Information needs at the end of life: a content analysis of one person's story

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During the last phase of life, a person may need a variety of information to help her or him cope with dying and death. This article describes the nature of information needed during this stage. A content analysis was done of a book of conversations between a husband who was dying and his wife who is a grief counselor to determine his information needs. Four categories of needs were proposed, including physical, emotional, spiritual, and financial. Information needs germane to each category were identified. More research needs to be done by library and information science professionals to determine the information needs of people who are dying, as well as those of their families and the health professionals who care for them.

Death happens in one of four ways. For some people, it arrives suddenly, thus robbing them of the luxury of preparing themselves or their families for this event. For other people, death comes from frailty (e.g., old age, dementia); terminal illness (e.g., cancer, amyotrophic lateral sclerosis); or organ system failure (e.g., chronic obstructive pulmonary disease) [1]. This slower entrance into the end-of-life phase allows people time to seek information. However, library and information science (LIS) professionals have done very little research on the information needs and information-seeking behavior of people at the end of life. In this article, the author describes a process used to determine the information needs of one person as he passed through the final phase of his life.

BACKGROUND INFORMATION

The author is a member of the Interdisciplinary End-of-Life Project (IELP) at Wayne State University, Detroit, Michigan. The IELP group is composed of academics from different departments, such as nursing, anthropology, gerontology, political science, sociology, and interdisciplinary studies. A number of practitioners from medicine, social work, pastoral care, hospice care, mortuary science, and law complete the group, the formation of which has been described elsewhere [2]. The interdisciplinary nature of the group required a consensus about how end-of-life issues could be discussed. A conceptual model was developed that has the person who is dying at the center and concentric circles that radiate out to involve the family, the community, and the environment (Figure 1). The model is divided into wedge-shaped pieces that reflect various disciplines, including information. As the "informa-

tion" member, the author has encouraged others to interpret this term in a broad sense to encompass, for example, dialogues between individuals, information needs and seeking behavior, and nonverbal communication. Information is now seen as permeating all disciplines.

Stories about dying and death are used to promote interdisciplinary discussion about the end of life because, as Parry and Doan have noted, it is through stories that a person "interprets the text of her/his life in order to give it meaning" [3]. Kleinman, in his book *The Illness Narratives*, stated that "patients order their experiences of illness—what it means to them and to significant others—as personal narratives. The illness narrative is a story the patient tells, and that significant others retell, to give coherence to the distinctive events and long-term course of suffering" [4]. Thus, stories provide a basis upon which the IELP members can build an understanding of the unique experiences of not only people who are dying, but their family and friends as well.

One activity of the IELP group was the development of a graduate-level course, taught once a year, on end-of-life issues. The course attracts a variety of students because, although it is based in the Interdisciplinary Studies Program, it is also cross-listed in the Department of Sociology, the Department of Anthropology, the College of Nursing, and the Library and Information Sciences Program. Each week, a speaker from a different discipline presents a lecture and leads a discussion on dying and death from her or his perspective. For example, the anthropologist discusses dying and death from a cultural perspective. The lawyer focuses on legal issues, such as advanced directives.

As the LIS professional, the author addresses dying and death from the perspective of the information needs and information-seeking behavior of a person who is dying and, to a lesser degree, those of the family. Theories of information seeking are also covered as well as issues involving communication between the physician and the patient and the patient's family. This article focuses only on the first topic because the other two have been covered elsewhere [5–7] and describes the method used to develop the ''information'' part of the course.

LITERATURE REVIEW

A search of the medical literature revealed a number of articles on physician-patient communication about end-of-life issues [8–10] and family decisions to forego lengthy treatment [11, 12]. Few articles were retrieved that focused on the actual information needs of people who are dying. Kutner and colleagues conducted an in-depth study of the information needs of terminally ill people receiving palliative care. To understand their needs, the researchers interviewed twenty-two people and asked them to ''construct a time line of critical events throughout the course of the illness'' [13]. They also asked, among other questions, about sources of information and the usefulness of the information received. From the data collected, the researchers constructed a semi-structured Likert-scale questionnaire of thirty-seven statements about a participant's ''preferred source for information regarding diagnosis, prognosis, treatment options, changes in disease status, financial issues, advance directive and spiritual issues'' [14]. Eight open-ended questions on the most common topics discussed in the initial interviews were also included, four of which were information-related (i.e., the most helpful information, the least helpful, success in finding out what they wanted to know, and most useful sources of information). They interviewed another fifty-six terminally ill people and found that twenty-three people wanted more information about their illnesses, while the other twenty-nine did not. Overall, the researchers found that over 80% of the participants wanted their physicians to be honest and optimistic (the authors acknowledged the difficulty this situation creates for physicians). They also wanted information about treatments and their side effects, course of disease, and changes in disease status. Less consensus was noted among the fifty-six people on matters of financial information, pain relief, cures, resuscitation, and spiritual issues. Physicians were the preferred sources of information for disease-oriented items (mentioned above). For financial issues, 16.1% of the participants listed family members, and 10.7% mentioned physicians. Lawyers (28.6%), family members (17.9%), and physicians (16.1%) were the preferred sources of information about advance directives. The researchers found that thirty-nine participants (75%) were ''very'' to ''pretty'' successful in finding the information they wanted, five people (10%) were not successful, and the remainder (8 people) respond-ed ''don't know'' or ''I haven't wanted to know anything'' [15]. This extensive study provides valuable insight into the diversity of information needed by people who are dying and suggests a starting point for future LIS studies on the role of librarians in meeting these needs.

STORIES

As mentioned above, the IELP group looks at end-of-life issues through people's stories. Why stories? Because they are integral to our lives. Parry and Doan noted that personal stories ''give a life intelligibility by placing it on a meaningful continuum containing a past, a present, and a future, which are linked by a particular quality'' [16].

Stories are ubiquitous, as Simpkinson acknowledged when she stated, ''[w]e live our lives immersed in stories'' [17]. We tell stories on a daily basis, and hear them from family, friends, and the media. For example, our depictions of the events of a meeting, the movie we saw, or conversation we had with a friend are, in essence, stories we are telling others. ''In a radically pluralistic world, everyone has his/her own story *and* participates in the stories of each family member, as well as of each person with whom he/she has significant contact'' [emphasis in the original] [18].

Stories are powerful because they ''help us to understand our place in the human community . . . Through stories, we can understand our lives'' [19]. Bibliotherapy is a prime example of the power that stories have to help people understand their lives, to find solutions to problems, or to cope with abuse or the death of a loved one [20, 21].

In his book, *The Wounded Storyteller,* Frank [22] described people who are ill as wounded storytellers, that is, people who tell their stories ''*through* a wounded body'' [emphasis in the original]. Illness, he maintained, requires people to learn to think differently about their lives. Stories provide the conduit for people who are living with an illness to learn ''by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared'' [23]. Thus, stories enable people who are ill ''to reaffirm what [they] mean to each other and who they are with respect to each other'' [24].

Because stories involve at least two parties, the storyteller and the listener, they can be seen as conversations. As such, they are not static. Some factors that may cause the storytellers to alter their tales include the situation at hand, the rapport between the individuals, or the time frame within which the stories are told. For LIS professionals, the important point about stories is that they are an excellent medium through which to discover information needs about a phase of life that, to date, has not received much attention.

PREPARING THE LECTURE AND DISCUSSION

To prepare for her lecture, the author chose to ascertain the information needs of a person who is dying by

analyzing a book titled *Conversations at Midnight: Coming to Terms with Dying and Death* [25]. The title refers to the dialogue between Herbert (Herb) Kramer, a communications consultant and writer who was diagnosed with incurable prostate cancer at the age of sixty-seven, and his wife, Kay Kramer, who is a clinical social worker and grief counselor. This book was chosen because it contains not only Herb's story about his passage through the final stage of his life, but also Kay's responses to his questions and her explanations of, or elaborations on, his thoughts and feelings.

The book has six chapters, three of which were analyzed to determine Herb's information needs. In the first chapter, Herb briefly talks about the deaths of his first wife, his half-brother, and his father as a way of demonstrating his previous experiences with death. He then describes his encounter with the physician who diagnosed him with incurable prostate cancer and handed him his death sentence. Also in this chapter, Kay describes her entrance into the field of grief counseling, as well as her reaction to Herb's diagnosis. The second chapter is devoted to definitions of death. The third and most substantive chapter in terms of information needs is divided into twelve sections, each dealing with a separate topic. Each topic is subdivided into Meditations (Herb's thoughts, feelings, observations) and Conversations (Herb's questions and Kay's responses). The last three chapters (Guided Imagery, Dreams and Visions, and Sources of Consolation and Inspiration) are not germane to information needs.

The Kramers state that they read books and talked with others to obtain an understanding of what they were experiencing. Their unique backgrounds and their open dialogues made it easier to identify and categorize Herb's information needs. The analysis of this book did not include an attempt to construct a time line of Herb's information needs; rather the intention was to determine the nature of them.

CONTENT ANALYSIS

Content analysis entails a systematic and objective analysis of "any type of communication," including the examination of documents [26]. Powell described it as "a systematic analysis of the occurrence of words, phrases, concepts, etc. in books, films, and other kinds of materials" [27]. The process of analysis requires the "use of a coding scheme, which consists of categories and operational definitions for specific variables. Content-bearing units are identified in the texts and coded for appropriate categories" [28].

Before reading the book, the author determined that words and phrases would be the basic units of analysis. The concept of information needs was defined as the "recognition of the existence of uncertainty" [29] and operationally defined as words or phrases used by Herb or Kay that suggest uncertainty or the need for information. Four categories of potential information needs were established: physical (words or phrases relating to the body or the disease as it affects the body); psychological or emotional (words or phrases relating to affect); spiritual (words or phrases that connote religious or nonmaterial matters, such as afterlife, eternity, etc.); and financial (words or phrases that relate to money or expenses).

FINDINGS

Definitions of dying and death

There are many terms that describe death, including, for example, "passed, passed on, passed away, or passed over." The terms "dead or died" seem so final, and, as the authors note, "Death is un-American" [30]. While admitting that he hates the "passed" terminologies, Herb acknowledges that it may not be possible to determine the exact moment of death. When he asked a physician the time of his first wife's death, he was unable to get a specific moment because the doctor did not know. Instead, he described what Herb considered to reflect the concept of "passed away." "Her breathing might not have been a sign of life. Her brain might have stopped functioning hours earlier. Her heart might have stopped beating long before that final exhalation. 'She just passed way' " [31].

Three definitions of dying appear at different points in the conversations. Dying is described as a "long spiritual and physical journey" [32] and as the "process of transition from one state of being to another" [33]. The definition of dying that provided Herb and his first wife the most comfort came from the words of Lewis Thomas in his book *Lives of a Cell.* What impressed them was Thomas's emphasis on the "quiet efficiency of the organism's preparation for death" [34]. Quoting Thomas, Herb writes:

It is, after all, the most ancient and fundamental of biological functions, with its mechanisms worked out with the same attention to detail, the same provision for the advantage of the organism, the same abundance of genetic information for guidance through the stages, that we have long since become accustomed to finding in all the crucial acts of living. [35]

While dying was definable, death seemed more difficult to explain. At one point in the conversations, Herb states that it is "only a portal to an eternity that has both mystery and meaning" [36]. How one defines death may depend on one's beliefs. Death can be the end of consciousness, the eternal sleep, or, for those who believe in a life after death, it can be an entry into another state of consciousness.

Information needs

The Kramers' conversations suggested information needs, which the author identified and categorized according to the nature of the information needed: physical, psychological or emotional, spiritual, and financial. The division of information into these categories was not always clear because some needs fell into more than one category. Where this occurred, they are repeated in each category to demonstrate the different perspectives from which a topic can be viewed.

Physical needs

The physical information needs identified were related to Herb's prostate cancer and his physical deterioration and included the following items:

- treatment of the cancer
- prognosis
- quality of life during the period of dying
- relief of pain
- death, suicide, and euthanasia
- loss of sexual function and desire
- loss of interest in activities of daily living
- loss of the purpose of life
- instructions about end-of-life care—no artificial life support
- where to die: home, hospital, or hospice
- burden to family in terms of care
- disposal of his body: burial, cremation, destination of ashes

Psychological or emotional needs

As expected, the Kramers identified a number of information needs concerning Herb's death that can be categorized as emotional or psychological. Hope and fear were the predominant ones.

- hope for
–a remission
–an easy, pain-free death
–courage and energy to fight the cancer
–a cure for prostate cancer
- fear of
–pain
–dying alone, being abandoned by family, friends, physician
–the unknown
–leaving unfinished business
–letting go
–loss of dignity
–being a burden to the family
–loss of physical and mental control
–not being allowed to express anger or rage
–not being able to resolve conflicts
–eternal punishment

Other psychological or emotional needs identified included the following:

- resolving unfinished business with family and friends
- grief at what had been lost or never would be
- despair at not having lived
- confusion about choice of treatment, place of death, right time to die
- depression
- acknowledgment of the preciousness of time
- concern about how he would be remembered

Spiritual needs

Despite the fact that the Kramers devote approximately seventeen pages to the topic of ''spiritual journey,'' it was difficult to extract specific information needs from their discussion. Kay defines the term ''spiritual'' as

- finding answers within yourself,
- gaining trust and confidence in pursuing your inner journey,
- following a process of deeper thought and curiosity, and
- recognizing the preciousness of the experience of dying [37].

It seems that spiritual needs include the ability to reflect on life and to gain a sense of inner peace. In addition, the authors address the meaning of ''eternity'' and whether there is life after death (i.e., another state of consciousness).

Financial needs

Herb and Kay did not discuss financial issues per se. Several items, however, seem to fit into this category, including:

- money matters (pension, life insurance for his wife)
- durable power of attorney
- place of death (hospital, home, or hospice)
- coffin or no coffin
- funeral or memorial services
- disposal of body (burial, cremation, disposal of ashes)
- living will

CONCLUSION

The story of Herb Kramer's end of life is powerful for several reasons. Readers who are dying may find solace in Herb's comments and reflections and may find Kay's answers helpful and enlightening. Readers who have suffered the loss of a loved one will feel a sense of connectedness with Kay as she struggles to cope with Herb's dying and death. Finally, readers (such as health care or LIS professionals) can live vicariously through Herb's end-of-life experience in order to obtain a better understanding of the many concerns facing a person who is dying.

Conversations at Midnight provides considerable insight into the information needs of one person who was facing death. The limits of this approach to determining information needs must be acknowledged. The Kramers are well educated, and, as one reviewer of this manuscript noted, they appear to be the ''perfect'' couple to write such a book. Although the Kramers are more articulate, their information needs were similar to those of the participants in the Kutner and colleagues' study [38]. The findings suggest the need for a more active approach from LIS researchers (through observations, interviews, or oral histories) with people who are dying in order to build a body of knowledge about the information needs and seeking behaviors of people at this stage of life.

Another area of research that has received little attention of LIS professionals is the information needs of the families of people who are dying or who have recently died. Although some of Kay's information needs could be identified, they did not seem to differ much from those of her husband. It is plausible to suggest that survivors' needs may be quite different. For

example, they may want information on how to care for a dying person at home, how to deal with the anger or sorrow at being left alone, how to manage the financial aspects of long-term care, how to live their lives while caring for the person who is dying, or how to decide on medical treatments.

Finally, although articles on the physician's role in end-of-life care exist, it would be interesting to assess doctors' needs for information about death. As Herb and Kay point out, many doctors see death as a personal failure, a treatment failure, or non-compliance by the patient. But physicians' perception of death may be changing as medical education becomes more holistic and patient-centered. Furthermore, as Harvey points out, an aging society is forcing health care professionals to confront this topic and ''to deal with the unique issues'' of the person who is dying [39]. Knowing how the attitudes of physicians are changing would help LIS professionals better meet their information needs.

During the end-of-life phase, people need information to help them make informed decisions about their care and their finances. Librarians can meet these needs by providing the factual information requested. People who are dying also need information to help them cope with a phase of life that is full of mystery and uncertainty. Librarians can help them emotionally and spiritually by suggesting stories of people who have left a legacy of their journey through the end of life.

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