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Direct communication, the unquestionable ideal? Oncologists' accounts of communication of bleak prognoses

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Abstract

Objective: **To explore the factors that influence the clinical practice of oncologists concerning disclosure of prognostic information.**

Methods: **Focus group interviews with oncologists in three Norwegian university hospitals. Interview guide consisting of three patient cases where challenging aspects of prognostic information delivery were presented to the participants. Each group consisted of six participants, all groups with a mix of men and women, and ranging from very experienced consultants to relatively inexperienced residents in oncology. Transcribed interviews were qualitatively analyzed through categorization and condensation.**

Results: **The importance of openness when dealing with prognostic information towards the end of life was strongly advocated by all participants. However, there was a reluctance to give tangible information regarding survival, and a feeling that this part of clinical practice was a challenge. Skills in how to communicate negative prognostic information were attained primarily by observing colleagues, but also from personal experience. Existing guidelines for communication were not perceived as useful.**

Conclusion: **Primarily focusing on open communication regarding bleak prospects of life expectancy entails a risk of overrunning the information needs of individual patients. Oncologists still see communication skills primarily as personal, and are at risk of not exploring and responding to the individual patient's wish for information.**

Keywords: cancer; oncology; patient–physician communication; prognosis; attitudes

Introduction

In the literature regarding communication of bad news, the emphasis has been on open and honest information, sensitively given by a physician who perceives and responds to the patient's needs [1]. There has been a focus on the physicians' moral obligation to inform the patient, with a body of evidence supporting the advantages of full disclosure [2–5].

The change from non-disclosure to disclosure of the cancer diagnosis took place around 1970 [6]. Full disclosure was partly based upon the doctrine of informed consent, first introduced in relation to clinical trials. This doctrine has influenced other parts of patient management, and informed consent and shared decision making are now important principles in oncological practice in North America and North-western and Central Europe. The importance of truthful information is supported by several studies showing that most patients want to be informed, including bleak prospects [7,8]. However, the mode of communication is crucial since it influences patients' subsequent ability to adapt to the harsh realities [9,10].

Compared with the dichotomous nature of diagnostic information, prognostic information can vary considerably. Furthermore, the level of prognostic information can be varied considerably in detail. Communication of prognostic information thus challenges physicians' ability to understand patients' preferences as to information and the ability of the physicians to estimate patients' expected lifespan under different treatment regimens. The task of informing is of course even more challenging with increased severity of the prognosis.

In the present study an understanding of bleak prospects and bad news which implies likelihood of a dramatically shortened life expectancy is applied. The many considerations as to what individual patients perceive as devastating scenarios are not dealt with here [1,11].

Disclosure of prognostic information is much less researched than disclosure of diagnostic information [12]. Some approaches used by oncologists have been identified; realism (bordering on truth dumping), optimism or avoidance of the subject all together [13–15]. There are indications that this part of the patient–physician relationship functions sub optimally [16]. Physicians fail to uncover patients' information needs and to what extent patient and family have understood the prognostic information [17,18]. Patient participation in decision making is not encouraged by vague or absent discussions of expected survival or potential benefits of treatment [16]. Patients identify hope as an important element within prognostic discussions. Whether avoidance of sensitive topics or detailed information nurtures hope, will vary from patient to patient [10,19,20]. In addition, patients' demand for ambiguity in the communication of prognoses has been found in several studies [10,19,21,22].

Given these contradictions, imparting prognostic information is of a different and probably more challenging nature than conveying diagnostic information. To what extent physicians are aware of these challenges and how they try to deal with them, is to our knowledge not explored sufficiently.

The aim of this study is to explore factors that govern oncologists' communication of bleak prognostic information. More specifically, the oncologists' notions of how they communicate unfavorable prognostic information is investigated, as is their opinion regarding on what grounds they base their practice.

Material and methods

Participants and design

Oncologists from three Norwegian University hospitals were recruited. The recruitment was done by contacting the head of department at each unit, asking for a minimum of six and a maximum of eight participants, both residents and consultants. The head of department chose participants that were available at the time. No participant asked to participate declined to do so. Oncologists from a fourth university hospital were involved in piloting the interview guide. Evaluations of new topics was done after each group interview, and since no new topics or considerations emerged in the second and third group interview, the data collection was ended [23]. At each hospital a focus group was constructed consisting of six physicians, ranging from residents with only months of practice to consultants soon to retire. Most participants had a minimum of 2 years of practice in oncology. In Norway oncologists are specialists in both oncology and radiotherapy. Furthermore, all oncologists meet patients with all types of cancers during calls and they are organized within each hospital at one department. All focus groups consisted of both male and female physicians, in total 6 men and 12 women.

We used focus group interviews since this method generates relatively large amounts of qualitative information during a short time, and give additional insight because colleagues discuss presumably difficult matters with each other [23–26].

Data collection

The focus group interviews were conducted by a moderator (LR), with an assistant experienced in the focus group method (OA or Viktoria Akre). The moderator is an oncologist by training. The interview guide (in Norwegian) consisted of three patient cases that included challenges and dilemmas in communicating prognoses. The cases had particular emphasis on shifts in prognosis, from curative to palliative phase, and functioned as triggers in the discussions. In addition, the moderator also used scripted probes when needed. The interview guide was developed through discussions between the principal investigator (LR) and a researcher experienced in focus group techniques (VA), based on clinical experience and literature concerning communication of bad news and prognoses. Finally the interview guide was piloted and thereafter revised. The group sessions lasted for about 90 min each. All focus groups were audio taped and fully transcribed by the principal investigator.

Data analysis

The transcribed texts were qualitatively analyzed according to Giorgi [27], the method modified by Malterud [28]. There were four steps in the analysis: (i) reading all the material to obtain an overall impression and bracketing passages that linked to previous preconceptions derived from literature and clinical experience; (ii) identifying units of meaning, representing different aspects of the theme and coding for these; (iii) abstracting the content of individual meaning units; and (iv), summarizing their importance.

The translation of quotations from Norwegian to English was done by a certified translator.

Analyses were done by the principal investigator and a co-author experienced in qualitative research (OA). Actively looking for contradictory meaning units in the transcribed text, as well as alternative interpretations of the meanings was done to ensure validity.

Results

Three major topics were identified in the transcripts: Communication practices regarding unfavorable prognoses, Openness as an ideal, and Rationale for practice. The quotings are labelled with (R), designating researcher, and (I), designating informant. The numbering is given consecutively, so that an informant who is quoted several times is labelled with the same number each time.

Communication practices regarding unfavorable prognoses

Imparting information of disease recurrence

When asked how the oncologists would inform patients about the discovery of the first metastases, and thus a change in prognosis, similar strategies and phrasings were suggested by many participants.

> *(I4) I usually say that 'you are probably anxious about this', and then go straight to the point and tell her (about the metastases), because I know that's what she is interested in. 'Unfortunately, the test shows a tumor from the breast cancer in your lung', and I often think that she doesn't actually hear what I am saying from then on.*

Avoidance of accuracy

Despite an expressed obligation to impart prognostic information to the patient, avoidance of accuracy was suggested, both in the choice of wording and when patients requested information regarding survival time.

> *(I2) Yes ... The words 'you will die from this' are missing. But I always use the words 'can not wipe out' ... and 'can not cure'. And the great majority, maybe not all, but the great majority of Norwegians know that cancer which you cannot wipe out or cure is lethal .... It is rare that you need to say that 'yes, and in the end you'll die from it'.*

> *(I10) But on the few occasions when the question has turned up, I do my best to avoid answering or even refuse to say anything about length of life.*

While some information of prognoses is given as a result of direct questioning from the patient, more is implicit in the discussion of treatment plans and expected benefits from proposed treatments. The statement below shows an example of how oncologists try to meet the obligations to keep the patient informed without being too blunt about the transition from a curative to a palliative phase of the illness.

> *(I2) 'Unfortunately, we cannot wipe out the disease, but with treatment we can at best control it, and for some this lasts a long time, but at some point the disease will develop, in spite of treatment. We cannot cure you of the disease'. That's how I often say it, and my experience is that the majority understands the message, that it is palliative treatment they will get, that we cannot cure them, and most people don't want much more than that. But that is the minimum I think I have to say to a patient who is not going to get curative treatment.*

Metacommunication

Several participants suggested the importance of warning the patient before bad news was delivered, and one indicated a sort of metacommunication as to the level of precision wanted by the patient.

> *(I6) In my experience, it is very important to get an idea of at what level of precision the patient wants the information, and, before you get to that, that you give some sort of warning, 'here is some information ..., it's important that you are a bit prepared', so that they don't feel completely knocked out.*

Attempts to promote hope

Some oncologists presented phrases intended to support patients' hopes for unrealistic disease trajectories.

> *(I1) A normal, not medically educated patient might think that 'maybe there is something special about me', and this gives room for a kind of hope that is rather vague. I feel that I can give this kind of hope, and that I can say 'from what I know I wouldn't bet on it, but from time to time things happen that not even we can explain'. To give this to a completely devastated young patient, I don't feel that's hypocrisy, if you have said that 'building on my knowledge I don't believe it, but ...'*

> *(I5) There is more between heaven and earth than we can explain.*

> *(I1) Yes, exactly, I have used that one quite a few times, and I don't feel that I am lying.*

Unexpected patient reactions

Some special situations were mentioned when the patients' reactions were perceived to be somewhat unexpected. When facing patients with overly optimistic ideas regarding survival the oncologists stressed the importance of giving them a more realistic timeframe.

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> *(I7) It is incredibly important to inform such a patient about the realities.*

Understanding patients' potential range of reactions to bleak prospects helped some oncologists to recognize unexpected responses.

> *(I2) There is a certain culture in some hospital wards. I remember a patient on the ward who was very high spirited, we had talked about it, how we couldn't cure and how the prognosis was and all that, and he said 'oh well, but I have always been happy as a fiddle, and I'll take it as it comes', and the nurses went on nagging about how badly informed he was, since he seemed so cheerful.*

> *(I6) Well, I don't necessarily think you have achieved your purpose when everybody breaks into tears.*

Openness as an ideal

The participants stressed the importance of making sure that the patient understood the severity of their medical condition. Confronted with dilemmas of patients with advanced disease not wanting information about their prospects in life, or not wanting this information shared with family members, the oncologists almost universally stressed the importance of open communication, sneaking in the information if necessary.

> *(I5) I think, the first times we (patient and oncologist) meet, we sit down, get to know each other, and then you can sneak in a bit of information. And then you can make a deal, okay, we won't talk about this every time you come to the clinic or to get your radiotherapy, but we will do it a little at a time.*

> *(R) Is it not acceptable for a patient to die and not want to know? Is that something that is unacceptable? It somehow lies a bit implicit in what you say.*

> *(I5) In a way, yes, in our culture maybe we don't accept that people don't want to know.*

However, some experienced a dilemma inherent in this straightforward communication of prognoses, which entails the risk that the patient only catches the first part of the message, and stop listening to all the things the physician says can be done to ameliorate the situation.

> *(I9) I don't know, maybe it's some sort of honesty, I think they have to know, I need to assure myself that they know how serious it is. If not, I feel that I am deceiving them. But maybe this is wrong, even if we come in and say 'but we can do this and that'. I think you have to be honest, but there is something about the weight that you put on different things you tell them.*

Rationale for practice

The physicians found imparting prognostic information challenging. Several pointed out the lack of a ready made 'recipe' for this part of their job, as opposed to the many guidelines that govern other parts of oncological practice. This was most explicitly stated in the following conversation.

> *(I4) Communicating is difficult, it's one of the most difficult things we do.*

> *(I5) One should make a protocol* (laughs a little).

> *(I4) You can't read in a protocol and make guidelines for this, that doesn't work. You just have to hope ..., you learn all the time, you mustn't feel you know it all, then you've lost, I think.*

The learning by doing approach in communication style was implicit in statements from several informants, and more explicitly expressed in the following quotation:

> *(I1) When I was younger and less experienced I made the mistake of saying everything very straightforward, I wanted to be honest. Later I understood that this is not always so wise (...) I hope I'm still quite honest, but I choose different words now, so that they can put in a touch of hope.*

In the formation of their communication style the informants almost universally pointed at the importance of seeing and hearing the practice of senior colleagues as well as learning from one's own experience. Communication courses were not perceived as equally useful.

> *(I2) When it comes to how to communicate with patients, there are many ways, (...) and I dislike the patriarchal attitude implied in these communication courses: 'Yes, we who know how to communicate will teach you poor souls who don't'. (...). There are many ways, and everyone has to find his own way. So I tell those I work with to see how I do it, and I don't say that what I do is right, but that is a way I have found to communicate with patients. So we can do it together, you can see how I do it, and then you have to find your own way.*

The opinions as to the master-apprentice approach as a way of acquiring skills to improve prognostic communication varied among the informants.

> *(I3) I think learning by the master-apprentice method is really important in our speciality. I think (...)it's an important mix of facts and personality, you learn a bit of everything then, when you observe such a communication (between patient and consultant).*

> *(I2) That's why I think it is so important that we do it together, but this master-apprentice role-model thing, well, that's just words. Often the master isn't particularly good, I must say, in my training what I have learnt from this master-apprentice stuff, most certainly is what I shall not do.*

Discussion

In this study oncologists' accounts of how they communicate prognostic information regarding life-limiting disease have been explored. Their emphasis when describing their own practice is on openness. However, a general reluctance towards being factual and tangible was found. No one offered statistics for survival length, and the timeframe given if asked for specifically was vague. Informed consent was not explicitly mentioned as an underlying premise for open communication, but a sense of obligation towards honesty and towards making sure that the patient really had understood was shared. However, apart from one informant (I6) who described a sort of metacommunication, none of the participants reported exploring the level of their patients' awareness or their wishes for prognostic information. The lack of explicit statements in the interviews regarding negotiations of mode and content of communication does not exclude the possibility that such practice takes place in the patient–physician encounter. However, the near absence of apparent patient-focus in the data is a finding that suggests a lack of such considerations among the participants. Despite the importance attached to truth and honesty in imparting prognostic information, the content of these concepts were not reflected upon. Instead a dichotomous understanding of honesty was displayed.

The oncologists did not mention guidelines or results from research on patient's information needs as guiding their communication. Rather, their practice was based on an assumption that being aware of the realities was always in the best interest of the patient. Some acknowledged the possibility that their information style could hamper patients' ways of coping. Still, ensuring that the patient had heard the prognostic information was seen as important enough to risk over-informing. The potential use of guidelines was perceived as impossible as it could jeopardize an individual approach to each patient. Own experience and the observation of other colleagues were seen as the two most important sources of forming the communication practice. Communication courses were considered to be of limited importance, and were at best seen as a source for specific wordings to use when providing the patient with prognostic information. One of the participants even commented the communication course in dismissive terms. However, in spite of the findings of the present study the communication course referred to is generally evaluated as useful by the participants immediately after the course. The course has not been externally evaluated, and has not been revised during its 10 years of existence (personal communication from course leader). In light of the views presented by the participants in the present study it seems important to re-evaluate content and form of the communication course with a focus on prognostic information giving. To our knowledge, the way of viewing communication education schemes found among our participants has not been found in previous studies.

Methodological considerations

There have been few studies exploring physicians' attitudes and underlying considerations in relation to their communication of prognostic information. The present data contributes to this important, yet under-researched topic. This being a qualitative study, the aim has been to explore attitudes and underlying considerations in the communication of prognostic information. The small sample, along with the unrepresentative recruitment of participants, makes hypothesis testing inappropriate. Rather, the choice of focus group interviews as methodology gives benefits from group dynamics, but also entails a risk that the informants censor their true opinions. However, as the communication skills and attitudes at least to some extent were thought to be acquired through practice, the local college of physicians was seen as an important entity for research. The focus group interviews were conducted in a relaxed atmosphere, allowing for diverging opinions to be displayed. The fact that the group moderator is an oncologist by training could introduce a bias both in the governing of the group as well as in the subsequent analyses. Seeking to reduce this risk, the research group was supplemented with non-oncologists only, and by consistently looking for opposite ways of interpreting the transcripts. In spite of the limitations, we think the findings from the study can give increased insight into the approaches the oncologists choose in their communication of prognostic information. The generalizability to other clinical specialties can be questioned. However, oncologists were chosen because of their presumed insight into the many challenges in prognostic communication towards the end of life. The data collecting continued until no new themes emerged, hopefully reflecting the full range of attitudes and beliefs regarding prognostic communication among Norwegian oncologists. In earlier studies of Norwegian physicians and communication of diagnostic information [29] their practice seemed to be in line with their colleagues in North-western parts of Europe and North America. The present findings are also in accordance with findings from research on prognostic delivery in other countries [12,16], and are thus in all likelihood generalizable to other countries in which full disclosure of diagnostic information is the preferred practice.

Meeting challenges in communication of unfavorable prognoses

The medical term prognosis denotes the physician's prediction of the course of a patient's disease, and the possibilities of recovery. The treatment options available, as well as their potential for improving a condition, are thus a part of the prognostic consideration. However, the physicians in the present study apply a dichotomous understanding of their prognostic information delivery resembling the delivery of diagnostic information. The aim of the information given is to make the patient aware that the disease is incurable, and that treatment from then on will be aimed at relieving symptoms, delaying symptoms or at best, 'buying some (survival) time'. Similar to the findings in the study by Audrey *et al.* [16] detailed information as to the likelihood of achieving this aim is seldom presented. Instead, the uncertainty in any estimate is underlined. To acknowledge one's own shortcomings in prognostication is in line with the realities regarding physicians' abilities to predict survival in terminally ill patients [30]. However, leaving out predictions of survival reduces patients' abilities to understand the consequences of different treatment options [16]. Even in advanced stages of the illness, many patients give survival gain a greater importance than improved symptom control [31], and are willing to undergo treatment with minimal chance of obtaining such survival gain [32,33]. Understanding patient preferences for treatment is an important prerequisite for supporting the patient. This also relates to understanding how involved the patient actually wishes to be in the decision making [34], and to appreciating the potentially conflicting wishes experienced by the individual patient [10,19]. The modest patient-focus suggested in our data is found in other studies of communication regarding prognostic information [18,35]. Parallel to patients' ambiguity in their demand for information, a degree of ambiguity seems to be present in the physicians. They take a stance in support of truthful information, at the same time expressing worries that this practice may interfere with the patients' abilities to maintain hope. Faced with their own high standards for open communication, but without apparent considerations regarding the limits of this openness, the physicians try to meet mutually exclusive demands. From research regarding patient preferences for prognostic information, the need for an individualized approach towards each patient is highlighted [12]. However, the awareness of potentially differing needs for information among their patients is not met with negotiating strategies to explore these individual differences, thus enabling the physician to tailor the communication to the individual patient's needs.

The way forward

It is fundamental to ensure that assumptions, based on identified trends for prognostic preferences by age, culture, disease stage, or more private opinions, are not governing the physicians' participation in communication of prognostic information. A greater awareness of the complexity involved in patients' information needs may prevent physicians from making such assumptions. Focusing on existing scientifically derived knowledge regarding patients' changing wish for information and the range of coping behaviors patients may display, would be an important means to achieve this. But will it work? The classic works by Oken and Novack, in which the physician community reversed their practice (regarding disclosure of diagnostic information) and mainly based their practice on own experience [6,36], suggests a reluctance towards seeing communication as a professional skill, and a neglect of scientific findings as reasons to change or modify personal opinions. The present data, as well as other recent studies [12,16] indicate that this reluctance still governs physicians' attitudes towards challenging clinical encounters such as conveying prognostic information. However, implementing research findings into clinical practice is generally known to occur slowly, and is a challenge that is not pertaining to communication alone [37,38]. Applying knowledge of the cognitive processes involved in behavioral changes [39] can possibly facilitate the implementation of research findings to improved clinical practice.

Conclusion

This study displays an ambiguity in the oncologists' consideration as to how they provide prognostic information to their patients. A concern that disclosure of information could destroy the patients' hope and optimism co-existed with a sense of obligation towards open communication. To find the balance between too much and sufficient amount of information is further complicated by the patients' ambiguity towards receiving information, and by the fact that their wish for detailed information changes throughout the disease trajectory. Physicians need to acknowledge these challenging aspects of prognostication, and to assess patient preferences in a considerate manner. Future communication training should focus on these skills as well as inform the physicians as to the changing and ambiguous nature of patient preferences.

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