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ORIGINAL ARTICLE

The creation of hope in patients with lung cancer

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ABSTRACT

Background. Lung cancer is associated with biomedical and psychological symptoms as well as a generally poor prognosis. When healthcare staff communicate with lung cancer patients it is essential that they consider the patients' own views of the situation to avoid putting unnecessary strain upon the patients' shoulders. The purpose of the present study is to better understand how a group of patients with lung cancer reflects upon their new life situation after diagnosis and primary treatment.

Method. Fifteen patients with non-small cell lung cancer were consecutively included and, where possible, repeatedly interviewed during the course of the disease process. The 29 interviews were conducted in a thematically structured narrative form that facilitated a dialog between the interviewer and the patient. The interviews covered experiences with health care, living an everyday life, and thoughts about the future.

Findings and reflections. By focusing on how the patients more or less preconsciously elaborated mentally with their vulnerable situation, it was possible to detect different mental manoeuvres that they used as a way of creating hope. The patients distanced themselves from their disease, relied on a feeling of a sound body, idealised treatment possibilities, relied on healthy behaviour, focused on a concrete project, found that they were better off than others, and took solace in the fact that there were patients who had successfully managed the disease.

Discussion. The patients were not passive victims in the face of their diagnosis, but were actively trying to find ways of looking at their despairing situation in a positive light. A creative process for psychological survival had thus been initiated by the patients. We suggest that acknowledging this process should be the starting point from which physicians can engage in hope work with their patients.

Lung cancer is associated with symptoms such as dyspnoea, cough, and pain that affect daily life, and its obvious threat to life can cause a high degree of psychological distress [1]. The median survival is approximately one year and the five-year survival is less than 15%. When a cure, as the main rational source for hope, is not attainable, the relief of symptoms and the relationship with the healthcare staff becomes paramount. Since the abandonment of paternalism, this relationship has to a great extent been reduced to a question of information, and the autonomy discourse emphasises that it is necessary for patients to receive all of the information about their disease, despite its gravity [2]. In a recent publication based on questionnaires in *The New England Journal of Medicine* by Weeks et al. [3], the authors were concerned that patients receiving palliative treatment did not seem to have realised that

a cure was not attainable. The authors, as well as the editors', conclusion was that this 'misunderstanding' should be corrected by 'repeated truthful information' for the benefit of the patients' well-being. Such a discourse focused on providing all of the available information has, however, been empirically questioned as one-dimensional and simplistic. By means of interviews, the *interaction* between patient and physician has been scrutinised [4–7]. It seems that not all patients want to know 'the whole truth and nothing but the truth' [8] and that a complex dynamic process, aligned with what the patients' said they wanted, is taking place in the patient-physician relationship in order to balance information needs with a sense of hope. This process has previously been described as 'hope work' by Perakyla [9]. These studies suggest that the task of the physician is not solely restricted to sending 'repeated truthful information',

but is to take a broader responsibility for the patient's vulnerable situation during their consultations. This is particularly important for patients with a poor prognosis for whom managing hope is a priority [7].

With this perspective in mind, it becomes essential that the health system considers the patient's psychological vulnerability so as not to put unnecessary strain upon the patient's shoulders. We can not regard patients solely as receivers of information, but need to view them as human beings who are actively seeking ways to cognitively elaborate on their situation, in order to survive psychologically, in the face of a truncated future [10].

Understanding this mental process is a way for physicians to sharpen their ability to walk the fine line between providing truthful information and providing hope as a way of facilitating the patient's hope work. The present study investigates how patients with lung cancer reflect on their life situation after their diagnosis and primary treatment. By means of thematic interviews, the purpose of this study is to show how the patients, not the least preconsciously, elaborate on their new life situation, by reconstructing their views of reality in order to create hope. The study is thus primarily not about how they are doing psychologically (outcome), but about the mental *process* (means) that is initiated by the threat of cancer. We did not deliberately ask them what means they were using to manage their situation, as is commonly done in coping research, but we looked indirectly at how their way of expressing themselves about their situation might tell us something about their ways of maintaining hope. This methodology has previously been shown to be rewarding [11].

Method

Subjects

Fifteen patients at a university hospital in Sweden (Table I) who received an initial diagnosis of non-small cell lung cancer were consecutively included from 2010 to 2013. The inclusion criteria were the following: performance status 0–1 according to the WHO-scale, an expected survival time ≥ 3 months, and the ability to communicate in Swedish or English. The eligible patients were asked about participation at the time of their radiotherapy. The project received ethical approval from the local ethics committee (09–170M).

Interviews and analysis

The patients who participated in the study were interviewed one to three times depending on their medical status. The first baseline face-to-face interviews were conducted during the radiotherapy

Table I. Characteristics of the patients with non-small cell lung cancer included in the interview study.

Patient	Age at inclusion	Sex	Stadium	Interviews	Survival after inclusion (months)
1	65	F	IIIA	2	> 44
2	59	F	IIIA	2	25
3	75	F	IA	3	20
4	85	M	IIA	3	> 36
5	75	F	IIIB	1	10
6	75	M	IIIB	3	> 32
7	81	F	IIIA	1	14
8	80	F	IIIB	1	> 31
9	67	F	IIIB	3	> 30
10	67	F	IV	3	25
11	58	F	IV	2	> 28
12	56	F	IIIB	1	4
13	62	M	IV	1	5
14	67	F	IIIB	2	> 21
15	76	M	IIIB	1	3

treatment at the hospital, and the second interviews were conducted about four months later by telephone (one of the second interviews was however face-to-face). The third interviews took place about one year after the baseline interview, all by telephone. All interviews were conducted by the second author (an experienced social worker) in a thematically structured narrative form [12]. In addition to socio-demographic information at the baseline interview, the interviews covered themes about receiving the diagnosis of lung cancer, the patient's experiences with the care they had received, their ability to live an everyday life after treatment, and their thoughts about the future. The interviews were conducted in a conversational tone, and the interviewer avoided asking closed questions. Instead she facilitated a dialog with the patient by using prompts and reflections. Six patients were interviewed once, four patients twice and five patients three times. A total of 29 interviews were conducted. The baseline interview lasted one hour, and the follow-up interviews lasted 30–50 minutes.

The interviews were transcribed verbatim and the analysis of the data was conducted by the first and second authors independently of each other. As the purpose of this study was to find out how the patients mentally elaborated on their vulnerable situation, phrases and statements from the interviews that could directly or indirectly shed some light on this topic were collected by these authors and pasted into two new documents. The authors then, still independently of each other, used the constant comparative method to sort the phrases into categories [13]. Finally, the authors discussed the categorisations jointly and minor revisions were made until they reached consensus, i.e. until they reached dialogic intersubjectivity [14].

Findings and reflections

Awareness of the severity of the disease

All patients acknowledged that lung cancer is a severe disease, but none discussed their prognosis in terms of years or months. They expressed satisfaction with the information provided by the physicians, and it was obvious that this information primarily concerned examination and treatments. None of the patients had been independently looking for additional information on the Internet. Mr. Fifteen reflected a rather typical position when asked about what he had come to know about his disease:

“I know it is in the lung and that the physicians are doing their best, but they might not succeed. I don’t know if I need to know anything else. What I want to know they don’t really know anyway. How long I will live. /.../ I haven’t searched for information on the Internet, but I do know that the children and grandchildren to some extent have, and I guess that’s fine, as I can’t provide them with answers for all their questions. I stick to what the doctors have told me, that’s enough. I guess I will not be healthier by getting more information”.

In different ways the patients acknowledged despair at the time of diagnosis, and some hoped for an alternative diagnosis: “It doesn’t have to be lung cancer /.../ it doesn’t have to be the worst” (Ms. Five). For quite a few of them the diagnosis did not come unexpectedly and they faced the fact that their lives would be different from that point onwards. They commonly mentioned things like “this is how things are” and that “you live as long as you can” (Ms. Nine). Even if few of them openly mentioned death or dying the impression is that they as a group were aware of the gravity of their situation.

Mental manoeuvres for creating hope

Overall, the patients did not give the impression that they had become passive victims in a hopeless situation and this emanated from seven different ways in which they expressed themselves. Taken together, these ways of expressing themselves could be interpreted as mental manoeuvres for creating hope in an otherwise hopeless situation. The manoeuvres included Hope from mental distancing; Hope from the perception of a sound body; Hope from idealisation/treatment; Hope from a positive attitude; Hope from a project; Hope from downward comparison; and Hope from a positive model. Each manoeuvre will be highlighted by excerpts from the interviews.

Hope from mental distancing

A large number of the interviewed patients were afflicted by other medical complaints, primarily by COPD. The COPD-inhibited respiration and limited overall physical function and this caused psychological distress. The impact of COPD as a medical reality on everyday living was thus experienced as the primary problem that overshadowed the cancer, and focusing on COPD might enable the patients to mentally distance themselves from their lung cancer. Some were instead focused on their age because they could believe that being older made them less physically capable and not their cancer. Another identified way of distancing oneself from the lung cancer was by means of the language being used: “It is a bit unfamiliar for me to say ‘lung cancer’, I used to say that I have a tumour on my left lung” (Ms. Five).

Referring to the fact that cancer is a common disease that affects many other people also seemed to dilute the impact of the patients’ cancer as did focusing on positive circumstances. Mr. Six emphasised that living in Sweden was a privilege and that in his mind one cannot complain because one always has food, clothes and the basic necessities of life.

Reflection. By putting the lung cancer diagnosis within a certain context, the devastating meaning of the diagnosis could be lessened.

Hope from the perception of a sound body

In some patients, lung cancer does not cause devastating symptoms. From a superficial point of view, it is possible in such cases to rely on the seemingly healthy body as a form of hope. After receiving the diagnosis of lung cancer, Ms. Three described herself as being shocked and burdened by a bad mood that she just “had to throw away”. She went on:

“From the beginning I just didn’t care, why do things tomorrow when I know I’m going to die. At that time I hadn’t considered the information I had in my body”.

Later on she elaborated on her ‘sound body’:

“I feel fit in my body. I don’t feel sick or anything like that. All blood specimens and everything else are fine so far, so I guess it’s okay then. In that way at least”.

Reflection. The feeling of health concealed or contrasted with the physician’s information concerning their disease. Paying attention to the information ‘given’ by the body was more comforting and provided a sense of hope.

Hope from treatment/idealisation

In addition to focusing on positive outcomes from follow-up examinations, some of the patients found, as a surprise, that they had tolerated the treatment without any side effects. Thus these patients could be subjected to an optimal treatment regimen, which, in their own mind, made them a bit more special when compared to other patients with lung cancer. Another possibility for building hope was to idealise the relationship with a physician in charge of treatment:

"It didn't become a catastrophe and that is due to my lifeline – the physician in [city]. He said: 'We will never leave you, get that scenario out of your mind, we will follow you and we will keep in contact'. He said that after the operation and that made me feel safe and filled with comfort". (Ms. Seven)

Reflection. The physician is the expert in medical science, and the treatment is often seen as the only thing standing between the patient and death. Treatment is the rational source for hope, but it can lend itself to a more or less irrational elaboration in order to develop a sense of trust.

Hope from a positive attitude

Besides relying on treatment, it was quite common for the patients to mention the importance of being positive. Being positive was first of all connected to the will and motivation to endure and to not to give in, but a few also connected a positive approach to a better prognosis:

"Yes, you have to think positively, otherwise it won't work out. It helps a lot if you are happy, feel safe and just forget that you are ill..., then I do think it's possible to become healthy". (Mr. Thirteen)

Only one patient referred to believing in God. Just a few referred to physical activity as a means to be physically better off:

"I have started bicycling inside...if I'm able to go on with that I guess I can fight the disease in a better way". (Ms. Two)

Reflection. The main impression is that mentioning the importance of having a positive attitude was more of a way of expressing oneself, a kind of mantra, than it was expected to change the course of events.

Hope from a project

Some patients emphasised that they had something waiting in the future that occupied their attention.

It was in the forefront and overshadowed their cancer:

"We have just bought a puppy and now I'm looking forward...actually, I'm not thinking so much about the disease. I take one year at a time and now I'm focused on the dog show this coming summer". (Ms. One)

At a later interview she continued, "I cannot die now, I'm going to the dog show...you see, we have reserved a place at the camping resort".

Others were less focused on a specific project and just referred to their ability to live their ordinary everyday life:

"I've been content, vital, and alert because except for the treatment period I've been pottering around with my ordinary business. I've been fishing, picking berries, and doing a lot of other things". (Ms. Ten)

Still others expressed the importance of everyday life in an even more pronounced manner:

"You know something – I never think about the disease. For Gods sake, I just haven't the time (laughs). ...I've decided that I'll manage this". (Ms. Nine)

Reflection. It seemed that anchoring oneself in the more concrete here and now made it possible to create a future, and this implied that the disease was transferred to the back of the patient's mind.

Hope from downward comparison

A few patients compared their present situation with their own previous experiences that they found worse, but first and foremost they compared themselves with other patients and found themselves far better off. Their own previous experiences were connected to other bodily complaints:

"I've actually not realised that I have lung cancer...I think it was harder when I broke my leg. Anyway, that truly hurt. Now I have no pain at all". (Mr. Six)

Comparisons with other patients usually involved concerns that they had other cancer diseases or that they were affected by the treatment in a negative way:

"I coughed a little tonight with some mucus secretion. But, that's the only time. I haven't had any problems before. ... I'm thinking of a fellow patient. She's been coughing so awfully that I just can't understand how she stands it". (Ms. Ten)

Reflection. The essence of these comparisons is that it is possible to count oneself fortunate because it

could have been worse. Referring to others' pain has an impact on the point of reference for one's own vulnerability.

Hope from a positive model

A few patients referred to positive prognostic information they had received about other patients with the same diagnosis:

"I've been told that it [the tumour] will come back, but I do know that there are those who have lived for eight years with this kind of tumour". (Ms. Twelve)

Discussion

The purpose of this study was to explore how the patients mentally – either directly or indirectly – elaborated on the fact that they were afflicted by lung cancer, which is one of the deadlier cancers and is associated more than other cancers with decreased well-being [14]. By using their vulnerability as a screen it was possible to detect different mental manoeuvres that the patients used to create feelings of hope. The patients distanced themselves by means of making use of less stigmatising words, relied on a feeling of a sound body, idealised their treatment possibilities, relied on a positive attitude, focused on concrete projects, found that they were better off than others, and took solace in the fact that there were other patients who had managed the disease.

On method

The present study was intended to be a consecutive study. However, due to administrative omissions (the department of oncology was reorganised in a new building and the researcher responsible for inclusion was partly off duty) some patients eligible for the study were missed. The age distribution is in accordance with data from other studies [15], but the present study is not representative as to the sex distribution because women are overrepresented (73% compared to approx. 51% in previous studies). Whether this reflects a selection bias due to more men being missed is unknown. Excerpts from the interviews as a whole were chosen exclusively for the purpose of displaying data in a condensed and representative way. The fact that the of sex distribution among the excerpts turned out to be proportional to the sex distribution among the patients is in accordance with our impression that sex per se is not a distinguishing factor when it comes to creating mental elaborations.

Categorisation is a fairly complicated process, and the confirmability in the categorisation of the

patients' statements was probably facilitated by stressing that the context was essential for the categorisation. The context made it reasonable to interpret the statements as ways of finding hope. However, the aim of the categorisation was not to find a new and distinct nomenclature for how patients' with cancer deal with strain, but merely to show different expressions of a mentally elaborative process. With this rationale in mind, the representativeness of the studied sample is of less critical importance. Even if we missed including patients who were depressed and unable to create hope, this would not change our identification of a process. However, including such patients would raise new and important questions about how the different outcomes could be understood.

Another important question not considered in the present paper is the creation of hope in a contextual perspective. The paper is restricted to the individual patient's own expression of hope work, but this hope work takes place in a more or less 'facilitating environment'. Close relatives can be supportive by taking care of the patient as well as by being sensitive and permissive to the sick person's hope work.

The strength of the study is its prospective design with repeated thematic interviews in a conversational atmosphere that allowed the patients to freely express themselves in their own way about their situation. This method of interviewing was necessary for detecting how the patients elaborated on their vulnerable situations.

On findings

Lung cancer is associated with short survival and is associated more than other cancers with a decrease in quality of life and to a depressive mood [16]. Patients with lung cancer, therefore, are in a particularly vulnerable situation. The Hippocratic Oath says that you should always try to cure, if you cannot cure you should alleviate symptoms and if you cannot alleviate symptoms you can always provide comfort. Patients with lung cancer can usually not be cured, but we can alleviate their symptoms, prolong their lives, and offer them comfort. In order to comfort, we must understand the 'voice of the life world' – the patient's mind – when they are confronted with unpleasant facts. The patient's mind is our point of departure.

The patients expressed themselves in ways that we interpreted as different ways of lessening their vulnerability. They made use of what we might call mental manoeuvres in order to find some hope. Some of these manoeuvres have previously been described in different contexts. 'Hope from mental distancing', i.e. focusing on another threat that overshadows the lung cancer, seems to be close to the

concept of 'minimising', but the latter has been described as less precise and more like 'wishful thinking' in a study of patients with malignant brain tumours [11]. 'Hope from the perception of a sound body' has previously been described by Lindquist in a study of patients with prostate cancer in a palliative phase [17]. 'Hope from treatment/idealisation' hardly comes as a surprise and is the most self-evident manoeuvre. However, we should keep in mind that this manoeuvre is not just a reflection of a matter-of-fact medical rationale saying that treatment might cure the disease, but that it also reflects an *attribution* from the patient saying that treatment cures. In her own mind, Ms. Seven is safe due to her idealisation of her patient-physician relationship. The relationship seems to load the treatment with healing power. She is not special, however. People did not suddenly start to seek healing at time of the introduction of modern medicine in the 18th century. Before that, sick people consulted Galen and his imitators and were treated with crocodile dung, fly specks, earthworms and 817 other such similar substances [18]. Despite the fact that these treatments did not cure any diseases, the patients returned to their healers probably because of the simple fact that they could not stand to be left without hope. 'Hope from a positive attitude' is familiar from studies showing that after being diagnosed with cancer people are prone to be more attentive to healthy behaviour, probably reflecting a need for a self-contribution to getting better [19]. It can also be suggested that a motivation for the healthy behaviour is that it per se reflects a change – the world turned out to be dangerous, but now, in a sense, it is different [20]. 'Hope from a project' has, to the best of our knowledge, not been described in this way previously even if it is tangential to the well-known 'changing perspective' [21]. The patients in our study, however, did not qualitatively change the focus of their interests – which is typically going from focusing on work and money to focusing on relationships – but they just seemed to become more involved with and attentive to their interests in everyday life. This manoeuvre easily lends itself to associations with existential philosophy and Sartre's idea about the necessity for people to have a project in front of them – in the absence of such a project life has no meaning. It furthermore connects to Wittgenstein and his suggestion that the meaning of life is embedded in our way of shaping our everyday lives. Finally, 'downward comparison' and making use of 'a positive model' are well-known ways that people, not just patients with cancer, express themselves and try to shed a more favourable light on bad situations [22].

Some of these manoeuvres have been highlighted in coping research, patients are said to make use of different 'mechanisms' in order to cope with their strain and in different studies different 'mechanisms'

have been shown to be recommendable. As an example, Vos et al. [23] in a study of patients with lung cancer made use of a one-dimensional conceptualisation of 'denial' and found that patients tried in this way to protect themselves psychologically and that this should be respected. This conclusion seems reasonable, but the pre-conceptual perspective limits our ability to understand the patient's own perspective, i.e. what the patient is actually doing mentally to create hope. As shown in our study, the patient is not just a *respondent* to strain but an *actor* in creating hope. This distinction is important.

Taken together, the manoeuvres identified here give us a glimpse into this creative process. The patients were not just warding off the inevitable, but were actively creating hope by looking at their situation in a more positive light. They were satisfied with the information they had been provided with about the disease (in Sweden it is not customary to give a prognosis in term of years and months), and they did not search for additional information on the Internet. It is reasonable to believe that this paved the way for their own creative hope processes. This is close to a UK study where none of the patients asked for detailed prognostic information [7]. Patients seem to shift attention from something disturbing to something more favourable by creating what the psychoanalyst Dorpat called 'cover stories' [24]. Another psychoanalyst, Basch [25] discussed the process that emerges when people are faced with an external threat in terms of disavowal, i.e. 'self-deception in the face of accurate perception'. People thus seem to know the situation but decide to deceive themselves which might be helpful in dealing with difficult situations.

Acknowledging this psychology enables physicians to provide the comfort described in the Hippocratic Oath. Understanding how the patient with lung cancer 'plays with reality' [10] can provide the physician with some guidance in the complex task of providing for the patient's information needs while simultaneously facilitating their hope work. This perspective on the patient-physician relationship is in line with findings from other studies examining the interactional field in cases of other severe diseases [4–7]. The physician and patient are sensitively navigating together, and the constraining and reframing of unpleasant facts is essential in order to succeed in the primary task of creating hope [7].

These studies tell us something different than studies that advocate the 'information discourse'. As an example of this discourse, we previously mentioned an article by Weeks et al. [3] who were concerned that patients in a palliative phase had not realised that a cure was impossible. They argued that it was essential that this 'misunderstanding' be corrected by 'repeated truthful information'. Information is of priority to them, and in their opinion this would be to the ben-

efit of the patients' well-being. This position can be questioned, however. Relying on the studies above, another opinion is that the patient's ability to find a creative way of surviving psychologically is hampered by such a discourse. Just being faced with unpleasant facts and an amputated future might lead to a feeling of meaninglessness. One suggestion is that these different perspectives are due to differences in terms of study design. Studies solely focused on knowledge and the provision of information, like the study by Weeks et al., are restricted to questionnaires with closed questions. They are not making use of open-ended interviews or recorded clinical consultations and this means that they cannot detect the dynamics in the interactional field. In our mind, these studies lack sufficient connection to everyday clinical reality and their suggestions should, therefore, be carefully scrutinised; we cannot rule out that it is the authors themselves, not the patients, who have 'misunderstood'.

Conclusion

This study of patients with lung cancer contributes to previous studies showing that patients with cancer elaborate on their vulnerable situation by means of different mental manoeuvres. They are not passive victims in face of their diagnosis; instead they are actively trying to find ways of looking at their severe situation in the best light possible. A creative process for psychological survival is thus initiated by the patients. Acknowledging this process is, and should be, the starting point for the physician's role in their relationship with the patient, in their joint 'hope work'. Information about the disease is subordinate in this context, and compulsory 'telling the truth' until the patient 'understands' is not compatible with this perspective.

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