

What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study

Peter Kirk, Ingrid Kirk, Linda J Kristjanson

Abstract

Objective To obtain feedback from patients receiving palliative care and their relatives from various ethnic backgrounds about their experiences of the disclosure process and their satisfaction with information sharing during the illness.

Design A qualitative study with semistructured single interviews.

Setting Perth, Western Australia, and Winnipeg, Manitoba, Canada.

Participants 72 participants registered with palliative care: 21 patient-family dyads in Perth and 14 dyads and 2 patients in Winnipeg.

Results Participants described their experiences in great detail. The analysis indicates that in information sharing the process is as important as the content. The timing, management, and delivery of information and perceived attitude of practitioners were critical to the process. This applied to information interactions at all stages of the illness. Main content areas mentioned related to prognosis and hope. Hope can be conveyed in different ways. Secondary information from various sources is accessed and synthesised with the primary information. All patients, regardless of origin, wanted information about their illness and wanted it fully shared with relatives. Almost all patients requested prognostic information, and all family members respected their wishes. Information was perceived as important for patient-family communication. Information needs of patient and family changed and diverged as illness progressed, and communication between them became less verbally explicit.

Conclusions Information delivery for patients needs to be individualised with particular attention to process at all stages of illness. Patients and families use secondary sources of information to complement and verify information given by health carers.

Introduction

The provision of information to terminally ill patients and their families within the context of obligations for full disclosure can cause uncertainty. Breaking bad news is a complex communication task, affecting the patient's comprehension, satisfaction with care, and level of hopefulness.¹ A patient's dissatisfaction with information is often related to doctor-patient interaction.²

Few qualitative studies have included both patients in palliative care and families with specific focus on information needs.³ We elicited views of patients in palliative care and family members regarding their experiences of disclosure and information sharing during the course of the illness to identify common concerns or issues that might be used by health carers

to shape and develop plans with respect to communication, with particular sensitivity to ethnic and cultural differences.

Methods

Recruitment process

Criteria for patients were a diagnosis of cancer and registration with a palliative care programme. The patient and family member had to be aged over 18 years and able to speak and understand English, without obvious cognitive impairment as judged by referring health professionals. Access protocols were respected; the palliative care or primary nurse approached patients, who phoned researchers or gave permission to be contacted. Patients designated the family member most involved in decision making regarding their illness (often but not necessarily the immediate carer) and both were given separate written information; formal consent was obtained from all participants.

Data collection and analysis

We developed an interview guide to elicit detailed descriptions of participants' perceptions of their experiences of disclosure about the illness and information sharing interactions (see the full version on bmj.com). Face to face, semistructured audiotaped interviews (average one hour) with patients and family members were conducted separately after a brief demographic questionnaire. No information was shared by the interviewer with the other interviewee. One investigator (IK) conducted all interviews at the venue of choice of participants, usually the home. The investigator, a counsellor familiar with palliative care topics, was not involved in the care of any participant.

We transcribed interviews verbatim, noting emotional content. All three investigators read and independently coded transcripts using latent content analysis and constant comparison techniques.⁴ The data were managed with QSR N5 (qualitative data analysis software that facilitates extensive coding, analysis, and text searches of documents).

We addressed recognised criteria for qualitative research: credibility, fittingness, auditability, and confirmability.^{5,6} Credibility was assessed by regular debriefing of the data collector with the team and independent coding and analysis by the investigators. Fittingness was assessed through line-by-line analysis of the interview transcripts and by providing extensive examples of the data. Detailed coding and memos written throughout the analysis enhanced auditability, enabling an examination of the "decision trail" used.

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Consistency of the investigators' independent coding was examined and confirmed.

Participants

We determined the number required to reach saturation in Perth and then interviewed a similar number in Winnipeg. We interviewed 72 participants: 21 patients (16 home hospice and five inpatients) and 21 relatives in Perth, and 16 patients (14 home palliative care and two inpatients) and 14 relatives (two were later unavailable) in Winnipeg.

Results

Participants described the process of obtaining information about the illness during the course of the disease in considerable detail and with notable consistency. Information was received through two major sources: primary (including primary and specialist health providers) and secondary (family, friends, literature, internet, support groups, complementary therapists). Primary information transfer occurred in response to the initial diagnosis, new information about the illness, or change in the patient's condition. The primary source was the main focus of the interviews and analysis.

The two major themes we identified were process and content. Another related theme was the changes in needs for information.

Process

Many participants reported dissatisfaction with the communication process, especially at disclosure of the initial diagnosis. Six attributes were identified to be important in communicating information: playing it straight, staying the course, giving time, showing you care, making it clear, and pacing information (box 1).

Information transfer occurs repeatedly during the course of the illness; in the earlier phases surgeons and oncologists were more apparent as information providers whereas in the terminal stage it was the palliative care team. Each new phase required the same sensitivity to the process attributes to allow integration of new facts. If trust was compromised in the initial disclosure, it often remained an issue at subsequent stages, even if the health carers had changed.

Content

The two most important content areas were prognosis and hope.

Prognosis—Participants described their need for information about prognosis, its accuracy, and the importance of being able to refine their understanding about prognosis as the disease progressed. Many reported that it enhanced communication with family. The timing of disclosure about prognosis was important. Although most patients and families requested this information as soon as or shortly after diagnosis was confirmed, many reported that they were distressed at how it was given. Some stated the information had been given too soon or when they hadn't asked for it. Participants sometimes verbalised ambiguity: they wanted to be told but they did not want to know. Often the exact words used by doctors were vividly remembered. Participants were distressed when information about prognosis was perceived as vague or inaccurate, was presented along with conflicting or

inconsistent information, or was given by someone not perceived to be an expert or directly in charge of the patient. Evasiveness was often perceived as unhelpful (box 2).

Hope—The second most important content area was the provision of hope and the need for hopeful messages at all stages, described as a possibility for cure or longer life or related to short term visions of the future or continued care or an indication that the health professionals are not giving up. Patients expressed a continuing need for hope even when they knew and accepted that they were in the terminal stages of disease and had a limited life expectancy. Even in the end stages, patients and families still wanted the door to be left open for the possibility of a

Box 1: Primary information source—process attributes

Playing it straight

The extent to which healthcare providers are honest and direct in conveying information:

"He is rather reluctant to commit himself to what IS wrong with you actually . . . I would have sooner known right from the start and be done with it and accept it, you know what I mean?" (patient 15, Perth)

Making it clear

The extent to which healthcare providers convey information in ways that the patient/family can understand:

"But he doesn't know how to speak in layman's terms, and I have to say well come on, make it so I understand it" (patient 17, Perth)

Showing you care

The extent to which verbal and non-verbal messages conveyed by healthcare providers are given in a compassionate and empathetic manner:

"We'd ask [the doctor] a question and it was like her back was towards us. I don't know, I just didn't think she cared. I didn't really want to ask her anything . . . The ones at the hospital are great. They actually sit down with you and talk to you eye to eye" (relative 1, Winnipeg)

Giving time

The extent to which healthcare providers offer the patient and family enough time during the information discussions:

"One of them in particular is very good, and he will talk to you for quite a while and explain everything" (patient 1, Perth)

Pacing information

The extent to which the healthcare provider gives information in the amounts and at the rate that patients and families can assimilate:

"I always thought, why are they pushing her to her grave. For instance, her GP, when she told him that she had the cancer, the first thing he said to her, are all your affairs in order? So in other words, you don't have any time" (relative 4, Winnipeg)

Staying the course

The extent to which messages given by healthcare provider indicate that they will not abandon the patient/family as the illness progresses:

"He set everything up to see [specialist] . . . then he said "by all means, come back . . . we are not going to forget about you. We don't want you lost between the cracks," were his exact words. They were super, great people" (patient 5, Winnipeg)

Box 2: Key elements of information content related to prognosis and exemplars

Expert disclosure

The need for prognostic information to be given by the health provider perceived to be an expert: "I was annoyed that he [admitting doctor] was just giving a prognosis from his point of view—[but] the other doctor would have had a good knowledge of the prognosis from discussing it with the oncologist, so what she said we believed" (relative 22, Perth)

Specificity of prognostic information

The need for honesty and respect for the level of detail wanted by the patient/family

"I asked how much time and he said he couldn't tell me because he wasn't God . . . I didn't care for that answer very much. I thought maybe he could be a little more specific. Sometimes it seems that the information is strictly for the medical staff and not for the people" (patient 6, Winnipeg)

"I don't want to know when. I would like to go to sleep and don't wake up, eh, that would be the best thing. I'm not scared, but if somebody is going to say, you've got two days, four days . . . I don't want that" (patient 12, Winnipeg)

Illusion and need for predictability

The need for control as a means of coping that may or may not be met by prognostic information:

"You can deal with things a lot easier I think if you know what's going on than if you don't know what's going on, you know. I can talk about it to them [the family]" (patient 3, Winnipeg)

"I would have been dead cross if I hadn't found out, [because] you start to think, are my affairs in order, mine weren't. And it has taken me almost till now to sort of get things all organised" (patient 7, Perth)

Individual timing

A need to assess the readiness of patient/family to hear information about prognosis:

"I don't want to know about [palliative care] at the moment. I sort of live in hope and the chemotherapy has done wonders for her . . . there is probably a lot they could do for my mother but I sort of associate palliative care with the dying process . . . That's why I get upset to even think about it" (relative 1, Perth)

"The prognosis has sort of changed, so with the change in prognosis then you get a change in what kind of information you need to have. Now I get anxious as to what is going to happen to me as I get worse" (patient 16, Winnipeg)

miracle; many expressed a compartmentalised awareness, simultaneously acknowledging the terminal nature of the illness, while retaining a need and sense of hope. To have hope dashed by a rushed or insensitive health carer was experienced extremely negatively. Two dimensions of hope were described: patient/family orientations to hope (box 3) and messages from the healthcare providers supporting hope (box 4).

Information gathering from secondary sources

Most patients and especially family members obtained additional information from the internet, friends, support groups, books, or second opinions from other health providers, conventional or alternative. Secondary sources expanded information, which decreased uncertainty, allowed the search for hopeful alternatives (treatment options or alternative therapies), gave some

sense of control, and helped to make or confirm decisions about care, treatment, or lifestyle choices (box 5).

Changes and divergence of information needs

The needs of patients and families were similar but diverged somewhat as the illness progressed. Many

Box 3: Patient/family orientations to hope: perspectives of patients and families

Needing to believe in a miracle

Patient's or family member's continuing need to believe that the patient will not die:

"I would like to know the truth, but there is a way between saying 'Well, you have cancer of the cervix and it's incurable,' instead of, 'We'll do our best . . . and there are miracles in the world' [a miracle] still can happen . . . I'm still here [laughs]" (patient 15, Perth)

Living parallel realities

The capacity to acknowledge both the terminal nature of the illness and still hope for a cure/remission:

"Well, I feel invincible, even though I know it's growing again I still feel invincible but I still know that I'm going to die . . . I manage to have these two things in my head at the same time, right and left" (patient 14, Perth)

Box 4: Supporting hope: words and approaches to communication that respect the need for hope

Leaving the door open

The extent to which the health professional communicates in ways to allow preservation of hope:

"We want the information but there has to be a sliver of hope left . . . Her oncologist said to her, 'I want to continue with the treatment, there's a 30% chance here.' He has not ever said a 30% chance of what or for how long, but just hearing that has been what has kept her quality of life for these past six months so much more bearable and better than without hearing that" (relative 14, Winnipeg)

Retaining professional honesty

The need for health professionals to acknowledge their own difficulties in giving a hopeful prognosis:

"[The doctors] said I probably only have months to live. . . . And she said nobody can tell how long you have. But just to get everything in order. I think it was the right thing to do" (patient 10, Winnipeg)

Pacing the move toward palliative care

The need to present information about palliative care at a rate that patient/families can assimilate:

"And she said I have come to talk to you about palliative care, and he just went into an absolute heap. And of course, that word when you say 'palliative care' he immediately thought death in three months. He just went into absolute shock—burst into tears . . . It was too soon" (relative 6, Perth)

Respecting alternative paths

The need to allow patient/families to explore other possibilities for hope:

"I go to the library over here, on the internet, and I also get a lot of information from my brother. I take a lot of vitamins and stuff like that. I asked [the doctor] at the first if it was all right if I took them. And he said, 'That's fine, keep doing it, don't stop'" (patient 11, Winnipeg)

patients reported not wanting as much detail about prognosis as they had asked for initially. In early stages families and patients talked to the health carers together. In later stages family members often talked to them alone, often at the patient's request, and did not confirm the patient's exact state of knowledge. They often assumed less awareness in the patient than was evident in our interviews. Patients and family members did not talk as openly and sheltered each other from knowledge (see box 5). All reported that they complied with their relative's requests for the amount of information they wanted. Patients focused more on daily living and concerns about managing symptoms; families were more concerned with prognosis and details related to care.

Discussion

In this study of patients with terminal cancer and their relatives the need for sensitivity and respect for individual wishes in the communication process emerged as a central theme in the interviews. While this was especially important at the time of the initial disclosure, it recurred at all the different stages of information provision during the illness and affected the way in which content was perceived. The content needs most important to families and patients related to prognosis and hope. Open communication regarding all aspects of the illness and its progress was reported as desirable by almost all participants, regardless of cultural backgrounds.

Limitations

We had hoped to target participants of specific ethnic-cultural backgrounds, expecting to find considerable cultural differences in the desire for openness in information sharing as reported by others.⁷ Although participants came from various cultural backgrounds (22 had been born outside of Australia or Canada),

Box 5: Information

Changes and divergence in need for information

"At the beginning I needed tons (of information). And then at one point I just got tired, you know . . . And right now I believe I have plenty of information and I would just like to be left to my own devices for a while" (patient 14, Winnipeg)

"On one hand I would like to [know my prognosis now] . . . if I know, I can tell myself, so that's it. But I'm not so interested any more." [It has changed?] "Yes" (patient 15, Winnipeg)

Changes in communication patterns between family members

Family and patients stop communicating openly:

Daughter: "I don't believe she has a lot of time left. No one will actually tell me which is in some ways good. I wouldn't tell, I don't think mum needs to know. She seems to think she has a year or more" (relative 19, Perth)

Contrast with mother:

"He didn't tell me how long I had though . . . can't get them to tell me that. [Laughter] But anyway it's been quite exciting since . . . getting everything done—wills made and all sort of things . . . The way it's deteriorated since [previous month] I sort of feel that I want to be ready" (patient 19, Perth)

Daughter: "The conversation's pretty open between us. [A few moments later in interview] I believe that she doesn't acknowledge the extent that the changes are happening" (relative 21, Perth)

Mother: "They [family] know anything I know . . . what I haven't done is ask them, you know, what's going to happen . . . I think they've taken it, in a sense, a lot harder than me . . . all I'm going to have to do is die. They've got to watch me die and then get on without me" patient 21, Perth

What is already known on this topic

Communication of prognosis to patients with cancer is a sensitive issue

Patients' needs for information should be individually assessed

Few qualitative studies have been done to assess needs of patients and their relatives

What this study adds

The process of communication regarding diagnosis and prognosis affects how information is perceived

Six attributes were identified as necessary for sensitive information sharing: playing it straight, staying the course, giving time, showing you care, making it clear, and pacing information

access protocols dictated a large measure of self selection, so it may be assumed that patients in families experiencing conflict with regard to the sharing of information would not volunteer to participate. A more narrowly targeted ethnic group would probably lead to different observations and might show different preferences.

Integration of information was an ongoing cyclical process; it takes time to integrate prognostic information.⁸ Others have noted that some patients with advanced cancer may behave as though nothing is wrong despite being fully informed about prognosis,⁹ although this was evident only in an attenuated form in this study.

Prognostic information needs to be individualised.^{2,3} Contrary to findings in another study,¹⁰ awareness of prognosis was remarkably similar between patients and relatives, possibly because most were in a close relationship (over half were spouses and nearly a third were daughters). This aspect needs further study. The importance of hope is consistent with other findings.³ Hope and need for hope were expressed in different ways, even when participants were fully aware of the terminal stage, and health carers can convey hopeful messages at any stage.

Information transfer is not a discrete event related to diagnosis or the discussion of specific issues. The consistency of the comments regarding unsatisfactory perceptions of this experience indicates the need for further awareness of individual needs of patients and families by health carers. Other studies confirm that needs for information vary at different stages.¹¹ We have provided a framework for understanding the overarching importance of process in communication between health professionals and patients and families in the context of a terminal cancer. Six critical attributes of good communication are important: playing it straight, staying the course, giving time, showing you care, making it clear, and pacing information. They affect the quality of the relationship between health professionals and patients and families and should be emphasised in the teaching of communication skills.

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Characteristics of consultants who hold distinction awards in England and Wales: database analysis with particular reference to sex and ethnicity

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Abstract

Objective To determine whether women, ethnic minorities, and particular specialties are discriminated against in the receipt of NHS distinction awards.

Design Analysis of database of consultants eligible for distinction awards.

Setting England and Wales, 2002.

Main outcome measures Holding of B, A, and Aplus distinction awards, analysed for all awards, irrespective of when made, and for awards made in the last five years studied.

Results Women and doctors from ethnic minorities were substantially under-represented among award holders when no account was taken of potential confounding factors. Differences diminished after multivariate analysis, but some remained significant. For example, the adjusted odds ratio of women holding awards compared with men was 0.69 (95% confidence interval 0.59 to 0.82) for any award and 1.37 (0.86 to 2.20) for Aplus awards; the odds ratio for any award for non-white doctors trained abroad compared with white doctors trained in the United Kingdom was 0.45 (0.37 to 0.56). In the last five years studied, the adjusted ratio of women to men was 0.94 (0.79 to 1.10) for B awards and 1.54 (0.85 to 2.83) for Aplus awards. The adjusted ratio for non-white British trained consultants was 0.86 (0.62 to 1.17) for B awards and 1.20 (0.37 to 3.87) for Aplus awards; for non-white consultants trained abroad it was 0.68 (0.54 to 0.85) for B awards and 0.69 (0.15 to 3.10) for Aplus awards; and for white consultants trained abroad it was 0.70 (0.54 to 0.91) for B awards and 0.90 (0.38 to 2.15) for Aplus awards.

Conclusion Historical under-representation in award holding by women and doctors from ethnic minorities was partly explained by time spent as a

consultant. Recent awards showed no under-representation of women and no appreciable under-representation of ethnic minorities overall. However, doctors who trained abroad—both white and non-white—remained under-represented for B awards.

Introduction

A system of distinction awards for medical and dental consultants was established at the inception of the NHS.¹ The principles of the system (see box) have been endorsed at various times,²⁻⁴ but the precise criteria used were somewhat obscure. The criteria have been progressively refined and increasingly publicised.⁴

Some people have been concerned that women, doctors from ethnic minorities, and consultants in certain specialties are discriminated against in the awards system.^{4,5} In our analysis, the most comprehensive undertaken, we report on the distribution of awards for all award holders and for those given awards in the past few years.

Method

Database—The Department of Health maintains a database of all consultants who hold substantive or honorary contracts with the NHS in England and Wales. This includes year of first appointment as a consultant, current award status (B, A, or Aplus) and date when it

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An appendix and additional tables are on bmj.com



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