

Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review

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Many health professionals (HPs) express discomfort at having to broach the topic of prognosis, including limited life expectancy, and may withhold information or not disclose prognosis. A systematic review was conducted of 46 studies relating to truth-telling in discussing prognosis with patients with progressive, advanced life-limiting illnesses and their caregivers. Relevant studies meeting the inclusion criteria were identified by searching computerized databases (MEDLINE, EMBASE, CINAHL, PsychINFO and Cochrane Register of Controlled Trials) up to November 2004, with handsearching of studies, as well as inclusion of studies satisfying selection criteria reported in 2005 by the authors. The reference lists of identified studies were hand-searched for further relevant studies. Inclusion criteria were studies of any design evaluating communication of prognostic information that included adult patients with an advanced, life-limiting illness; their caregivers; and qualified HPs. Results showed that although the majority of HPs believed that patients and caregivers should be told the truth about the prognosis, in practice, many either avoid discussing the topic or withhold information. Reasons include perceived lack of training, stress, no time to attend to the patient's emotional needs, fear of a negative impact on the patient, uncertainty about prognostication, requests from family members to withhold information and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment. Studies suggest that patients can discuss the topic without it having a negative impact on them. Differences and similarities in findings from different cultures are explored. *Palliative Medicine* 2007; **21**: 507–517

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Introduction

The majority of patients with an advanced, life-limiting illness have high information needs concerning prognosis and life expectancy.^{1–11} However, patients with a terminal illness frequently have misunderstandings about their illness, prognosis and goals of treatment.^{12–15} Patient misunderstanding may be in part due to reluctance by doctors' to prognosticate: doctors may either fail to broach the subject or avoid it if the patient raises it.¹⁶ Health professionals (HPs) present fewer

facts and less detail concerning prognostic information compared with other types of information.¹⁷ Reticence to provide prognostic information to patients may be based on a concern that the information could be contrary to patients' wishes by making them lose hope or become unnecessarily upset.¹⁶ However, in the long-term, well-intentioned practices of withholding information may have detrimental consequences for patients, their family and friends, and the healthcare team.¹⁶

If guidelines and interventions are to be developed about discussing prognosis and end-of-life (EOL) issues, it is important to understand the impact on all parties of this most difficult communication task. The authors conducted a systematic review of truth-telling regarding prognostic information in HPs caring for patients with progressive, advanced life-limiting illnesses and their caregivers. The reasons

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for HPs attitudes and behaviours surrounding reticence to disclose and the impact on patients and caregivers are discussed. In the context of this review, truth-telling is defined as honest communication about prognosis or EOL issues. This does not imply forcing unwanted details upon a patient or family member, rather a willingness to explore and meet the patients' information needs about these topics.

Methods

Searching

We conducted a systematic review of discussion of prognosis and EOL issues in adult patients with advanced life-limiting illnesses and their caregivers. This paper presents the findings in relation to a subset of studies evaluating perceptions of HPs, patients and caregivers about truth disclosure regarding prognosis and EOL issues. Relevant published English language studies that met the inclusion criteria (Table 1) were identified by searching the following computerized databases: MEDLINE, EMBASE, CINAHL, PsychINFO and the Cochrane Register of Controlled Trials. The key search terms used were palliative care, terminal (ill patients, care), death and dying, hospice (care), incurable, death attitudes, communication (skills, training), decision-making, decision support systems, prognosis, truth disclo-

sure and client participation. The reference lists of identified studies were also hand-searched for further relevant studies. Although databases were searched up until November 2004, studies (and a systematic review) written by the authors already identified in the literature review that were in press at that time (published in 2005), and that satisfied the criteria for selection, were included in this review.

Selection

We developed an eligibility checklist for the review, with two rounds of assessment (Table 1 and Figure 1 for further details). Each study was graded for the level of evidence according to recommendations for intervention studies by the Australian National Health and Medical Research Council's Standing Committee on Quality of Care and Health Outcomes.

Data abstraction

Individual authors extracted data from each of the included studies using a standard format [study type and description, study aims, sample, setting, recruitment, ethics approval and type of analysis (quantitative or qualitative)]. Two authors independently assessed the studies, with a third person adjudicating where there was disagreement. We established an advisory panel with expertise in palliative care in order to

Table 1 First round eligibility criteria

1. Eligibility criteria for studies where patients form the study group	<p>(a) Patients in specialist palliative care or hospice settings (inpatient or community) or patients in any care setting with a diagnosis of advanced life-limiting illness being treated with palliative intent and with a life expectancy of less than two years (excluding patients with chronic diseases where the illness trajectory is indeterminable such as dementia or multiple sclerosis)</p> <p>(b) Where samples are mixed (ie, acute and advanced disease), studies are included if more than 50% of the study group have an advanced life-limiting illness or where the results for such patients are provided separately. Studies are not included where it is not possible to determine what percentage of the study group is being treated with palliative intent and has a life expectancy of less than 2 years</p> <p>(c) The patients are not being treated with curative intent</p> <p>(d) The patients are not being cared for in intensive care units</p> <p>(e) The patients are adult (defined as 18 years or over)</p>
2. Eligibility criteria for studies where caregivers form the study group	<p>(a) The situation of care is restricted to the advanced stages of a life-limiting disease, either inpatient or in the community. This includes studies where the caregiver was asked to recall information about the communication of prognosis or EOL, retrospectively</p>
3. Eligibility criteria for studies where HPs form the study group	<p>(a) All disciplines of health professionals are included as long as they are fully qualified</p>
4. General study eligibility criteria	<p>(a) Only those articles published in 1985 and after are included (a period of 20 years is deemed appropriate for inclusion in this review based on changes in patient and community expectations, health professional attitudes)</p> <p>(b) The aims/objective of the study are clearly stated or easily inferred from the text</p> <p>(c) Articles from non-English speaking countries are included and allocated if directly relevant to discussion of prognosis and end-of-life issues</p> <p>(d) Articles on disclosure of diagnosis are included where the disclosure is related to a transition from active treatment to palliation</p> <p>(e) Articles dealing with hope are included if they relate to the relationship of hope and communication</p> <p>(f) The paper is a reported study or systematic review (excluded are review or discussion papers)</p>

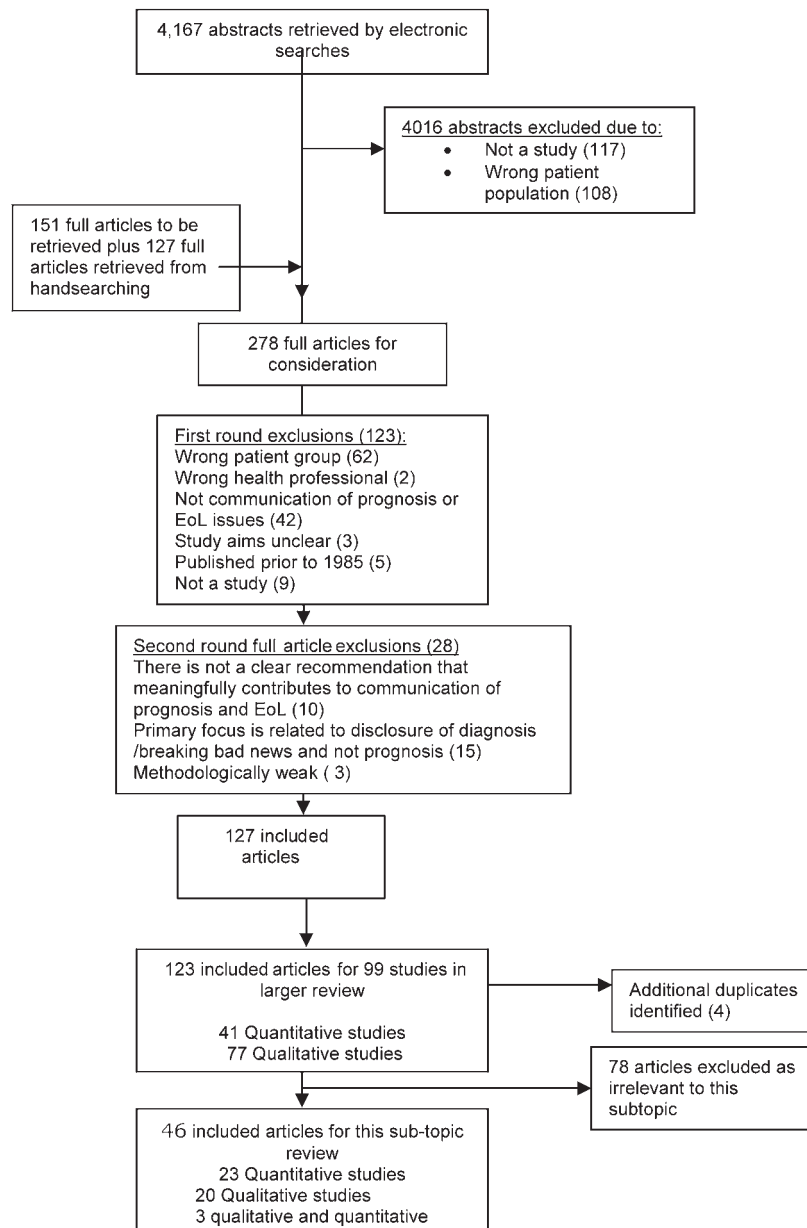


Figure 1 QUORUM flow chart.

provide clinical content expertise and advice to the review authors.

46 studies were quantitative, 20 qualitative, and 3 were both qualitative and quantitative. The participants in 35 studies were from Anglo Saxon backgrounds and from other cultures in 11 studies.

Results

Trial flow (Figure 1)

Of the 4167 references initially identified in the full systematic review regarding prognostic and EOL communication,¹⁸ 123 met the inclusion criteria. This manuscript reports findings from the subset of 46 papers out of the 123 included in the full systematic review, which related to truth disclosure regarding prognosis and EOL issues. Twenty-three of these

Study characteristics

Participants included:

- 1) adult patients with an advanced life-limiting illness in any care setting (except intensive care units) being treated with palliative intent and with a life expectancy of 2 or less years, including patients with cancer, end stage pulmonary disease, end stage cardiac failure and motor neurone disease;

- 2) their caregivers;
- 3) qualified HPs (all but five of the studies, HPs refer to physicians, including interns, palliative care specialists and oncologists, with two studies including physicians and nurses, and three, nurses only).

Studies ranged in size from 7 to 1046 participants. Table 2 shows the number of studies comprising patients, caregivers, HPs and combinations of these categories. However, in studies comprising both HPs and patients or caregivers, most of the findings relevant to this paper reported HPs perceptions or practices. The majority of studies (71%) were conducted in English speaking/Northern European countries.

The majority of studies were rated as Level IVa evidence (descriptive studies of provider practices, patient behaviours, knowledge, attitudes or a systematic review of the descriptive studies). A summary of the studies can be found in a report of the full review.¹⁸ Unless specified, all studies presented are level IV evidence.

Wherever possible the findings are divided according to the country of origin of the included studies to highlight cultural differences. For the purpose of this review, studies were split into two groups according to the predominant cultural group of the sample: (a) English speaking/Northern European cultures (Anglo Saxon) or (b) other cultures. The cultures were grouped in this way because English speaking/Northern European countries primarily consist of people of Anglo Saxon background,¹⁹ and previous research has found differences in attitudes towards truth-telling and patient autonomy between people of Anglo Saxon backgrounds and those from other cultural backgrounds.¹⁰ Where the study was conducted in an English speaking country but with a patient or caregiver sample mainly consisting of non-English speaking (NES) people then they were included in the second group. The limitations of this division are acknowledged in terms of cultural differences both between and within these countries.

Presentation of the review findings about truth-telling regarding prognosis and EOL issues are outlined below under three main categories: 1. Studies of HPs' views from Anglo Saxon backgrounds; 2. Studies of HPs views from non-Anglo Saxon countries; 3. Studies of patients' and/or caregivers' views and the impact of disclosing/withholding

prognostic information on patients/caregivers (findings from Anglo Saxon and other cultures are compared within this category). The studies of HPs' views (1. and 2.) are further subcategorized regarding the following: (a) reasons for withholding information and being reticent to discuss these topics and (b) approaches to dealing with family requests to withhold information about these topics.

Studies of HPs' views from Anglo Saxon backgrounds

The majority of studies from Anglo Saxon cultures (reported in the full systematic review)¹⁸ reported that doctors mostly believed that patients should be informed of the terminal nature of their illness,²⁰⁻²³ and that realistic and truthful disclosure is recommended over withholding of information.^{5,8,24-27} However, some studies noted that doctors were either reticent or avoidant of providing prognostic information to patients with advanced, life-limiting illnesses. For example, a study of 106 Norwegian and Danish nurses revealed that between 25% and one-third of the nurses said they had lied to a dying patient or their family member, or had heard the doctor do so.²⁸ Reasons for reticence to disclose amongst HPs from Anglo Saxon cultures are explored in the studies described below. Studies of HPs' views about how to respond to family requests to withhold prognostic information from patients are also reviewed.

HPs reasons for withholding information or being reticent to discuss prognosis and EOL issues

Discomfort of HPs. Seven Anglo Saxon studies documented discomfort on the part of HPs in either broaching the topic or responding to patients' requests to discuss prognosis. In two studies,^{29,30} stress was cited as a major factor inhibiting open conversation. In a study by Baile *et al.*,²⁹ the majority of 167 doctors from various countries reported that it was stressful to deal with their patients' families, respond to their patient's emotions, to be honest without depressing their patients and to handle their own negative feelings during prognostic discussions. These situations were stressful regardless of how commonly they were confronted, and particularly in relation to making prognostic predictions.^{29,30} Christakis and Iwashyna³⁰ also cited inadequate training as a factor with 57% of the 1311 doctors surveyed reporting their training in prognostication to be inadequate. Similarly, Curtis and Patrick³¹ reported that finding of focus group with 47 patients having AIDS and 19 physicians, and found that discomfort in discussing death was a barrier to communication about EOL issues.

Other studies reported HPs' discomfort in disclosing information related to advance directives and do not resuscitate (DNR) orders, although results were variable. In

Table 2 The numbers of studies according to the study group

Study group	n (%)
Patients	6 (16%)
Patients and caregivers	2 (4%)
Caregivers	5 (11%)
Health professionals	22 (48%)
Patients and health professionals	4 (9%)
Caregivers and health professionals	1 (2%)
Patients, caregivers and health professionals	4 (9%)

the study by Tulsky *et al.*,³² only 33% of the 101 interns surveyed reported being uncomfortable about DNR discussions. In contrast, most of the 15 doctors in the study by Sullivan *et al.*³³ found discussions around mechanical ventilation (MV) with end stage pulmonary disease patients difficult either because of the unpredictability of the disease and outcomes of MV or because patients find the idea difficult to grasp. They also reported sometimes initiating discussions about advance directives and DNR, but it was easier if the patient raised the topic. Likewise many of the 214 GPs in the study by Elkington *et al.*²¹ found it difficult to discuss prognosis with chronic obstructive pulmonary disease (COPD) patients. One-third of GPs surveyed reported that they found it difficult to start discussions of prognosis with severe COPD patients and 30% left it for patients or their relatives to raise the subject. In this instance, GPs were undecided whether most patients wanted to know about their prognosis and nearly half found it difficult to ascertain which patients wanted to discuss the subject. Of the 167 oncologists in the study by Baile *et al.*,²⁹ many reported that while they typically have the discussion of DNR orders late in the disease trajectory, it would be better to have the discussion earlier to help patients plan and make decisions about EOL issues.

Another reason for reluctance to discuss prognosis lies with physician attitudes towards death. A US study³⁴ reported that caring for dying people frequently evokes thoughts about mortality for HPs; therefore, the degree to which the HP has reconciled these feelings will affect their ability to provide care.

Uncertainty about illness trajectory. Many cancers and other life-limiting illnesses have an unpredictable illness trajectory, so it is rarely easy to prognosticate with precision.^{16,30} The estimated survival of a particular patient was raised in five studies as impacting on doctors' inclination to disclose prognosis. The US study by Kaplowitz *et al.*²² found that 64% of the 51 doctors surveyed said they would disclose a prognosis to patients with a median survival expectancy of three months even if not requested. Gordon and Daugherty's study of 20 oncologists found that they were more likely to disclose prognosis when patients have a very short life expectancy.³⁵ On the other hand, Eggerman and Dustin²⁰ found that the majority of 15 doctors in this US study stated they were less hesitant to tell a patient that they were dying if they had a life expectancy of a year or more. Only 23% said they would impart this information if the patient had less than one week to live.

Several US and Australian studies noted HPs' reluctance to provide survival estimates when discussing prognosis.^{22,24,30,35} All studies emphasized the importance of explaining the uncertainty of predictions of life expectancy. Most doctors and nurses stressed the importance of not being too restrictive or definite with time frames, except when the time frame is very short, such as hours to days.

Too little time in consultation. Two studies reported on this topic. Curtis *et al.*³⁶ found that one of the most frequently identified barriers to communication about EOL care by 57 physicians and their patients with AIDS was too little time in appointments to discuss everything that should be discussed; as did Baile *et al.*²⁹ in their study of 167 cancer physician's perceptions.

Patient requests for information. Three studies found the doctor's decision to disclose prognostic information was based on whether the patient requested the information.^{22,30,35} In Gordon and Daugherty's study³⁵ many doctors reported sometimes feeling pressured by patients to give information.

Concerns for negative impact on patient. Six studies reported on this issue. The 20 oncologists in the Gordon and Daugherty study³⁵ reported that they do not volunteer prognostic information unless they think the patient can handle the information; the therapy is failing; the patient is symptomatic; in pain; sick; having bad complications; treatment decisions need to be made; when patients make unrealistic therapy requests or expectations; and when recommending palliative care. Some participants indicated that disclosure could hamper the establishment of trust and the doctor-patient relationship. They were reluctant to disclose prognosis as they wanted to preserve hope, but at the same time they realized the need to impart this information in order to ensure that patients' expectations about therapy were realistic. In the US study of 122 doctors by Anderlik *et al.*,³⁷ the top five reasons that doctors withheld information were sensitivity to patients'/families' cultural norms; the patient's fragile emotional state; respect for the patient's expressed wishes; concern that the information would destroy hope; and respect for family's expressed wishes. It is noteworthy that physician issues such as anxieties about discussing death were not rated in the top five reasons. A US study by Curtis and Patrick³¹ of 19 physicians caring for patients having AIDS and 47 patients found that barriers to discussion of EOL issues were: the patient is not sick enough to talk about EOL care; discussing death can cause harm or death; patients avoid EOL discussions to protect physicians; both patient and HP waiting until the other brings up EOL care. Doctors of patients with AIDS in another study by Curtis *et al.*³⁶ reported that they were concerned that the discussion would take away a patient's hope.

The study by Clayton *et al.*,¹ of palliative care HPs found that the more proactive HPs felt there may be adverse consequences if the patient and their family did not have the opportunity to discuss these issues and adequately prepare for their death. On the other hand, some participants were reluctant to raise the topic for fear of harming the patient if they were not ready to think about these issues. Gordon and Daugherty³⁵ also found that on one hand HPs were aware of the ethical value of preventing patient harm or

non-maleficence, but they also had an ethical prerogative to disclose prognosis.

While many doctors claim to be protecting their patients' best interests and respecting their wishes when they do not disclose, most of the doctors in the study by Kaplowitz *et al.*,²² felt that the vast majority of patients want to know the prognosis. Despite this, less than a third sought to learn the patients' knowledge or their information preferences about the disease.

Family/caregiver requests for withholding of information. Family members have been found to influence, or attempt to influence a HP's decision to disclose or withhold information concerning a patient.^{29,38,39} There were three English speaking/Northern European studies on this topic. In the study of 122 US doctors by Anderlik *et al.*,³⁷ one of the top five reasons that doctors withheld information was respect for family's expressed wishes ($n = 22$). In a study of 167 oncologists attending an international conference by Baile *et al.*,²⁹ more than 40% of the doctors reported that they occasionally to almost always withheld the prognosis from the patient at the family's request and used euphemisms to discuss bad news. Doctors from Anglo Saxon cultures were under-represented in the group that complied with family requests, compared to doctors from other cultures. In an Australian study³⁹ families requesting that information be withheld from the patient were reported to be commonly (not always) from a NES background.

HP's approaches to dealing with family requests to withhold prognostic information. Two studies reported on this topic. An Australian study by Butow *et al.*⁹ discussed the difficulties of catering for the needs of the family. Most of the 13 HPs interviewed declared that the patient was their primary responsibility, whose autonomy and information preferences were paramount. Therefore, if families wished to keep the prognosis a secret from the patient, HPs attempted to build up a trusting relationship with the family, and to convince them that such a course would not be helpful. Clayton *et al.*³⁹ also discussed the need to balance families' versus patients' rights to information, autonomy, non-maleficence and confidentiality. The 22 HPs in this study reported a number of approaches to these situations. Some said they would try and encourage the family to have an open conversation and acknowledge what is going on with the patient. Others said they would respect what the family did not want the patient to know and not raise it with them but would answer direct questions from the patient honestly. A few HPs said they would negotiate what was to be discussed. Where different family members have different opinions on how much information the patient should be told, most HPs suggested a family conference, others suggested nominating a family spokesperson who could make decisions and communicate information to the rest of the family.

Studies of HPs' views from non-Anglo Saxon countries (other cultures)

There were 10 studies of HPs' views from other cultures. Consistent with Anglo Saxon studies, two studies, one from South America⁴⁰ and another from Spain,⁴¹ found that doctors primarily believed that all patients should be informed about the terminal nature of their illness.^{40,41} However, in most of the studies from 'other cultures', doctors were less in favour of disclosure of prognostic information. A Spanish study⁴² reported that approximately 65% of the 153 doctors surveyed at least partially agreed with not telling patients they were dying, although the remainder were supportive of allowing the patient to know, and thereby accept their situation.

Some studies reported that doctors were more likely to inform family of the prognosis than the patient. These were studies from Japan,⁴³ Hong Kong,⁴⁴ Spain⁴² and Greece.⁴⁵ In the Fielding *et al.* study,⁴⁴ 12% disclosed to the family first or passed information to the patient through the family. In the study by Barroso *et al.*,⁴² 7% of 153 doctors said it should be the family to impart the information to the patient, with 69.2% saying it should be the doctor and the family together. In the Georgaki *et al.* study⁴⁵ of 144 oncology nurses, 89% of nurses believed that the truth about the diagnosis should be told to the relatives with only some cancer patients being told.

In addition, 69% of the nurses avoided using the word 'cancer', despite knowing that some patients were already aware of their disease and 66% found it difficult to engage in open conversation with patients concerning the disease or the prospect of dying. A Japanese study⁴³ reported that nurses had felt the need to lie to a dying patient. Some nurses in this study said that a problem with direct telling is that the doctor tells even when the patient is not ready to know and this is uncaring to some patients who become depressed.

HPs reasons for withholding information or being reticent to discuss prognosis and EOL issues (other cultures)

HP fears and attitudes. Two studies reported on this topic. Doctors who believe that dying patients should never be made aware that they are dying were found in the Israeli study by Amir⁴⁶ and the Spanish study by Barroso *et al.*⁴² to have a greater fear of their own death, to avoid references to their own death, have higher trait anxiety and to express more rigid attitudes towards the problems surrounding terminal patients.

Patient factors. There were five studies from other cultures on this aspect. In Amir's⁴⁶ study of 104 Israeli general surgeons and Miyaji's¹⁷ study of 32 Japanese physicians, the major factor related to disclosure of information was the patient's request for information. In the case of the Spanish study of 108 doctors and 102 nurses by Pacheco *et al.*,⁴¹ the doctor's perception about the patient's ability to understand

and accept the situation was a factor in the level of prognostic disclosure. Similar to the US findings of Eggerman and Dustin,²⁰ 70% of 100 doctors in a United Arab Emirates study⁴⁷ said they would not tell a patient who has a 50% chance of dying within the next 6 months. Consistent with the US findings of Christakis and Iwashyna,³⁰ more than 60% of 74 doctors in a Japanese study⁴⁸ also said they gave patients a 'very' or 'somewhat' optimistic account of their prognosis, but this was done considering the patient's preferences, personality, trusting relationship, psychological support, age, social status and family's consent.

Caregiver/family members' concerns for patient (HP and caregiver views). There was one study in this area. In a study of HPs and families of seven culturally diverse patients (including two Chinese and three Latino patients) many doctors felt that family members would withhold information if they felt it was in the best interest of the patient.⁴⁹ The families in this study thought most information was 'not good' for patients. Particularly where family members would act as interpreters, they would request the doctor not to tell the patient what was wrong or disclose how much time they had left. Family members used as interpreters may choose to monitor and/or censor what the patient is being told whereas getting external interpreters is seen by the family as questioning their competence and may damage the relationship between health care providers and family members. In this study, other reasons for family non-disclosure were to protect the patient, because it was inappropriate or impolite (Chinese and Latino), it was considered bad luck (Chinese) and withholding information keeps hope and the patient alive.

HPs' approaches to dealing with family requests to withhold prognostic information. Only one study examined this issue and is similar to Anglo Saxon findings for HPs. Hu *et al.*⁵⁰ surveyed 229 HPs from Taiwan regarding ways of reducing family related barriers to prognostic disclosure. Strategies included having a gentle discussion to determine what the patient knows, to also identify what the family knows and to find the appropriate time and person to give them more information. They also saw it important to communicate with and encourage families to accept the patient's prognoses, inform families about the possible emotions those patients will experience and enhance ways to provide support.

Studies of patients' and/or caregivers' views and impact of disclosing/withholding prognostic information on patients/caregivers

One of the reported obstacles to disclosing information is the belief of the HP that disclosure will cause unnecessary upset

or harm to the patient.^{37,1} Eight studies, all but one from Anglo Saxon countries, explored the impact of withholding information from patients on patients and caregivers. Caregivers formed the study group in two studies, patients in four and both in one study.

Anglo Saxon studies

In interviews with 21 US caregivers, Carter⁵¹ noted that there were instances where the delivery of the information seemed to divide the patient and the caregiver and this ultimately caused caregivers more stress. When caregivers had been told more than the patient this left them with a decision about what the patient should be told. This placed an immense strain on the caregivers and a sense that they were isolated from the patient with whom they would have naturally shared fears and worries. Rose⁵² also reported on stress in 21 caregivers. This UK study highlighted the impact of fear and lack of knowing what to expect as increasing stress for caregivers. Caregivers also described instances when they and patients had been told what they felt they should know but in some instances this information had been divisive, resulting in more stress. On the other hand, Johnston and Abraham⁵³ conducted a qualitative study of 16 patients with advanced cancer and caregivers, with participants believing that the ability of the caregiver to cope with the knowledge of the patient's prognosis could influence the amount of prognostic information requested by the patient.

A Swedish study of 30 patients and family members³⁸ found that rather than family members directly requesting the doctor to withhold information, they assumed various roles as ways of influencing the disclosure of information to the patient surrounding the discussion of transition from active treatment to palliative care. The secret-keeper role was the family member who wanted the information but did not want to tell the patient. They tended to silence previous warnings about the progress of the disease with positive words, thereby 'protecting' the patient from unpleasant thoughts and discussions. The controller role communicated with the doctor instead of having the patient do so, thus 'protecting' the patient. Information was delivered by the family when they judged the patient was ready for it.³⁸

The Australian study by Gattellari *et al.*⁴ administered a pre- and post-consultation questionnaire to 118 patients, and found that greater information disclosure was not associated with increased anxiety levels. Tattersall *et al.*⁵⁴ audiotaped 118 consultations of Australian patients with incurable cancer and their oncologist. Greater information given about prognosis was not associated with increased anxiety. They concluded that if information provision is not honest and detailed, patients may perceive that HPs are withholding potentially even more frightening information. In the study by Johnston and Abraham,⁵³ that increased awareness was noted to have no effect on the immediate fear of separation for the 16 patients and 14 caregivers. The Canadian study of

200 advanced cancer patients conducted by Chochinov *et al.*⁵⁵ found no significant relationship between awareness and survival time (measured by the number of days from time of interview to death), educational background, pain intensity, hopelessness or desire for death.

The *et al.*⁵⁶ conducted a qualitative study of 35 Dutch patients with advanced cancer. They reported that patients and their families who received little information about their prognosis had a sense of false optimism. In hindsight they regretted this approach and the resulting decisions they had made regarding their medical care.

In a US study of 20 nurses, 10 doctors and 5 caregivers by Norton and Talerico⁵⁷ participants reported that HPs who were uncomfortable with discussing prognosis and EOL issues tended to avoid these conversations, resulting in patients receiving burdensome and painful treatments and not having sufficient time to prepare for death.

Other cultures

Japanese family members ($n = 318$) in the study by Morita *et al.*⁵⁸ found that families with high levels of distress were significantly more likely to report that the doctor told them that nothing more could be done, and that patient had informed them of an estimated prognosis. This group was less likely to report that the doctor was willing to explore their feelings, explain treatment goals or encourage questions.

Discussion

This review found that some HPs tend to either withhold information or reticent to disclose prognosis and EOL issues with patients and/or their families. There were many reasons for this situation, including perceived lack of training of HPs; stress; no time to attend to the patient's emotional needs; fear of a negative impact on the patient; uncertainty about estimating illness trajectory; requests from family members to withhold information; and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment.

Although many HPs expressed discomfort at having these discussions or felt ill-equipped with this task, the majority believed that patients have a right to open and accurate prognostic and EOL information. This is consistent with the modern medical principle of patient autonomy and involvement in decision-making. However, in practice, there was a tendency for HPs not to be forthcoming unless the patient openly requested the information, or the HP made a judgment that the patient needed to know (such as in the case of a short predicted survival time). The underlying assumption behind not telling because the patient did not ask is that the patient will ask what they want to know. However, the patient may be afraid to ask for this information, or not know

how to broach the topic. A situation of collusion may also occur in order to preserve hope and optimism. However, this review suggests that the assumptions on which the doctor colludes are unfounded. Studies reviewed showed that patients could have these discussions without impacting on anxiety, that withholding information from the patient but not the family can cause friction. Research has also found that being honest with patients rather than adopting an avoidant approach is a way of fostering hope.^{7,26}

Although the review found that a reported reason for not disclosing was that it would interfere with establishing trust, trust implies that doctors will tell the truth about prognostic information, so that patients can make informed decisions. In order to build trust and maintain hope, patients need to know symptoms will be controlled²⁶ and their doctors are honest without being blunt.⁷ Rather than protecting the patient, the doctor's well-meaning attempts to keep the truth from patients may harm the patient more than open and honest prognostic discussions.^{16,54-56} In the absence of informed prognosis, patients may embark upon treatments that are not only ineffectual, but also potentially harmful, and they may die in a way that they did not want.

One pragmatic reason given by doctors for not discussing prognosis was time constraints during a consultation. It is acknowledged that health care systems operate under tight fiscal restraints, with great demands of HP's time. However, the adverse consequences of not discussing prognosis and EOL issues as discussed above must be considered. It is also possible that addressing patients concerns about these issues may reduce the duration of subsequent consultations, although research is needed to confirm this hypothesis.

This review showed that in some non-Anglo Saxon cultures, families take control of information from the patient. Prognostic and EOL information was seen by some caregivers to impact negatively on the patient's condition as opposed to empowering them. Doctors from non-Anglo Saxon cultures were more likely to withhold information from the patient at the family's request, and doctors from these countries had a tendency to impart information to family members before, or instead of, to the patient. It is also possible, as several studies have found, that patients from these cultures simply prefer a lower level of information compared with those from Anglo Saxon cultures.^{11,59,60} Also, a pervasive cultural belief of many non-Anglo Saxon cultures and religions is that the well-being of the family is the first priority, as opposed to Anglo Saxon cultures where the individual is the first consideration.⁶¹ Research on attitudes and beliefs of HPs have shown that in some cultures physicians, or families, or both, deem full disclosure to be prejudicial to the patient.⁸

However, these beliefs may conflict with Anglo Saxon ethical principles of respecting patients' rights to information, autonomy, non-maleficence and confidentiality.³⁹ Firm conclusions cannot be drawn from this review about the impact of cultural differences on the prognostic discussion, as

discussed in the limitations section. It is however, imperative that the HP is able to convey respect for beliefs of different cultures, particularly regarding the importance of family, while still providing the best possible care to the patient.

Although findings from the review suggests that HPs should tell the truth rather than withhold information or avoid discussing the topic, there is still the potential for HPs to do harm if they lack relevant communication skills. Several studies reported that one reason for not discussing prognosis was that HPs felt they lacked the necessary skills to discuss the topic. There is evidence that HPs do not elicit the majority of patient concerns, especially psychological concerns linked to death and dying.⁶² They may also fail to respond when patients express concerns about these topics.⁶² HPs need sophisticated and sensitive skills when discussing prognosis and EOL issues with patients and their caregivers. The skills of knowing how and when to discuss these topics are not necessarily acquired naturally over time; rather they are skills that can be formally taught, the importance of which is being increasingly recognized.⁶³

Limitations

Most of the studies in this area are level IV (descriptive qualitative research), which is regarded as low-level evidence. However, as this research focused primarily on HP, patient and caregiver perceptions, descriptive qualitative research evidence is an appropriate way of increasing our understanding of the issues. Another limitation is that much of the research has focused on particular patient groups (eg, cancer patients), which may limit the generalizability to other progressive, life-limiting illnesses. The issue of culture was not able to be fully explored due to lack of direct comparison of culturally and linguistically diverse populations and lack of reports from NES countries. In addition, only studies written in English were included in this review. Although the situation is improving, traditionally many palliative care journals are not indexed on many databases, so that some studies may not have been identified due to lack of indexing. Another limitation of studies that have used audiotape analysis of consultations is that an audiotape at a single time point is unlikely to capture the complex and evolving nature of communication about prognosis.

Recommendations for research and practice

The findings highlight the needs for HPs to undertake communications skills training to equip them for prognostic and EOL discussions. However, more research is needed to demonstrate the value of these programs in improving patient outcomes. Although the review suggests that the patients can be told prognostic information in an honest way without increasing anxiety, there were only a small number of studies that assessed the impact of prognostic discussions on patient outcomes. Further research is needed in this area including the impact of prognostic disclosure on: patient and

caregiver satisfaction, use of invasive treatments at the EOL, preparation for death, achievement of preferred place of death and bereavement outcomes in caregivers. It would also be valuable to conduct randomized controlled trials or even descriptive studies comparing the effects of truth-telling regarding prognosis during the first consultation versus later consultations, or not at all, on patient outcomes and subsequent consultation times. Audiotapes/audiovisual recordings of consultations over time as well as assessment of patient and caregiver outcomes are needed to assess this.

The tendency for families of other cultures to request information be withheld from the patient suggests that HPs should be aware of cultural differences in information preferences and attitudes to discussing prognosis and dying, while at the same time not making assumptions about information needs based on their cultural background. Future research should directly compare cultural backgrounds in order to elucidate the impact of cultural differences on the prognostic discussion.

In addressing family requests to withhold information, it is recommended that HPs respectfully explain their ethical obligation to give the patient the opportunity to ask questions about their illness and to respond honestly. Finally, it is important to not assume that patients do not want to know their prognosis, simply because they do not ask a question about this. Rather, it is recommended that patients and their families be offered the opportunity on more than one occasion to discuss these topics if they wish.

Conclusion

Many reasons were identified as to why HPs may be reluctant to disclose information regarding prognosis and EOL issues to terminally ill patients and their families. However, the studies reviewed suggest that patients can discuss the topic without necessarily increasing anxiety. Furthermore, avoiding the topic can have adverse outcomes. By discussing this information sensitively, and encouraging the patient to share in decision-making, the HP can help the patient reset goals and choose appropriate supportive treatments rather than those that are burdensome. Communications skills training may equip doctors to discuss prognostic and EOL issues more confidently.

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