Towards more prognostic information to patients with life threatening diseases: Why, how and when?

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Towards more prognostic information to patients with life-threatening diseases:

Why, how and when?

Lena Hoff

Prologue

One day in 1996, while I was visiting a hematologic ward, a patient I will call Karin – not her real name – got my attention by saying something like: “so, you are the hospital chaplain… Could you please pay me a visit? You see, the doctors have told me that I am dying! Was that really a necessary thing to do? I did not want to know.” At the time I met Karin, I had been working as a hospital chaplain for nearly ten years, the previous four at a university hospital in the south of Sweden. I had met many seriously ill patients before and had often reflected on the consequences of bad news on patients’ self-narratives. It took Karin’s question to what has become an ongoing passion for the problem of disclosing bad news. That is why I chose this topic for my dissertation.

In the beginning, I had no intention of interviewing physicians. My primary concern was the information needs of severely ill patients. As I came to understand, however, communication always involves *at least* two partners. I was able to listen and learn much through the patient interviews, but part of the conversation was missing. What about patient information from the physician’s perspective? So in the end I approached the physicians, albeit several years later.

Background

Change of attitudes

In the 1960s, most physicians still withheld cancer diagnoses from their patients; it was more or less taken for granted that patients would not be able to handle such knowledge. According to a study from a Chicago, USA, hospital, 90% of the 219 physicians interviewed did not disclose cancer diagnoses as routine practice. (Oken, 1961). This practice of nondisclosure was soon to change. In a study from the same hospital 18 years later, 97% of the 264 respondents answered that they routinely *did* disclose cancer diagnoses. (Novack, et al., 1979). This change happened not only in the USA but in Australia and all the northern and western countries of Europe: “a complete reversal of attitudes had taken place.” (Ariés, 1983:589). Several factors may well have converged to bring this about. New treatments had been developed, by which many cancer illnesses had become – if not curable – at least to some degree treatable. (Beach Campbell, et al., 1983). The connotation of the word “cancer” changed: it no longer meant “death sentence”.

The aftermath of World War II brought a growing emphasis on individual integrity and autonomy. The Convention for the Protection of Human Rights and Fundamental Freedoms was signed in Rome 4 November 1950. (The UN, 1948). The principles of this convention were extended to the areas of biology and medicine in the Oviedo Convention, adopted by the Council of Europe in 1997. (Council of Europe, 1997). Several protocols have since been added to the Oviedo Convention, and many states have ratified it. Sweden has signed the convention but not yet ratified it: i.e., given it force of law. The convention stipulates that all patients have a right to be informed about their health as well as a right not to know. “Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.” (Council of Europe – ETS no. 164, III; Article 10:2). This is what Swedish law also stipulates, via a 1998 law on Swedish health and medical services (SFS 1998:1660) and it is further supported by ethical rules adopted by the Swedish Medical Association in 2002. “The physicians shall respect the patient’s right to be informed about his or her health condition.” (The Swedish Medical Association, 2002). The 2009 Treaty of Lisbon applied this to the entire European Union. (Official Journal C 306 of the European Union Treaty). A new patient law (SFS 2014:821) in Sweden, effective from 2015, stresses these same ideas. The World Health Organization (WHO), tasked with protecting and promoting health worldwide, has contributed to the change of attitudes. Its founding charter states that “health is a state of complete physical, mental and social wellbeing and not merely the absence of illness or infirmity.” (WHO, 1948) Health has multiple dimensions: physical, psychological, social, cultural, and spiritual. Health promotion requires economical and social development, peaceful conditions, and a supportive environment. Several proposals have been floated for additions to WHO’s original health definition and mandate: WHO 1978, WHO 1986, WHO 1991.

One example of the shift in attitudes has been the development of the hospice movement and palliative care. Cicely Saunders of St Christopher’s Hospice in London (established 1967) has been of particular importance. St Christopher’s website describes Saunders’ efforts as “a holistic approach, caring for a patient’s physical, spiritual and psychological wellbeing” that has “marked a new beginning, not only for the care of the dying but for the practice of medicine as a whole”. Refusing to accept the statement “there is nothing more that could be done”, Saunders has proclaimed “there is so much more to be done.” The goal at St. Christopher’s, as elsewhere in the hospice movement, is that hospice patients should be aware of their approaching death yet encouraged to keep taking an active role in life. (Twycross, 1986). From the 1970s, Elisabeth Kubler Ross’ *On Death and Dying* (1970) and other of her writings (1974, 1975), along with writings in e.g. Sweden by Loma Feigenberg (1972) and Ulla Qvarnström (1987), contributed to a debate that is still going on. The philosophy of palliative care emphasizes the rights and needs of patients to meet their death with open eyes, to have the possibility to prepare themselves adequately for the end of life.

Central concepts in healthcare

A number of key concepts need to be clarified before proceeding: particularly, “bad news”, “prognosis”, and “prognostic information”.

Bad news

What is “bad news”, in the field of medicine? Buckman describes it as “any news that drastically and negatively… alters the patient’s view of her or his future.” (Buckman 1992:15). The Northern Ireland Regional Guidelines (2003) describes it as any message in a situation that “can include disease recurrence, spread of disease, or failure of treatment to affect disease progression, the presence of irreversible side effects… or raising the issue of palliative care and resuscitation.” Bad news comes in degrees. Much depends on who the patient is and how she receives the news. (Fallowfield & Jenkins, 2004).

Most patients will receive not one piece of bad news but many. Patients diagnosed with cancer, whether treated with curative or palliative intentions, face a seemingly endless series of tests and examinations, the results of any one of which could reveal or confirm declining health or progression of cancer. Most are forced to come to terms with many setbacks before the final stages, the withdrawal of cancer treatment, and subsequent death. The question is if, when, and in what way changes for the worse are or should be revealed to and discussed with patients suffering life-threatening diseases.

Prognosis and prognostic information to the patient

Medical prognoses are predictions based on statistical probabilities, derived from select populations. It is usually not until late in the game that the doctor knows for certain that the patient’s death is approaching. The outcome for any patient depends on various factors: type of diagnosis, genetics, co-morbidity, patient condition and age. (Christakis, 1999: 1–29). Hemingway describes patient populations as tracing a pyramidal structure over the course of their disease: the higher up the pyramid, the more detailed the assessment of prognostic factors and the more proximal and hence better the prognoses. (Hemingway, 2006). At the apex of the pyramid, patients – much reduced in number – are in the final stages of their disease. Throughout the process, the physician’s goal is to formulate an individualized prognosis for each patient, starting with her knowledge of general prognosis for the relevant condition, modifying it according to all available information concerning the patient’s history: symptoms, performance status, co-morbidities if any, and will to live, etc.

Knowledge of statistics aside, in making prognoses experienced physicians draw on their clinical experiences with a great number of patients. (Glare & Sinclair, 2008). They know which scenarios are likely to occur for such diagnoses as acute lymphocytic leukemia (ALL), acute myelocytic leukemia

(AML), myeloma, and inoperable lung cancer. They know how to interpret the signs of declining health at each stage along the illness curve. They know – not in detail, but on the whole – what to expect. They know that recurring symptoms are generally a bad sign. They know whether treatments are available or limited. They know – or think they know – what to expect even before their suspicions are confirmed by tests. The question is, why and when should this information be revealed to the patient?

Disclosing bad news

Patients' views and wishes

A succession of studies suggests that a majority of patients in the US as well as the north and west of Europe want to know the truth about their health condition. (Meredith, et al., 1996; Fallowfield, 1997; Jenkins & Fallowfield, 2001; Hagerty, et al., 2005; Baile, et al., 2000; Innes & Payne, 2009; Christakis, 1999). That is, they want to know not only their diagnosis but also an honest appraisal of their prognosis. Most of the studies I refer to concern cancer, which has many different diagnoses and treatment possibilities, and hence many different needs for the handling of prognostic information. One needs to be careful about drawing any general conclusions. Nevertheless, one finds an overwhelming consensus among the findings. Patients often feel uninformed. They want honest information but claim that sometimes they do not get it. They want to discuss how much time they have left – though with considerable variation in when and how. (Step & Ray, 2011). Some prefer a more indirect approach, others a more direct one. (Curtis, et al., 2008). The way information is given – explicitly, implicitly, or "passed over in silence" for the patient to discover for herself – is, in my view, vital for the patient's understanding of her situation.

Patients may express conflicting desires: they both want and do not want to be told the truth. (Kirk, et al., 2004). They want honest, accurate information delivered in a sensitive and personal way with empathy and understanding, as part of a continuous, step-by-step process: not all at once. (Yardley, et al., 2001; Leydon, et al., 2000; Clayton, et al. 2008; Salander, 2002; Deschepper, 2008). Some patients resort to denial. (LaFarge, 2012). The taking in of what is often complex information is a demanding task, intellectually and psychologically. (Schneider, 2005). Some patients have underlying false beliefs that conflict with the information disclosed. (Farell, et al., 2002). Some are cognitively affected. Others are depressed. All these circumstances might change the patients' normal abilities for receiving negative information.

The studies I refer to are representative of both qualitative and quantitative approaches. The qualitative studies generally have sought to have patients describe, through open-ended or semi-structured interviews, their views on the information they receive. Interviews are time consuming and therefore limited to a small number of respondents, although usually this is enough to achieve saturation: i.e., no important further information will be obtained. The interviewer potentially influences respondents' answers, introducing the risk of bias. Quantitative studies have their own advantages and disadvantages. Questionnaires can be distributed to a great number of patients, but the information is usually more superficial.

To some extent, attitudes towards disclosure of bad news may be culturally determined. In Japan, some Mediterranean European countries, and collectivist Asian and Muslim cultures, physicians usually give the information not to the patient but to the patient's family. The family decides if, when, and what to tell the patient. (Weisstub, 2008). In many Jewish cultures, full disclosure is seen as negative, causing patients to give up hope and bringing them to an earlier death. (Rosner, 2004). In Nigeria, physicians tend to be truthful about cancer diagnoses but conceal poor prognoses. (Nwankwo, 2011). In Pakistan, a majority of patients in one study argue for their absolute right to know bad news; they want their doctors to be both honest and outspoken. (Ishaque, 2010). A study from Saudi Arabia shows that, while relatives of cancer patients believe that telling the patient the truth could lead to harm and suffering, all except one of the 114 patients interviewed did *not* want information to be withheld. (Al-Amri, 2009).

Physicians' views

At least so far as physicians are concerned, open and honest discussion of cancer diagnoses is now common practice across most of northern and western Europe and the US. (Ptacek & Eberhardt, 1996; Hancock, et al. 2007). At the same time, discussion of prognosis – particularly when the prognosis is poor – seems not to have changed much. (Innes & Payne, 2009). Most oncologists will tell a patient if her disease is incurable; but, in general, physicians will not disclose details of survival chances unless the patient insists. (Smith & Hillner, 2010; Baile, et al., 2000). They wait for signs of the patient's imminently approaching death or until effective treatments have been exhausted before talking to the patient about death and dying. (Keating, et al., 2010; Hancock, et al., 2007). That is to say, they avoid openly prognosticating so long as the clinical situation is considered uncertain or treatment is available. (Rogg, et al., 2009; Hagerty, et al., 2005; Christakis, 1999: 84–106). They resort to nondisclosure or oversimplification or focus on the treatment calendar or on examination or test results. (Parascandola, et al., 2002; The A-M, et al., 2000). They may be more optimistic than the situation suggests or use negated "positive" formulations instead of "negative" ones: e.g., "this is not that good" instead of "this is very serious", a phenomenon sometimes called "bad to good by negation." (Beukeboom, 2014; Burgers, et al., 2012). Physicians and patients often collude by focusing strictly on the treatment calendar, thereby avoiding discussion of the patient's imminent death. (O'Rourke, et al., 2001; The A-M, et al., 2000). Prognostication has even been referred to as "the lost skill of medicine." (Kellet, 2008). 2008).

Summary

A clear pattern concerning patients' wishes for prognostic information appears in study after study. A majority of patients – at least in Western Europe and America – wants to be honestly informed. The same studies report that patients often feel uninformed. Although most patients want truthful information, physicians are reluctant to provide it.

Existing guidelines

On the one hand, improved treatment options have made the disclosure of cancer diagnoses easier; nowadays, nearly all patients outside of developing countries can expect at least some treatment, even for severe cancer. On the other, increasing knowledge of how cancers progress has raised demands on clinicians who must convey complex, uncertain, and often unwelcome news. “These situations include disease recurrence, spread of disease or failure of treatment to affect disease progression, the presence of irreversible side effects, revealing positive (i.e. negative from the view of patient) results of genetic tests, and raising the issue of hospice care and resuscitation when no further treatment options exist.” (Baile, et al., 2000). Studies show that, where guidelines are followed, physicians claim to experience less stress. (Fallowfield & Jenkins, 2004; Baile, et al., 2000). A 2010 study of physicians following the SPIKES protocol found that both physicians and patients reported less distress. (Kaplan, 2010).

Many guidelines have been established to help physicians to know how to inform patients. So e.g. Buckman (1992) proposed and Baile, Buckman, et al. (2000) refined the six-step protocol SPIKES: **S**etting, **P**erception, **I**nvitation, **K**nowledge, **E**motions, **S**ummary. SPIKES guides the physician through getting started, finding out what the patient knows, finding out how much the patient wants to know, sharing that information, responding to patients’ and families’ feelings, and doing planning and follow-up.

Other guidelines include the regional guidelines for Northern Ireland (Northern Ireland Group of the National Council for Hospice and Specialist Palliative Care Services, 2003) and East Anglia (ScillsCascade.com, 2000–2002), and the consensus guidelines for Austraila. (Girgis & Sanson-Fisher, 1995). A study by Narayanan, et al. (2010) supplemented the SPIKES protocol with guidelines based on a more patient-oriented communication style, called the BREAKS protocol: **B**ackground, **R**apport, **E**xplore, **A**nnounce, **K**indling, **S**ummarize. BREAKS begins with acquiring in-depth knowledge of the patient’s problem(s) from the viewpoint of the patient.

In Sweden one finds national and regional programs for the care and treatment of patients with various cancers, including acute myeloid leukemia (AML, 2014); lung cancer (2015); and myeloma (2011). However, one finds little guidance on the disclosure of prognostic information.

The thesis

This thesis is distinctive in a number of respects.

- Few other studies have taken the views of both patients and physicians into account. Most have focused on one or the other.
- Few other studies have interviewed patients regularly from diagnosis to death – in this case, to a maximum of two years.
- Several of the studies I refer to are based on one single interview with each patient. (Leydon, et al., 2000; Kirk, et al., 2004; Step & Ray, 2011).
- Others are based strictly on patients’ responses to questionnaires. (Meredith, et al., 1996; Jenkins, et al., 2001; Hagerty, et al., 2005).
- Few other studies have focused specifically on patients diagnosed with acute leukemia, myeloma, and inoperable lung cancer. Most have dealt with a diversity of cancer diagnoses.

Aims

Overriding aim

The overriding aim of this dissertation is to analyse, from a Swedish perspective, prognostic information disclosed to patients with severe cancer prognoses.

Objectives

- To explore how cancer patients with low chances for survival deal with the information given them by their physicians (I).
- To study patients' views about the information received, in relation to their awareness (or lack thereof) concerning the severity of their illness (II).
- To obtain a preliminary understanding of how physicians make decisions concerning patient information in situations where the relevant scientific knowledge is lacking or uncertain (III).
- To identify the communication challenges inherent in providing information about imminent death to cancer patients through interviews with patients and doctors, and to discuss ways to overcome obstacles to patients' understanding of their situation (IV).
- To relate findings from the interviews to basic ethical values and principles and to see if and to what extent the findings, together with these ethical points of departure, can provide a basis for recommendations on communicating prognostic information to patients.

Subjects and methods

Methodological considerations

Both quantitative and qualitative methods can be used to address questions of prognostic disclosure. Which methodology to use depends on one's purpose and research questions. (Neuman, 2003: 139–146, Kvale & Brinkmann 2009; 4–17, 23–32, 47–53).

The four studies (I - IV) comprising this thesis take a qualitative approach to capturing and analysing patients' statements. This seems to be the best and most fruitful way to study what are extremely complex situations. As is often the case with qualitative studies, the studies are based on responses from relatively few individuals. It is my hope that the results can help generate hypotheses for larger studies in the future. The studies are pre-theoretical: i.e., they were guided by no particular theory of physician/patient communication.

The interviews were semi-structured. (Kvale & Brinkmann 2009: 130). I began with an interview guide comprising a few questions; but, from the beginning, I encouraged patients to talk open-endedly. If I had wanted to ask a set list of questions, I could have used a questionnaire. I did not in part because, under the circumstances, the information provided by a questionnaire would have been likely either limited or superficial. Observational studies, on the other hand, would have been difficult to carry out and ethically problematic. Besides, I wanted my informants to feel free to open up their *life worlds* to me. (Neuman, 2003: 364–9).

The qualitatively inclined researcher may be described as a fieldworker. A fieldworker is seeing her work as a profound, experimental encounter with the lives, behaviours, and thoughts of others (Emerson, 2001: 21). The qualitative researcher wants to learn how their informants live, think, talk and behave. One chooses from a number of qualitative methods. I have taken a phenomenological approach, describing the *life world* of informants in as much detail as possible before any interpretation is made. The hope, of course, is to reduce the risk of over-interpretation and other forms of bias. My choice was inspired by my reading of Kvale & Brinkmann, (2009: 23–32, 48–53) and their notion of an *open phenomenological approach*. I wished to invite my informants to become my teachers. Using this approach, it became more and more clear to me over the course of the interviews that the key problems had to do with information and communication.

No research starts without foundation. Being a hospital chaplain, I was used to listening to patient narratives. This convinced me that here was an area of many questions and more than a few misunderstandings.

In conducting my research, I choose not to determine either the number of informants or the length of interviews in advance. I intended them to end as soon as saturation was achieved: i.e., as soon as no further meaningful information could be obtained. (Neuman, 2003: 395).

Patient interviews (studies I, II and IV)

The informants were all patients at a university hospital in the south of Sweden, all diagnosed with acute leukemia, myeloma, or inoperable lung cancer, with low probabilities for survival.

It is expected that a fifth of patients diagnosed with acute leukemia will survive at most two years. (Åström, et al., 2001). Patients with non-small-cell lung cancer have a 3–7% survival rate after five years, while one in two dies within seven months. (Scagliotti, et al., 2005). Median survival for patients with first-stage multiple myelomas is sixty-two months, second stage forty-four months, and third stage twenty-nine months. (American Cancer Society, 2015).

The patients were recruited by their physician during the physician's routine medical visits. The physician provided them with oral and written information on the study and its purpose. They were told that the study was being conducted by the hospital chaplain, who was also a doctoral student, and that the interviews would be carried out at regular intervals from diagnosis to cure or for at most two years. Participation was strictly voluntary; if they chose to participate, they could withdraw at any time with no negative consequences.

I wanted to make it easy for patients, if they so wished, to decline to participate. They did not need to say "no" to my face. Although only one of them knew me previously, all knew of my chaplaincy.

Seventeen patients were asked to join the study, and twelve accepted. The interviews were carried out 2002–2005. Eighty-eight interviews were conducted lasting 5-90 minutes, the length depending in part on the patient's health.

Table 1: Informants by category, and number of interviews

Category of patients	*Number of interviews*	*Gender (m/f)*	*Age*
7 hematologic	44	3/4	37–80
5 lung cancer	44	2/3	60–71
Total:	88		

Physician interviews (studies III and IV)

The head of the Department of Clinical Sciences at Lund University approved the study, as did the chief physicians of the relevant clinics, who approached the physicians and provided me with their email addresses. In all, twenty-three physicians at three Swedish hospitals were asked to participate, and twenty accepted.

All interviews were conducted at the hospital where the physicians worked. Prior to the interview, they were asked to complete a questionnaire. The interviews were carried out in 2008 and lasted 30–40 minutes. I used an interview guide, but all informants were encouraged to contribute from their own interests and experiences in an open-ended fashion.

Table 2: Physician participants

Category	*Sex (m/f)*	*Working years*	*Median years of experience*
10 hematologists	7/3	5–21	14.7
10 lung oncologists	6/4	3–27	12.9
Total: 20			

My role as interviewer

I cannot discount that my dual role as researcher and hospital chaplain may have influenced the interviews. I decided from the start that I would only visit my patient informants for the interviews. If they wanted a visit in between or asked for spiritual services, I referred them to my colleagues. I decided further that I would stop interviewing anyone whom my questions seemed to upset. Patients’ wellbeing needed to be my top priority. So far as I know, only one patient was upset by my questions. One other patient, at the start of my third session with her, told me that she had decided, after our second session, to leave the study.

According to Kvale and Brinkmann, the outcome of an interview depends on a combination of interviewers’ skills and knowledge. (2009:82). I wanted to create a relaxed atmosphere for the interviews, such that informants would want to answer my questions but also feel free to add their own thoughts. My intention in interpreting the responses was to be guided as much as possible by the informants themselves, though I cannot avoid the possibility of mis- or over-interpretation. To avoid misunderstandings, I sometimes did a quick rehearsal, and I used confirmation-type questions to check my interpretations of the patients' narratives: e.g., “is this what you mean? Did I catch your point of view?” All of the physicians and all but one of the patients allowed the interviews to be recorded. I transcribed all interviews verbatim prior to analysis. For the one patient who did not wish to be recorded, I took notes, from which I reconstructed a written interview for the patient's subsequent approval.

Method of analysis

Though no single approach to qualitative data analysis is generally preferred, several approaches start with informants' description of their *life worlds*, which are then systematically analysed, even though the steps in that analysis vary slightly between methodologists. For Neuman, (2003: 448) the steps are “examining, sorting, categorizing, evaluating, comparing, synthesising and contemplating the coded data as well as reviewing the raw and recorded data.” For Kvale and Brinkmann (2009: 195) the steps are (a) description followed by (b) discovery of new meanings (c) which the interviewer condenses and sends back before (d) analysing the recorded interview, focusing on meaning, language, and theoretical reading. This is followed by (e) approving the interpretations and (f) starting to act on the new insights.

I have chosen to use a third model: Graneheim and Lundman's content-analysis model from the field of nursing ethics. (2004). For them, the steps are (1) meaning units, (2) condensed meaning units, (3) coding, (4) categories, and (5) themes. The text is analysed; meaning units are established and condensed; these are transferred into code words that summarize the passages. In the process, the latent content – i.e., the theme – of the text emerges. I chose this method because I found it suitable to work with: in particular, appropriate to apply to the kind of material I collected during my interviews.

Ethical considerations

There is a risk that vulnerable groups may be exploited for research purposes and their participation less voluntary than it seems. I took care to follow Swedish (Swedish MRC report, 2003) and international guidelines (WMA: Helsinki 1964; Edinburgh 2000) for medical research and to gain approval for my studies from the relevant authorities.

Approvals

The patient studies were approved by the research ethics committee of Orebro University Hospital (No. 1056-01) and then by the chief physician of the relevant clinic. The physician interviews were approved by the head of the Department of Clinical Sciences at Lund University and the chief physician of the relevant clinic, or by someone to whom the task had been delegated. Patients were provided oral and written information about the study; physicians were given only oral information.

Informed consent

I obtained informed consent from each informant. I introduced myself and my research project, and together we agreed on a first appointment. All informants, both patients and physicians, were informed that their participation was strictly voluntary and could be terminated at any time with no negative consequences.

Protection of informants' integrity and identity

All informants were ensured confidentiality, and all data was handled so as to protect informants' integrity and identity. I examined no patient records. The information I obtained on individual patients' health I obtained solely from my conversations with them. In my interviews with the physicians, all discussion of patient health followed from hypothetical questions about their strategies in one or another situation. I used a simple coding system to keep the identity of all informants secret. This was done before disseminating the transcripts to readers, reviewers, researchers, and journals. I have ensured that no one but me has access to the original recordings.

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Protection of vulnerable informants

All patients were seriously ill and therefore vulnerable. Swedish law on medical research involving human subjects, drafted in 2003 (SFS 2003: 460) and modified in 2008 (SFS 2008:192), details how that research must be conducted – regardless of whether subjects are living or dead (in which case one is dealing with e.g. tissue samples). It details how potentially sensitive personal information must be handled and sets out penalties for non-compliance.

The patient interviews began before the law was passed. The hospital's research ethics committee approved the study, judging the risk for patients low. They emphasized that I, as the interviewer, was to meet the patients in a humble and cautious way – which, of course, was my intention.

The physician interviews began in January 2008, before the law had been modified to its present form. The head of the Department of Clinical Sciences at Lund University concluded that the physicians could make their own decision whether or not to participate.

The four papers

Paper I

In the shadow of bad news – views of patients with acute leukemia, myeloma or lungcancer about information,
from diagnosis to cure or death

In the first paper we identify four coping strategies among the patients, concerning how they deal with the information they receive: (1) information dependent and accepting, (2) information dependent but in denial, (3) medically informed and accepting, and (4) medically informed but in denial.

In the early interviews, the patients described themselves as well informed. In later phases of their disease, though, some came to express considerable uncertainty about the progression of their disease and their approaching death. Most expressed a desire to be well informed throughout the course of the disease, even when the news was bad.

Paper II

Information from physicians and retention of information by patients – Obstacles to the awareness of patients of progressing disease when life is near the end

In the literature, discrepancies have frequently been observed between the information that patients receive and the awareness of their condition. A number of explanations have been suggested. (Schneider, 2005; Lafarge, 2012). In this paper we report four levels of patient awareness concerning their health status: (1) informed and aware, (2) uninformed and unaware, (3) aware though uninformed, and (4) informed but unaware.

We propose four explanations for patients’ lack of awareness about the progression of their disease and their approaching death: (1) due to the physician, (2) due to the patient, (3) due to the physician and patient in collusion, and (4) due to neither physician nor patient but rather the insidious way in which lung cancers usually – and haematological malignancies occasionally – progress.

Paper III

Between uncertainty and certainty

Ten hematologists and ten lung oncologists were interviewed regarding the information they provide to patients in four situations of uncertainty: (1) determining the treatment that is in the patient’s best interests, (2) responding to recurrence or progression of the disease, (3) deciding when to withdraw life-prolonging treatment, and (4) deciding when to discuss death.

The primary conclusion of the paper is that the delivery of information to patients with low probabilities for survival can be improved through more and better disclosure by physicians at earlier stages of the disease. Patients can be told what to expect in the short and longer term as death approaches.

Paper IV

Identifying challenges to communicating with patients about

their imminent death

To identify the challenges in communicating information about impending death, the interviews were further analysed. The primary conclusion of this paper is a discrepancy between patients' desire for honest information and physicians' reluctance to prognosticate, until a patient's death is clearly approaching.

We conclude that existing guidelines for disclosing bad news need to be modified to encourage the disclosure and discussion of uncertain prognostic information – unless the patient is clearly opposed to receiving such information or otherwise not a suitable partner for dialogue.

Discussion

I wish to make a few brief comments on both the reliability and generalizability of my results. A researcher has the moral obligation to re-evaluate her beliefs in light of her results. "We have to ask ourselves how well-supported our beliefs are, what we know, but also what we do not know." (Persson & Sahlin, 2009:7). One can and probably should ask how much my role as hospital chaplain unintentionally influenced patients, allowing them to talk so willingly to me about death, but not to their physicians. Likewise, one can ask whether all my years among dying persons have given me a "cyclopean perspective" and made me one-eyed. (Sahlin & Persson, 1994). Certainly, my intention was to keep as open a mind as possible as I listened to my informants, and I regularly stopped and asked myself whether I might be over-interpreting. I would periodically ask patients to recall their answers and confirm whether I had understood their point of view correctly.

All of the patients that I followed died during the interview period, with one exception. One patient did survive for more than the two years, but not by much. My approach would probably not have changed, even if someone had stayed alive for many years. The gap between the knowledge physicians and patients possess would still have seemed too wide.

The more I studied physicians' disclosure of bad news, the more problems I came across. Not only must physicians know what to say, they must know how to handle patients' reactions, as well as how best to involve them in treatment decisions – remembering that, when one is severely ill, one is far more vulnerable. Physicians must deal with patients' frequent expectations for a cure without giving them false hope.

Regulatory aspects of patient information

The Oviedo Convention states that physicians are obliged to inform their patients, and patients have the right to be informed. "Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed." (Council of Europe – ETS no. 164, III; Article 10:2; 1997). In Sweden, patients' legal status has attracted increasing interest over the past two or three decades. The 1998 law on Swedish health and medical services (SFS 1998:1660) codifies patients' rights to integrity, autonomy, and information. In 2013, a Swedish governmental commission published a report on patients' rights to self-determination (*Patientmaktsutredningen*, SOU 2013:2). A new patient law was passed in 2014 (SFS 2014:821), effective from 2015. The new law not only demands that patients are informed but also that efforts are made to ensure that information is correctly understood. As discussed earlier, various guidelines have been suggested for facilitating physicians' disclosure of information to patients; but patients have different needs, and physicians have different abilities to communicate.

Ethical norms

What do the results of my own and others' research show, and what recommendations should follow? To answer these questions, and to explain why more and better prognostic information ought to be given to patients, I need to specify three values as points of departure.

(1) Respect for self-determination, respect of persons: patients want more and better prognostic information.
(2) Appreciation for benefits: patients benefit from more and better prognostic information; it improves their quality of life, helps them make better decisions regarding practical matters, etc.
(3) Dignity: what patients want and benefit from aside, not knowing important information about one's situation violates the basic dignity of being a human being.

Human dignity is a vague concept with a complex history and roots in various religious and philosophical traditions. That makes it none the less important. Dignity needs to be understood as an absolute, not a gradable, value and a universal, not a selective, one. (Official Journal of the European Union, C 303/01, 2007). It is essential for healthcare staff to respect the equal value of human beings and their equal right to respect and access to quality healthcare, including when they are suffering from life-threatening diseases. If physicians wish to respect the dignity of their patients, especially when these patients suffer from life-threatening diseases, they should provide more and better prognostic information, and try to make sure that this information and its implications are understood. All of this is possible only if patients are made aware of essential information about their situation, which means physicians providing that information whenever possible. This requires ongoing dialogue between physicians and patients and a careful understanding of dignity, self-determination, and what benefits the patient.

Arguments for and against more prognostic information

Various arguments have been made for providing more prognostic information to severely ill patients. I wish to discuss four of these briefly. The first is based on what patients say they want, the second on informed knowledge of patients' genuine wishes for information, the third on informed knowledge of how prognostic information is – over the long term – in patients' best interests. The fourth holds that more prognostic information is required if dignity is to be respected for those patients who want to be informed.

First argument:
What patients say they want

Other things being equal, it is good to have one's desires fulfilled, and people are generally capable of expressing their desires. The patient who asks for a glass of fresh, cold water appreciates when she gets it. The more serious the issue is for a person, the more urgent it is to fulfil her wishes. If a patient says she wants to have more and better prognostic information then usually there are good reasons for providing that information. According to the literature, most patients say they want to be honestly informed of their situation, even if the news is bad. The Oviedo Convention maintains that patients both have the right to be informed and the right not to be. (Council of Europe, 1997). Of course, the assumption that, *ceteris paribus*, it is a good thing to have one's expressed desires fulfilled can be disputed. This is what lies behind the second argument.

Second argument:
Not what patients say they want but what they really want

Patients are individuals; their attitudes to information vary. Some patients request information but, when they receive it, find it unbearable and deeply regret their wish to be informed. Some patients are suicidal, depressed, or cognitively affected by their disease or its treatment; for them, the value of prognostic disclosure is uncertain and varies from one person to the next. Cultural and social differences can affect patients' views on and responses to being and staying informed. In all cases, it would be wrong to follow patients' expressed wishes blindly. The informing physician must consider what the patient *really* wants to know.

The problem is that identifying a patient's genuine wishes is often complex. (Hermerén, 1996). A patient may only be saying what she feels she is expected to say; she may not understand; or she may not really be listening – she just ignores the message. Maybe she needs more time to think before answering. She may have different needs at different times, in different situations – depending how she feels. When she is weak or sad, she may only want to be left in peace.

If one wants to know patients' genuine wishes and needs, one should ask their preferences not only once – at diagnosis – but regularly over the course of their disease, as part of an ongoing dialogue. Such dialogue is far from a perfect indicator, but it may help to provide a good approximation.

Third argument:
Patients' best interests

Here the focus shifts, from patients' expressed wishes to whether information is in their best interests: i.e., whether it will improve their wellbeing, their quality of life. The term "quality of life" is ambiguous, referring vaguely to patients' subjectively perceived health. I prefer to use WHO's definition, of health as a state of complete physical, mental, spiritual, and social wellbeing. (WHO, 1948). WHO also defines quality of life as "a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment." (WHOQOL 1997: 29).

The question is whether more prognostic information increases patients' quality of life. One can argue that, armed with more prognostic information, patients are better able to decide what is in their own best interests. They are better able to take part in treatment decisions – nowadays considered a basic characteristic of good healthcare. (Smith, et al., 2011; Council of Europe, 1997). Informed patients, aware of their low chances for survival, might appropriately refuse further, often intensely discomforting treatment. Conversely, they might not – at least without further discussion – accept their physician's proposal to withhold further treatment, which the physician considers useless and only likely to harm the patient.

Armed with more and better information, patients are better placed to make the arrangements they should make before their lives end. They may need to draw up a will or make financial arrangements: e.g., to ease burdens for their heirs by selling off a company. They may want to make funeral arrangements, to save relatives the difficulty of making those decisions themselves. Such practical matters aside, they may want to go for an around-the-world trip, or arrange meetings with family or friends they have not seen in some time or wish to beg forgiveness for something past. They may want spiritual support along their *via dolorosa* as they seek to reconcile themselves with the realization that their life is ending.

The literature offers plenty of evidence that informed patients feel psychologically better and are more at peace for knowing what they know. (Gaston, 2005; Wilkinson, et al., 2005; Tattershall, et al., 2002). Their uncertainty and anxiety decreases. (Gattellari, et al., 2002; Tattershall, et al., 2002). A statement I have heard many times from patients, after bad news have been broken, is: "now, at least I know". Not only may knowledge bring relief, patients may feel physically better, even though they know their disease is still progressing. (Nauert, 2010; Hirsh & Inzlicht, 2008; Kurita, et al., 2013). Concerns to the contrary, repeated studies show that increased information lowers – not raises – patients' anxiety levels. (Gattelari, et al., 2002; Tattersall, et al. 2002). One study found depression to be nearly three times greater among patients who do not acknowledge their prognosis compared to those who demonstrate partial or complete awareness of it. (Chochinov, et al., 2000).

More and better prognostic information can facilitate open, honest communication not only between patients and their physicians but also between patients and their family and friends, in order to the better discuss and share what are inevitably difficult matters. Bad news often hurts and may initially decrease patients' wellbeing. This encourages some people to think that perhaps patients should not be told more than what, at the moment, is strictly necessary. Why destroy their hope, if that hope is helping to sustain them physically and mentally? (Wear, 1993). That said, the inevitability of approaching death can only be hidden for a time. Sooner or later, patients' bodies reveal the truth to them – at which point the well-intended withholding of information may have hugely detrimental consequences.

Fourth argument:
Respecting patients' dignity

The Oxford English Dictionary (1989) defines dignity with words such as worthiness, nobleness, and excellence. That dignity may be intrinsic to being human, or it may be attributed on the basis of noble behaviour, achievement of high position, or other recognition of merit. (Nordenfelt, 2009).

Ashcroft identifies four approaches to dignity within the healthcare profession. (Ashcroft, 2005). The first finds the concept "incoherent… at best unhelpful, at worst misleading". The term is strictly one to be avoided.

The second equates dignity with autonomy. Dignity is considered far too broad to be useful. Sandman (2002) concludes that it is “far from obvious that we have any use for the concept of dignity within (palliative) care.” Macklin (2003) calls dignity “a useless concept in medical ethics that can be eliminated without any loss of content.” (2003:1420). Dignity “means no more than respect for persons or their autonomy.” (2003:1419). Of course, equating dignity with autonomy means that persons who lack autonomy – persons who lack the capacity for autonomous choice – lack dignity. (Pullman, 1999). Dignity understood in terms of autonomy supports the second and third arguments for more prognostic information, but not the fourth.

The third approach considers dignity in light of “capabilities, functioning and social interactions.” (Ashcroft, 2005). Meritorious achievement adds value to the patient’s quality of life, as determined by individual circumstances, with a measure that varies from one person to the next. Autonomy remains of crucial value but is no longer the *only* value. (Pullman, 1999). On this perspective, more and better prognostic information has the potential to improve physical, psychological, social, and spiritual wellbeing. That said there are situations – as when a patient is dying – when none of this may be achievable. Another approach is needed.

The last approach sees dignity as a metaphysical property possessed by all but only human beings, a basic value, which they all have to the same degree, throughout their lifespan. (Pullman, 1999; Nordenfelt, 2009; Fagerberg, 1997; SMER, 2012: Etiska vägmärken no. 4). Being metaphysical, dignity is a basic principle (in German *ein höchtes Sollen*) underlying all ethical arguments. It is normatively presupposed, like an axiom in mathematics, not necessarily describing how the human world is but rather what it should be like. In German, human dignity renders as *Menschenwurde*, in Swedish *människovärde*. (Nordenfelt, 2003; Nordenfelt, 2009). More than the English equivalent, these words suggest that the worth of human beings – including those with life-threatening illnesses – precedes any claims based on merit or status. In the context of patient information, several situations could threaten or undermine human dignity: when a patient is seen as a disease statistic and not an individual; when a patient’s body is exposed in the presence of others; and when a patient is ignored, misled, or simply not listened to.

The *scale of participation in decision making* (Hermerén, 1996) describes five attitudes physicians may take towards their patients:

- The physician discloses information without concern for the patient’s wishes or values.
- The physician listens to the patient’s words but facilitates no dialogue.
- There is a dialogue, but the physician acts as if no discussion has taken place.
- There is a dialogue, but the physician only partly follows the wishes of the patient.
- There is a dialogue, and the physician – at every point – follows the wishes of the patient.

The fourth attitude requires that participants listen to each other and exchange information honestly. To respect the dignity of patients, healthcare staff must provide them with relevant prognostic information and make sure that this information and its implications are understood by those patients who want to be informed. If the patient says she does not want to discuss matters further but leaves them for her physician to decide, then her wishes ought to be honoured. *Patients should be listened to* – because they are ends, not means. *Each patient matters*. As Cecily Saunders writes, “you matter because you are you, and you matter all the days of your life.” (O’Brien, 2003).

Buber (1996) describes the way people see the world as “two folded”: either they speak the word pair *I-You* or *I-It*. The words one uses open into different modes of existence. He writes: “when I confront a human being as my You and speak the basic word I-You to him, then he is no thing among things.” (Buber, 1996: 59). In relation to prognostic information, the *I-You* relation – and not the *I-It* relation – acknowledges the patient’s dignity, treating her as a unique individual with unique needs and not as a “thing”. In contrast, the *I-It* relation is in play when, in the patient’s presence, the patient is talked about as if she were not there. (Kihlgren & Thorsén, 1998).

Some patients are unable to take part in any dialogue. They may be unconscious, cognitively affected, or dying. Their dignity must still be respected. Their dignity does not derive from any abilities or social status they once had but their uniqueness as human beings. Other patients will refuse dialogue. Their dignity must also be respected. Under best circumstances, patients unable or unwilling to take part in dialogue will have a “proxy”: a family member or close friend who knows more or less what the patient would have wanted, had she been able and willing to speak up. If no such family member or friend is to be found, the physicians and other healthcare professionals must do the best they can to fathom what they hope to be the patient’s desires and needs. Every step they take should be with an eye toward being as respectful and as honouring of the patient’s dignity as possible. (Widäng & Fridlund, 2003).

Conclusions

I have discussed four arguments, all helping to answer the question of whether, why, and when more prognostic information should be provided in the patients’ best interests. Several fundamental strands of ethical thought seem to point to the need for more and better prognostic information.

Martha Albertson Fineman (2010) writes that vulnerability is the very essence of what it means to be human. “All human beings stand in a position of constant vulnerability, [but] we are individually positioned differently. We have different forms of embodiment… While society cannot eradicate our vulnerability, it can and does mediate, compensate, and lessen our vulnerability through programs, institutions, and structures.” (2010; 60: 31). Much depends on what society we are striving for: in particular, what kind of healthcare we want.

The primary conclusion of this thesis is that, as a rule, patients should be more and better informed about their prognoses, not only when death is imminent. At the same time, the information provided should not be without limits. Hermerén (1994); Beauchamp and Childress (2001); Ross (1930); Audi (2004) have proposed guidelines that can be used as rules of thumb to facilitate that the information provided benefits patients – or at least does no harm.

Of course, circumstances may arise that need to be taken care of in some special way; (Dancy, 1993). In those cases, virtue ethics provides a way to balance the various aspects of the situation, prioritizing as appropriate. (Aristotle, transl. 2002; Möller, 2003). “What counts are flexibility, responsiveness, and openness to the external.” (Nussbaum, 1992:74). One learns by doing, in the same way that a house builder becomes a house builder by building houses and a cithara player becomes a cithara player by playing cithara. Virtues are arrived at by practise and habituation. The “right thing” is no more and no less than that which a virtuous person would do. (Aristotle, transl. 2002).

Even if the reasoning is noticeably circular, virtue ethics’ emphasis on practical wisdom is important to the discussions that frame this thesis. Experience builds on experience to strengthen and refine physicians’ ability to disclose prognostic information appropriately and gracefully to patients with life-threatening diseases.

Philosopher S. Kierkegaard notes an important prerequisite to dialogue: “if one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there.” (Kierkegaard, transl. 2009: 41). One begins with active listening, which requires more than simply hearing what the other is saying. One must attend not only to the words spoken but to *how* they are spoken and what non-verbal messages accompany them. In the context of this thesis, active listening – in both directions – fosters an honest exchange of information between physician and patient. When it is pursued from the start – from the patient’s first stay in hospital – it offers a powerful opportunity to clarify whether, what, and when information should be disclosed or withheld as well as what to do with patients who are unable or unwilling to take part in dialogue. They, too, must have their dignity respected. It derives from their nature as human beings and can neither be lost nor given away.

Suggestions for future research

The conveying of bad news to patients will continue to raise both serious and complex issues. What was urgent yesterday may not be relevant tomorrow. New treatment possibilities may open up. Attitudes may change. Societies, cultures, and religious traditions are living entities changing over time. Research is needed to discern the evolving information needs of patients and the implications of those changes for physicians.

The studies comprising this thesis could best be followed up with a combination of qualitative and quantitative studies asking patients and physicians in greater detail about the receiving and disclosing of prognostic information – from the moment of diagnosis, through the period of treatment, to the terminal phase. Studies are needed to investigate the prognostic needs of patients other than those diagnosed with terminal cancer and to address the perspectives of nurses and other non-physician healthcare workers. It would be enlightening to explore patients’ understanding of such medical terms as “remission”, “relapse”, and “palliative treatment”, perhaps through use of a multiple-choice questionnaire allowing patients’ understanding of those terms to be checked against their correct medical meaning. Another fruitful area for exploration is the tension between more or less paternalistic-style disclosure – where the doctor “knows” what is in the patient’s best interests – and more or less autonomy-promoting disclosures, where the doctor is a facilitator, helping the patient who wants to understand her situation. Most likely there is a time and a place for both styles of disclosures and both must sometimes give way to the other. By exploring how and when this happens, and reflecting on how and when it *should* happen, one might hope to reach a better understanding of the strengths and weaknesses of either approach.

Summary in Swedish
(Sammanfattning på svenska)

Det övergripande syftet med detta avhandlingsarbete har varit att studera hur svåra besked till patienter med cancer hanteras i vården i vår tid. Ännu på 1960-talet gav läkarna oftast inte besked om cancersjukdom till patienter. Men en attitydförändring skulle snart ske på grund av en rad samverkande faktorer. Dels handlar det om nyfunna behandlingsmetoder genom vilka diagnosen cancer för många cancersjukdomar förändrades från att ha varit ett dödsbud till att vara ett besked om behandlingsbarhet. Dels handlar det om den efter andra världskrigets slut ökade betoningen på patienters självbestämmande vid vård och behandling. Den dittills rådande läkarstyrda paternalismen frångicks för att istället så långt som möjligt inkludera inhämtandet av patientens informerade samtycke, vilket avspeglas i åtskilliga konventioner och fördrag inom FN, och EU, såväl som i enskilda staters hälso- och sjukvårdslagar. Även framväxten av hospice-rörelsen och den palliativa vårdformen har varit ytterligare bidragande faktorer till den förändrade synen på information till svårt sjuka patienter.

Avhandlingens bas utgörs av fyra studier. I den första studien (Studie I) närmades en grupp svårt sjuka patienter, med diagnoserna akut lymfatisk leukemi, akut myeloisk leukemi, myelom samt icke operabla lungcancerpatienter, dvs patienter med lågt beräknad överlevnad, för att undersöka hur de förhöll sig till den information de får av sin läkare om sin sjukdom. Dessa patienter följdes med intervjuer från diagnos till bot eller död eller som längst under två års tid. Resultatet av denna undersökning blev att patienterna kunde delas in i fyra grupper: informations-beroende och accepterande patienter, informations-beroende men förnekande patienter, medicinskt informerade och accepterande patienter respektive medicinskt informerade men förnekande patienter. Trots sina olika strategier var informationen viktig i sjukdomens alla faser. Patienterna beskrev sig som välinformerade från början, men däremot inte i senare skeden av sin sjukdom, dvs inte förrän vid avslutandet av cancerbehandlingen.

I den andra studien (Studie II) undersöktes hur patienterna uttryckte medvetenhet om sin sjukdoms dödlighet. Det visade sig att patienterna kunde delas in i fyra (ej statiska) grupper: informerade och medvetna, icke informerade och icke medvetna, medvetna fastän icke informerade respektive icke medvetna trots att de blivit informerade. Det fanns flera bakomliggande skäl till patienternas bristande insikter, som berodde antingen på läkaren, patienten, läkaren och patienten i kombination, eller på sjukdomars lömska sätt att progrediera, dvs särskilt för patienter med lungcancer. Tillhörigheten till respektive sjukdomskategori hade alltså betydelse för hur informerade och medvetna patienterna ansåg sig vara.

Den tredje studien (Studie III) bygger på intervjuer och enkätutfrågning med tio hematologer och tio lungläkare sammantaget från tre olika sjukhus i södra Sverige. Läkarna frågades om sina informationsstrategier i svåra lägen, när tillräckligt medicinskt underlag saknas för ett säkerställt beslut: i skärningspunkten mellan olika behandlingsalternativ, när sjukdomen börjar progrediera, vid avslutande av livsuppehållande behandling samt när samtal förs med patienter om döden. Det framkom, i enlighet med tidigare forskning, att läkarna undvek att vara alltför negativa om sin patients sjukdom, dvs så länge som patienten var i aktiv behandling för sin cancer. På det hela taget undveks att tala om patientens död, såvida inte patienten själv tog upp frågan. För den patient som önskar vara informerad och uppdaterad om sin sjukdom, kommer beskedet om deras annalkande död därför ofta sent, och för sent för att kunna vara användbart för patienten i beslut om behandling eller för förberedelser inför sin död.

I den fjärde studien (Studie IV) granskades de tidigare gjorda patient- och läkarintervjuerna på nytt för att undersöka hur patienter med avancerad cancer, med förmodad låg överlevnad, gavs förståelse om dödens närhet. Åtta informationsområden fastställdes och analyserades för hur patienterna informerades om risken att dö i sin sjukdom och huruvida dessa uttalanden skedde explicit, implicit eller inte alls. Resultatet visade att först vid avslutande av behandling är det som den individuella patientens död explicit tydliggörs. Implicita uttalanden gjordes men dessa visade sig patienterna ofta ha svårt att förstå. Slutsatsen var att även om den mer specifika individuella prognosen ofta inte kan ges förrän sent i patientens liv, så kan läkarna utifrån sin medicinska kunskap och kliniska erfarenhet mycket mer än patienten om sjukdomen ifråga och vad som patienten *troligen* har att vänta. Detta borde läkarna i högre grad och mer explicit delge patienter med livshotande sjukdomar, dvs de som önskar att vara informerade. Den osäkerhet som råder om sjukdomens förlopp kan långt oftare delas med patienten. Det betyder att existerande riktlinjer om hur läkare ska förhålla sig till delgivande av prognostisk information till svårt sjuka patienter behöver modifieras och utökas till att också omfatta hanteringen av icke-säkerställd prognostisk information.

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