physicians should use forewarning and fortifying words (such as “unfortunately”) and phrases (such as “going to help you”) and avoid the use of threatening words (such as “growing wild” or “uncontrollable”).
Hagerty <i>et al.</i> <sup>11</sup>	Format and timing were important factors.
Hagerty <i>et al.</i> <sup>11</sup>	Opportunity to ask questions, acknowledge patient as an individual, and hopeful style were important.
Kirk <i>et al.</i> <sup>3</sup>	This study stressed expert disclosure, specificity of information, need for patient control, individual timing, playing it straight, making it clear, showing you care, giving time, packing information, staying the course, and hopeful style.

of the patient’s feelings. The expert communicator was also aware of the impact of words used when giving information.<sup>18</sup> Forewarning words such as “unfortunately” were helpful as they helped prepare patients for the message. Fortifying words such as “we are going to help you with this” assured patients that they would not feel abandoned. Not feeling abandoned by their physician when receiving information about their prognosis was important in fostering hope.<sup>5</sup>

### Relationships

Patients at the end of life described how a trusting relationship with their physicians, in which there was mutual respect, helped them cope with information provided.<sup>17</sup> In this circumstance, patients had met their physician before and their relationship was characterized by mutual confidence and security. Another type of relationship viewed as helpful was with a physician who they had not met before but with whom they felt comfortable and respected.

### Hopeful Styles of Communication

Approaches to communication that respect the need for hope include leaving the door open to possibilities for quality of life, retaining professional honesty, pacing the move towards palliative care, and allowing patients/families to explore other possibilities for hope.<sup>3</sup> The view of health care professionals that hope is

defined as hope for a cure has been found to decrease quality of life for patients at the end of life.<sup>19</sup> Fostering hope by helping older palliative care patients refocus their hope may be a useful communication strategy for physicians. Other hope communication styles identified in a study by Hagerty *et al.*<sup>1</sup> were offering the most up-to-date treatment, being knowledgeable about the patients’ cancer, use of humour, and committing to control their pain.

### Timing

The concept of timing was described as readiness of the patient/family to hear information.<sup>3,11</sup> This was reflected in patients’ needs for pacing the move towards palliative care thus providing patients and families with time to assimilate information. The transition from focusing on a cure to comfort care is stressful for health care professionals as well as patients and families.<sup>20</sup> Unfortunately, referral to palliative care is often suggested to patients within days and sometimes hours of their deaths, adding to the stress of transitioning from hope for a cure to comfort goals of care focus. However, a study on transitions experienced by terminally ill patients suggested that a skilled introduction to palliative care as well as adequate information about illness and services were important issues in helping patients through this transition process.<sup>20</sup> Palliative patients and their families experience multiple transitions

(e.g., from cure to palliation, related to loss, changes in care settings, and psychological and spiritual transitions) and shifting of goals of care.<sup>21</sup> Future research that examines informational needs related to transitions may help practitioners understand these needs and processes better.

### Conclusion

There are several limitations to the studies reviewed. They were exploratory and descriptive in nature, and only a few considered age and other cultural considerations in content and communication style preferences. More research is needed in this essential practice area. However, the findings do provide insight into what older persons at the end of life want to hear and how they want to hear it. They prefer to have detailed information about their disease prognosis, the stage of their disease, possible treatment and symptom control, and how their illness will affect them and their family.

Just providing general information is not enough. Each patient’s circumstance is unique, and it is important to tailor the information to each person. Just as important as the information is how the information is given. The expertise of the physician, his/her relationship with the patient and family, and the use of hopeful communication styles combine to increase understanding of the information provided. Effective communication should result in

the patient understanding of the nature of his/her particular illness and its effect on the individual and the family. This understanding may improve quality of life and increase hope at the end of life.



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