

ORIGINAL ARTICLE

‘When I can ride my bike, I think, am I at all as sick as they say?’ An exploration of how men with advanced lung cancer form illness perceptions in everyday life

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Abstract

Objective: The purpose of this study was to explore how men with advanced lung cancer form perceptions of their illness in everyday life and how this influences perceptions about rehabilitation.

Methods: Constructivist grounded theory principles guided the collection and analysis of data from in-depth interviews with 10 men with advanced lung cancer.

Results: The findings show that the men's illness perception was fluid, contextual and formed by interrelated factors. Engaging in daily activities and maintaining everyday life was a strong influence on their illness perception.

Conclusion: In order to make rehabilitation relevant to men with lung cancer, consideration should be given to how the men's everyday lives may be incorporated into the service provision.

KEYWORDS

daily life, illness understanding, male, motivation, rehabilitation

1 | INTRODUCTION

In 2018 in Denmark, where this study was conducted, lung cancer was the second most common cancer type among men, and the incidence of new lung cancer cases among men was higher than among women (The Danish Cancer Society, 2020). Lung cancer has significant personal consequences. Fatigue, pain and respiratory problems encumber everyday life, and maintaining social relationships is challenging (Petri & Berthelsen, 2015; Polanski et al., 2016; Roulston et al., 2018). It is not uncommon for people with lung cancer to constrain themselves to inactivity and live sedentary lives to avoid worsening the symptoms (The Danish Cancer Society, 2020). To alleviate the consequences of lung cancer, cancer rehabilitation can be essential (Edbrooke et al., 2019; Raunkjær, 2022). In a Danish context, the purpose of rehabilitation is that people achieve the best possible participation, self-determination, mastery and a high degree of self-perceived quality

of life as possible in everyday life (Maribo et al., 2022). However, despite the immense challenges experienced by men with lung cancer, their level of participation in rehabilitation remains low.

Studies show that how people perceive themselves, as ill or as healthy, influences their motivation for participating in cancer rehabilitation (Berner & Tjørnhøj-Thomsen, 2017; Ingholt & Tjørnhøj-Thomsen, 2014). Illness perception is connected to how people respond emotionally to their situation, their coping behaviour and their perseverance with treatment (Hoogerwerf et al., 2012; Miceli et al., 2019; Petrie & Weinman, 2006). Research indicates that men and women form different illness perceptions, with men tending to be more optimistic about their illness and situation than women (Edelstein et al., 2012; Hansen et al., 2021; Zawadzka & Domańska, 2020). This implies that gender-specific investigations could be necessary when studying illness perceptions in people with cancer.

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For men with cancer, their perceptions of illness, health and how they manage their illness are connected to their sense of masculinity (Stapleton & Pattison, 2015). It can be multifaceted and associated with experiences in everyday life, not necessarily with factors that represent the biomedical perspective of health professionals, such as diet, smoking and exercise (Berner & Tjørnhøj-Thomsen, 2017; Handberg et al., 2014). For example, in the case of men with cancer, being healthy may be associated with the enjoyment of engaging in activities, such as get-togethers and participating in outdoor activities (Berner & Tjørnhøj-Thomsen, 2017).

From a health care perspective, understanding how men with cancer perceive their illness can be a prerequisite for motivating them to participate in cancer rehabilitation (Berner & Tjørnhøj-Thomsen, 2017; Ingholt & Tjørnhøj-Thomsen, 2014). This knowledge may be relevant in developing cancer rehabilitation services that align with the men's needs and wishes. Accordingly, the purpose of this study was to explore how men with advanced lung cancer form perceptions of their illness in everyday life and how this influences perceptions about rehabilitation.

In this study, advanced lung cancer is defined as the stage of cancer observed in the tissues of the lungs when the cancer is progressive and presumed incurable (National Cancer Institute, 2021; The American Cancer Society, 2021). In line with Sawyer et al. (2019), illness perception refers to how men with advanced lung cancer experience and develop personal understandings of their illness, how they mentally frame living with it and whether they perceive cancer as manageable or threatening.

2 | METHODS

2.1 | Design

To explore the process of how men with lung cancer form perceptions of their illness, constructivist grounded theory (Charmaz, 2014) was chosen as the overall methodology.

2.2 | Sampling procedures

Sampling, data collection and analysis went through the procedures of initial sampling and theoretical sampling (Charmaz, 2014). Initial sampling was broadly aimed at exploring how experiences in everyday life influenced the participants' illness perceptions. Participants were recruited using the following criteria: men, 18 years of age or older and considered (by themselves or doctors) to have an advanced stage of lung cancer.

As the analysis progressed, it became necessary to recruit participants with specific characteristics (theoretical sampling) to support the development of codes and categories. For example, by coincidence, the two first participants were living with a partner (either married or in a relationship). The analysis of these interviews indicated that the participants' partners influenced their illness perception. More men with partners were recruited to improve our understanding of the implications of being in a relationship. Men without a partner were also recruited to understand the implications of being single.

Participants were recruited from an outpatient treatment clinic at a Hospital in Region Zealand, Denmark. Eligible patients were given written and oral information about the study. If they agreed to participate, their contact information was passed on to the first author, who established contact. A total number of 10 men were enrolled in the study. Table 1 provides an overview of the participants.

2.3 | Data collection

Data were collected for a period of 1 year using in-depth interviews (Bryman, 2016). The four phases in the Interview Refinement Protocol Framework were followed rigorously to ensure alignment between the interview guide and the study focus (Castillo-Montoya, 2018). In phase one, a matrix was developed to ensure that the study focus areas were covered and aligned with the interview questions. In phase two, the appropriate order of the interview questions was decided. In phase three, the interview guide was discussed and refined in

TABLE 1 Overview of the participants

Pseudonym	Age	Primary diagnosis	Family status	Employment status
Tom	64	Lung cancer	Married, three adult children	Paramedic (sick leave)
Gabriel	69	Lung cancer	Married, three adult children	Military background (retired)
Dave	62	Lung cancer	In a relationship, three adult children	Unskilled work (early retirement)
Sam	63	Small cell lung cancer	Married, four adult children	Plumber (early retirement)
Jerry	65	Lung cancer	Married, two adult children	Carpenter (retired)
Hans	63	Lung cancer	Living alone	Worked with young children (early retirement)
Ben	60	Small cell lung cancer	Married, two adult children	Freight forwarder (early retirement)
Henry	70	Small cell lung cancer	Living alone, one adult child	Worked with IT (retired)
Dan	65	Lung cancer	Married, two adult children	Building constructor (retired)
George	54	Lung cancer	Living alone, one child living at home	Toolmaker (early retirement)

collaboration with a senior member of the first author's research unit. The interviews were conducted in phase four, continuously adjusting the interview questions to support the ongoing analysis. Interviewing continued until all data were collected. In all, 10 interviews were conducted. Five interviews were conducted in the participants' homes. Due to the Covid-19 pandemic, three interviews were conducted using a virtual platform Zoom® and two via phone. The interviews lasted between 36 and 130 min. The interviews were recorded and transcribed verbatim.

2.4 | Data analysis

Data analysis was an iterative process involving coding data, comparing codes and identifying relationships, developing categories, writing memos and raising analytical questions that were answered using incoming data and data already collected.

2.5 | Initial coding

Data analysis began when data were collected from the first two participants. The interviews were read through line-by-line to get an overview and a sense of the data. Sentences or paragraphs were coded using the participants' own words, such as 'questioning the doctor's words' (Charmaz, 2014).

2.6 | Focused coding

When data had been collected and coded from four participants, the codes were compared to identify those that captured essential experiences and the conditions that had shaped the participants' illness perceptions. The following incoming data were coded using these codes while at the same time remaining open to new insights. The codes were continuously compared to identify possible relationships. If relationships between codes seemed plausible and allowed for abstract understandings of the data, they were compiled and considered as categories (Bryant & Charmaz, 2007). For instance, the category 'The hazy presence of cancer' consisted of codes related to the participants' reflections about knowing they had cancer but not having symptoms. When data had been collected and analysed from seven participants, a core category resemblance emerged, binding the categories into a whole (Holton, 2007). More data were collected and analysed until all categories, and their relationships seemed fully developed.

2.7 | Memo writing

Memo writing composed the text pieces from related codes into cohesive descriptions with a narrative-like structure (Charmaz, 2014). The writing was essential to compiling codes into categories.

2.8 | Ethics

In Denmark, only research that entails biological material or pharmaceutical and hospital equipment testing on humans needs ethical approval (The National Committee on Health Research Ethics, 2022). Accordingly, ethical approval was not required. The study was approved by the university hospital research board. In accordance with The General Data Protection Regulation and National Guidelines, written consent was obtained from participants, and they were told that they could withdraw from the study at any time. Names have been replaced by pseudonyms to anonymize the data. Data were stored and handled following national guidelines (The Danish Data Protection Agency, 2022).

3 | RESULTS

The core category 'Shaping and reshaping illness perceptions' emerged as an abstract understanding of the men's illness perceptions. Several factors contributed to the changing and contextual nature of the men's illness perceptions, reflected in five categories and their relationships to the core category. Some categories were connected, revealing the dynamic nature of their illness perception, as illustrated in Figure 1.

3.1 | Shaping and reshaping illness perceptions

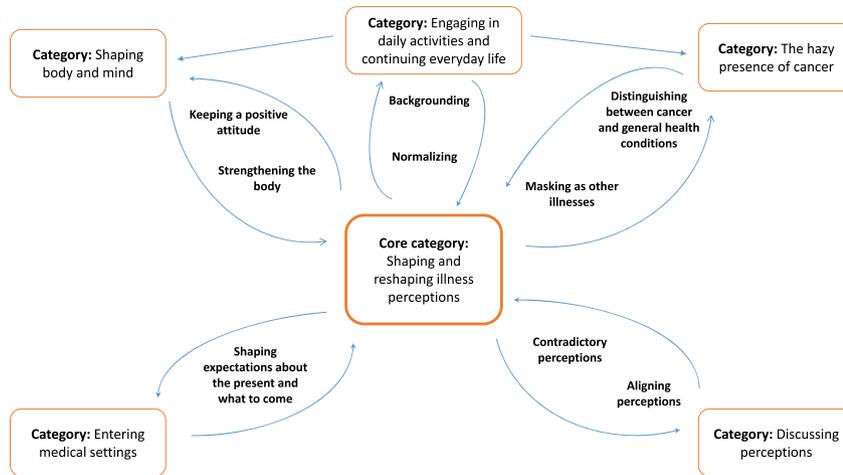
All the men knew they had life-threatening cancer: a message conveyed to them by doctors and nurses. However, from talking to the men, it became clear that their perceptions of being ill were not static. Rather, their illness perception was continuously shaped and reshaped by the challenges it posed to their daily lives and actions and interactions across contexts. Depending on what they were doing and where they were, their perception of being ill could shift. Notably, the shifting and contextual nature of the men's illness perceptions varied across the group. However, the factors described in the following categories were consequential on all participants' illness perceptions.

3.2 | The hazy presence of cancer

Those participants who were experiencing symptoms and the side effects of treatment had a more direct experience of their illness, a constant reminder of the seriousness of their situation. Going shopping left them exhausted and out of breath. For participants who were not feeling discomfort, in some cases due to pain-relieving medication, the experience of cancer was hazy. Cancer was something they knew they had but did not feel. George said:

I cannot feel it, I cannot see it, and I cannot hear it. It is a strange thing. An actual disease, like a wound on the

FIGURE 1 Illustration of the findings



hand, you can see it, and you can feel it. You tend to forget; you become unaware that you are ill.

The haziness of cancer was connected to the participants' illness perceptions in the following two ways:

Distinguishing between cancer and general health conditions

Determining if physical or mental discomfort was due to cancer, their general health condition or natural aging was challenging. When asked how cancer affected his daily life, Hans said:

It is difficult to say because I do not feel it that much. Of course, I get short of breath, but I did that anyway because I am in poor condition.

Masking as other illnesses

Distinguishing between indications of cancer and other illnesses was equally challenging, particularly when they received their diagnosis. Ben explained:

Typically, when I got back from East Asia (Business travels), I got a cough from the air conditioning (in airports and business offices). This time it just went on, and eventually, I lost my voice. I had no pain; I could not feel anything. It turned out to be small cell lung cancer.

3.3 | Engaging in daily activities and continuing everyday life

It was a recurring theme in all interviews that the men's perceptions of being ill were connected to their ability to maintain everyday life and do whatever activities they found meaningful. Engaging in daily activities, like gardening and hobbies, cycling and generally continuing life as it was before cancer, was linked with good health, living an

ordinary life and not feeling ill. Most participants said they did not feel ill because they could still do what they wanted. Sam said:

On the days I feel well, I cannot stop thinking about whether I am as sick as they (doctors) say I am. I sometimes question that. When I can ride my bike, I think: am I at all as sick as they say I am?

It seemed that some daily activities were more associated with being healthy and not ill compared with others. Many of these daily activities had been a part of the participants' everyday lives before cancer. They entailed some degree of physical activity, like fixing the car, hiking, photography and biking. Other more sedentary activities were associated with illness, resignation and giving up, like lying in bed and watching TV.

Being involved in daily activities and continuing their everyday lives were connected to the participants' illness perceptions in the following two ways:

Backgrounding

When engaging in activities they enjoyed, their illness would be pushed to the back of their minds, making room for positive thoughts unrelated to illness. This also contributed to the hazy presence of cancer in the men's everyday lives. Tom talked about his experiences when walking in the woods:

I do not think about it (cancer). Quite honestly, I just think about the natural surroundings I am walking in. If I have a good day, I do not think about it as such. If I'm a little out of breath, well, then I just have to take a little break. But I do not think about it.

Some participants would get involved in absorbing activities as an intentional strategy if they became overwhelmed by negative thoughts. To others, like Tom, this just happened as they went on with their daily lives.

Normalising

Daily life had a normalising effect on the participants' perceptions of their situation. Continuing daily habits and activities inside and outside the home were perceived as desirable, associated with normality and a life without illness. Ben explained his thoughts about feeling healthy:

Because I can walk, stand, run and live my life as I normally do, I feel healthy (not ill). Being healthy is living a normal life.

Ben also described how shocked he was when receiving his diagnosis because he had no symptoms and was living as he usually did, thus emphasising the link between a normal life and not being ill.

3.4 | Shaping body and mind

Except for Harry, all participants shared the assumption that they had some degree of physical or mental control of their cancer trajectory. Some described their cancer as an organism with a life of its own. They believed that the tumour was vulnerable to how they lived their lives. Some saw this as a battle between themselves and the tumour that they were determined to win. George said:

Of course, I am never going to give up. I know that I am going to get through this. I have these 'soldiers' (cells combating cancer) inside me, and they will win this war.

The participants' attempts to fight the cancer were connected to their illness perceptions in the following two ways.

Keeping a positive attitude

The men believed that their bodies and mind were connected. Avoiding thinking about cancer and keeping a positive attitude were described as vital ways to combat cancer. Tom talked about his chances of survival:

Only five percent survive lung cancer after five years. I am going to break that statistic because I am me! I am optimistic, so it is not going to happen—a positive attitude is a winner.

To some participants, being able to continue engaging in activities they found meaningful helped them preserve positive thinking about their situation and the time to come.

Strengthening the body

Exercise and healthy dieting were perceived as equally important in the war against cancer. For instance, Dave made juice from Aronia berries to kill cancer cells. Several others exercised in different ways, like using an exercise bike and taking long walks. These activities aimed to strengthen their bodies for the next round of

chemotherapy or restrict the spread of cancer. The men's motivation for cancer rehabilitation was related to this process. Rehabilitation was perceived as a way of strengthening their bodies before and after treatment. Tom talked about his experience with rehabilitation:

It was a good exercise. It helped me rebuild my strength. I was scrawny at that time. It (relevance of rehabilitation) depends on how frail you are; I do not belong to that group now.

However, most were reluctant or dismissive about rehabilitation services, which they found irrelevant, or said they preferred to exercise independently.

3.5 | Entering medical settings

When asked what they associated with cancer, all the men mentioned experiences related to being in medical settings, such as getting diagnosed and receiving treatment. They described how their illness became more vivid and present when they were sitting in the waiting areas in hospitals surrounded by medical staff and sick people. Dan described his experiences of talking to the doctors:

You cannot have a conversation with the doctors without being made aware of how severe your illness is. It is not what you want to hear.

Conversely, thoughts about cancer slipped into the background when not in contact with medical settings. Ben said:

The three months I did not receive treatment were just one long vacation. I had no thoughts about cancer at all.

Being in medical settings influenced the men's illness perceptions in the following way:

3.6 | Shaping expectations about the present and what to come

The experiences related to being in medical settings formed the men's illness perception by indicating the severity of their condition and what they could expect in the time to come. Hans talked about his expectations:

I expect a lot from immunotherapy. The doctors told me that we might be lucky. It (immunotherapy) might prevent my cancer from growing. The doctors have high expectations, well, not high, but reasonable expectations at least. So, I have to hope for the best.

3.7 | Discussing perceptions

This category emerged from interviews with men living with a partner (married or in a relationship). Observing changes in the men's eating patterns, energy levels and physical appearance prompted the women to discuss with their partners what they had observed. According to the men, the purpose of these discussions was to influence how they managed their illness, encouraging them to adopt a less cavalier attitude towards cancer, eat healthily or incorporate physical activity into their daily routines. Dan said:

When I play pool with my friends, we usually drink a couple of beers. This is now bothering her (wife), and she puts pressure on me to drink less. When I ask her, 'Why?' she replies, 'Because you are sick.'

Participants living alone had to rely on themselves, doctors and nurses to make the right decisions about their situation. Their partners influenced the men's illness perceptions in the following two ways.

Aligning perceptions

Discussing back and forth, the men would align with the women's perceptions because of their unwavering trust in their partners, whom they knew had an intimate knowledge of them through many years of living together. Sometimes these discussions would take the form of cheerful banter with an underlying seriousness. Ben described a conversation with his wife during chemotherapy:

Your legs feel like jelly, and your whole body is just 'Aarhh' (in pain). I just want to throw myself in front of the TV. I have done that many times. But Sophie (wife) is good at kicking me in the butt. 'Get up!' she says (laughing). So, I get up and do the things I can.

Contradictory perceptions

On other occasions, the men perceived suggestions made by their partners as meaningless and contradictory to how they viewed themselves and preferred to live. Sam said:

My wife manages our diet; lots of cancer-fighting vegetables. She knows all about it because she is a nurse. I did not care about healthy food before cancer, but now I eat a bit of it (reluctantly). If I were living alone, I probably would not eat it. Five hundred grams of vegetables make no difference. The only thing that helps is pure poison (Chemotherapy).

4 | DISCUSSION

The purpose of this study was to explore how men with advanced lung cancer form perceptions of their illness in everyday life and how this influences perceptions about rehabilitation.

An essential finding was that the men felt a strong connection between engaging in daily activities and maintaining their everyday lives, a sense of normality and being healthy rather than ill. Daily activities became an intermediary between the men's illness and their illness perception. The illness materialised in their minds and became palpable when using their hands and bodies and going about their day. Being ill was not a passive state of being and knowing but rather an active state of doing and engaging oneself.

These findings are supported by other studies. Several studies have similarly demonstrated that continuing daily activities are associated with positive feelings (Ikiugu & Pollard, 2015; Maersk et al., 2019; Peoples et al., 2017; Reeve et al., 2010; Svidén et al., 2010). In the case of people with advanced cancer living at home, Maersk et al. (2019) found that engaging in activities, like vacuuming, fostered positive perceptions of their illness status; they were still capable and active. Adjacent to this, although the men in this study knew they had a life-threatening illness, several said they did not feel sick. La cour et al. (2009) have pointed to the same contradiction and tension in the illness experience among people with advanced cancer. They found that feeling capable was associated with being healthy, paralleled by the notion of being severely ill. Stapleton and Pattison (2015) found that men with advanced cancer associated self-reliance and being in control with normality and their lives before cancer. They also found that changes to their bodies and appearance were perceived as visible markers and representations of their illness (Stapleton & Pattison, 2015). The men in this study did not explicitly mention their bodies but rather what they could do with them. Clearly, the activities encompassed by everyday life are essential to illness perceptions for this group.

To enable men with cancer to participate in everyday activities which they prioritise, it has been recommended that cancer rehabilitation and treatment be specifically designed to accommodate the preferences of the male group to stimulate and reinforce their motivation (Burns & Mahalik, 2007; Handberg et al., 2014; Handberg et al., 2015). To achieve this goal, this study offers insights into how illness could be conceptualised and how men with lung cancer might become motivated to participate in cancer rehabilitation. The findings show that the men's illness perceptions were fluid and contextual and formed by interrelated factors. Their motivation to participate in cancer rehabilitation seemed connected to their perception of cancer as an organism, the growth of which they could inhibit by strengthening their bodies. However, motivation may also be aroused by addressing factors other than physical strength, such as being involved in daily activities. Daily activities perhaps provide a readily accessible setting or language that enables health care professionals to communicate with men about their rehabilitation needs.

4.1 | Method discussion

A limitation of this study is the use of a telephone for data collection, which made it challenging to show empathy when participants

became emotionally affected. Block and Erskine (2012) also pointed out this. However, the physical distance between participants and researcher, which Zoom® and telephone allowed, made it possible to include participants who would not have participated due to the Covid-19 pandemic (Archibald et al., 2019; Block & Erskine, 2012).

Constructivist grounded theory research quality resides in theoretical saturation, which occurs when all categories and their relationships are defined and explained (Charmaz, 2014). To achieve this, we ended the collection of data when no new insights emerged from the analysis and all analytical questions seemed answered. A limitation of this study could be the relatively low number of participants for a grounded theory study. However, in tune with the underlying assumptions of constructivist grounded theory (Foley et al., 2021) (Charmaz, 2014; Foley et al., 2021), we strove for explanatory depth rather than representativity by rigorously adhering to grounded theory guidelines.

5 | CONCLUSION

This study offers insights into how men with advanced lung cancer form illness perceptions in everyday life and how this relates to perceptions about cancer rehabilitation. The findings from this study show that the men's illness perception was fluid and contextual and formed by interrelated factors. Of these factors, engaging in daily activities and upholding everyday life influenced their illness perception. Therefore, it is worth considering how men's everyday lives could be a more integrated part of cancer rehabilitation. Exploring how cancer rehabilitation could interplay with men's illness perception and its connection to their everyday lives, as outlined in this study, could be a topic for future research.

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CONFLICT OF INTEREST

The principal author Jesper Larsen Maersk declares no conflicts of interest concerning the research, authorship and publication of this article. I, Line Lindahl-Jacobsen, declare no conflict of interest regarding the manuscript. I, Elizabeth Rosted, declare no conflict of interest regarding the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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