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Butterflies in the Stomach: a qualitative study of patients' experiences during the diagnostic pathway for lung cancer

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Abstract

Background

In Norway, standardized fast-track diagnostic pathways for lung cancer aim to reduce time to diagnosis and treatment. Pathways are designed to improve clinical efficiency, little is known about how patients experience the diagnostic phase.

Objective

To explore patients' experiences of the diagnostic pathway for suspected lung cancer.

Methods

This qualitative study had an exploratory descriptive design. Semi-structured individual interviews with 17 patients referred to a fast-track diagnostic pathway for lung cancer at a Norwegian university hospital. Participants were at different stages of the diagnostic process. Interviews were audio-recorded, transcribed verbatim, and analyzed using reflexive thematic analysis as described by Braun and Clarke.

Results

Four themes were generated. *Honesty, trust and direct information* highlighted the importance of clear, timely, and transparent communication for patients' sense of safety and trust. *To be in a diagnostic pathway is a family project* illustrated how the diagnostic process affected not only patients but also their families, with patients balancing their own need for support against a desire to protect relatives from distress. *To wait and see or do something active* described diverse coping strategies, ranging from maintaining routines and staying active to experiencing life as "on hold," marked by anxiety, sleep disturbances, and emotional strain. *Everything happens so fast and not knowing what you get into* captured the dual experience of appreciating rapid and efficient care while simultaneously feeling overwhelmed and unprepared for the pace and implications of the pathway.

Conclusion

Patients experience the diagnostic phase for suspected lung cancer as emotionally demanding, shaped by communication quality, family involvement, individual coping strategies, and the speed of the fast-track system. Although the pathway ensures timely diagnostics, it is associated with psychological burden. Findings indicate a need for psychosocial support during the diagnostic phase and provide a foundation for developing prehabilitation interventions in a Norwegian context.

Introduction

In Norway, a standardized fast-track pathway for lung cancer has been implemented to ensure timely evaluation and treatment in cancer care (1). This pathway has specified short timeframes. Firstly, the time from referral to the start of the diagnostic process should not be more than one week. Then, the diagnostic evaluation should be concluded within three weeks. Treatment should start within one to two weeks after that, depending on the type of treatment modality. For healthcare providers, these timelines require rapid coordination, diagnostic testing and results interpretation to start cancer treatment. Health professionals perceive this timeframe to be short, but how do patients experience this period? Is waiting four to five weeks for a potentially lifechanging diagnosis too long? How do they deal with the uncertainty during this diagnostic phase? Little is known about how patients perceive and cope with this waiting period. Gaining a greater understanding of patient experiences of the time from referral to diagnosis is crucial for informing the development of the services.

Most research on lung cancer has focused on the post-diagnostic phase, while patients' experiences from the first suspicion of cancer until diagnostic confirmation remain underexplored. A Danish study has shown that there is substantial psychological strain associated with waiting for a conclusive diagnosis (2, 3). To our knowledge, no qualitative studies have been conducted in a Norwegian context that examines how patients experience the fast-track diagnostic pathway for lung cancer. This knowledge can be crucial for improving healthcare services to better accommodate the needs of this patient population and thereby improving patient-centered care and the overall quality of the diagnostic process.

Including prehabilitation as a routine part of the diagnostic phase is one of the possible ways to lessen patients' phycological distress, empower them and improve health literacy (4). Prehabilitation is a systematic, research-based approach that aims to maximize a patient's mental and physical strength prior to, during, and following cancer treatment (5). It usually includes several elements, such as psychological counseling, smoking cessation, nutritional counseling, and physical activity. Prehabilitation programs have shown benefits for cancer patients worldwide (6, 7). However, no Norwegian hospitals have yet implemented specific prehabilitation programs for patients with lung cancer. This underscores a critical knowledge gap: To develop supportive interventions, it is first necessary to map and understand patients' experiences to identify and address their needs.

Akershus University Hospital (Ahus) is developing and piloting a multimodal prehabilitation program for lung cancer aiming to strengthen both physical and mental resilience and improve treatment outcomes. As part of this initiative, we conducted a qualitative study to gain an in-depth understanding of patient experiences during the diagnostic phase.

Materials and methods

Design. The study had an exploratory and descriptive design (8), with semi-structured qualitative individual interviews (8, 9). Qualitative interviews are suitable when the purpose is to gain deep insight

into people's opinions, experiences and attitudes. The purpose is to understand the life world of the informants, their perspectives, and how they perceive it. An interview guide was used that allowed for non-scripted follow-up questions based on the interviewee's response to properly develop and examine all answers (8). The interview guide was developed by the last author (KN) and the second author (KF) with input from the project group. It covered topics such as the time before entering the fast-track pathway, hospital appointments, expectations and coping.

Participants, recruitment and context. All patients above 18 years of age, referred to the Pulmonary department at Ahus between January 2024 to the end of March 2024 and included in the fast-track diagnostic pathway for lung cancer were eligible to participate. Recruitment was based on convenience sampling. The invitation to participate was based on the physicians' assessment of the patients' ability to participate. Recruitment was done by the patient navigator. The nurses at the outpatient clinic provided information about the study. Oral and written informed consent was obtained from all subjects Originally the interviews were to be conducted face-to-face at the hospital, while the patient was already at the hospital as a part of the clinical diagnostic program. The interviews were planned to take place between the examinations or the consultations with members of the lung cancer clinical team. However, we experienced that taking part in an interview after spending several hours at the hospital was very overwhelming for the patients. Therefore, it was difficult to recruit participants in the beginning. Due to this, we had to change our recruitment strategy. Rather than having the interviews while they were at the hospital, we offered the option of a phone interview, where they could freely choose the time and day. Recruitment was easier when they had this option.

Data generation. Data generation was done through 16 individual telephone interviews and 1 individual interview face-to-face. All interviews were conducted by the first author (SP). The interviews lasted between 25–45 minutes. The interviews were audio recorded to support the work on the analysis and transcribed successively by the first author (SP). Participants were asked for specific consent to the recording. Field notes were systematically taken throughout the entire research process. The interview guide was reviewed along the research to ensure that the proper questions were used and that our decision to stop inclusion was made based on how the dataset was perceived to be rich enough (9).

Data analysis. The interviews were transcribed verbatim. Transcripts and field notes were analyzed through thematic analysis as described by Braun and Clark (9). The analysis was performed in collaboration between the authors (SP, KN, KF). This method entails a process of:

1. Familiarization with data through repeated reading and note-taking.
2. Initial generation of codes across the dataset.
3. Identifying and developing overarching themes and subthemes.
4. Reviewing and refining themes to ensure they represented the data accurately.
5. Clearly defining and naming each theme.
6. Structuring a detailed report to articulate the findings clearly and coherently.

Ethical considerations. The project was approved by Regional Committees for Medical and Health Research Ethics (#632356) and by the Data protection officer of the hospital (#2023_140). All methods in this study were performed in accordance with the relevant guidelines and regulations. We are mindful that ethical dilemmas continuously could occur through the process of a project and that we had to be conscious of that fact. The three ethical principles of informed consent, confidentiality and consequences are central to the project (8).

Rigor and reflexivity. The detailed description of the research process is part of the researchers' attempt to strengthen the credibility of the work, and the multidisciplinary nature of the study team is a strength in that it has different perspectives on the discussions of the data, and both an insider and an outsider perspective on the study. Acknowledge that a text has multiple meanings, that our analysis in one way of looking at the data and that as a researcher brings our preunderstanding to the research process influences the research (9).

Results

A total of 17 patients participated in the study, 7 woman and 10 men. The sample included patients at various stages of the diagnostic process: some newly referred, some undergoing active investigations, and others who had recently completed their diagnostic evaluations.

The analysis generated 4 themes; “Honesty, trust and direct information”, “To be in a diagnostic pathway is a family project”, “To wait and see or do something active”, and “Everything happens so fast and not knowing what you get into”.

Honesty, trust and direct information

Clear communication was critical for the participants. As illustrated in the following quote they wanted honest open communication:

They [health professionals] *were professional and effective, I could understand quickly how serious this situation was. They took good care of me and informed me. I’m the type of person that likes to know exactly how things are, not withholding information. I want to know everything exactly how it is*

When the participants were asked to elaborate on what was important to them when it comes to communication and information, they commented on various aspects such as the willingness of health professionals to answer any questions, the clarity of information and being met and acknowledgeable as a person:

It was easy to talk to the doctor, and he explained it well. For me, that is really important and good. If there were any difficulties, the doctor would explain until I fully understood the information. The information was understandable

Having the opportunity to bring other family members to accompany them during medical consultations improved the patient's feeling of safety. Some of the patients experienced having trouble remembering information and were struggling with mental stress caused by being in a diagnostic lung cancer pathway:

I lost my wife four years ago, so I know how life can be. One of my daughters has accompanied me to all my hospital appointments, so she has all the information and I feel safe. My children are good to have

Patients had varied experiences regarding adequacy, clarity, and timing of information provided by healthcare providers. Overall, the patients were satisfied with the communication, but some patients had experienced deficits in communication, particularly from primary care to specialist care, resulting in increased anxiety and uncertainty.

Participants emphasized the importance of trust, empathy, and professionalism in interactions with healthcare personnel. Positive experiences were linked to consistent and compassionate care.

I was in good hands, I felt safe. I could ask about anything I wanted to talk about. I felt very safe

Conversely, frequent changes in responsible physicians were experienced negatively, creating uncertainty and feelings of being inadequately supported. Some participants experienced fragmented care during the patient pathway due to interactions with multiple physicians, contributing to uncertainty and dissatisfaction with the overall care experience.

To be in a diagnostic pathway is a family project

Being in a diagnostic lung cancer pathway can be difficult for the patient, but it also affects the whole family. As such the process becomes about much more than just the reaction of the participants themselves. Some participants stated that their family members were more concerned about the future than they were themselves.

“My wife was there for me, but she was more shocked than me. We support each other, so it´s fine. She is a great support for me”.

Participants were concerned about the impact of their condition on their families.

I got the impression that the doctors thought that I had cancer, and I was thinking that the doctors wouldn't say that without a reason. So I was convinced that it was cancer. I felt so helpless. What will this be like? I want to continue living with my family. I was mostly thinking about how I would inform my daughter about this. I thought about this a lot, day in and day out. Difficult….

In some instances this even resulted in portioning the information about what they were going through in an attempt to protect the emotional well-being of their family members.

My wife cries a lot, she is very sad and has been affected very hard. We are home and she is with me all the time. My daughter just found out that I may have cancer, but we haven't told her everything yet. She seems to handle it quite well

Many participants felt torn between two feelings, on one hand they needed support from their family and the opportunity to talk about it with them. But on the other hand, they felt worried about how their family would cope with this.

"*My wife and my daughter are my supporters, and it feels good to have them*".

"Hmm...I brought my wife with me. I thought mostly of my wife and my nine-year-old daughter. I thought about how I was supposed to inform her of this. This bothered me a lot...actually, I thought this was going to go well. So, I thought mostly of my daughter and my wife".

Others emphasize that other members of their close social networks provided substantial emotional support for them.

My friends have been good to have, they have taken good care of me. I'm not alone. I talk to my friends about it, but I'm not the type of person to make a big deal out of stuff. Thats how I am.

To wait and see or do something active

The participants talk about a diverse range of emotional responses, ranging from calm acceptance of having to wait and see, to significant distress, anxiety, and persistent worry. This also manifested itself in their choices of coping strategies. Some patients carried on living like they used to and tried to keep themselves busy so that they would not think too much about what would happen. They attempted to maintain routines.

I live my life as similar as I can to what I always have. The difference is that I have more thoughts about the future than I had before, considering the situation I'm in. I can't let my thoughts take over. I have a full calendar, and that makes me motivated. I don't have a lot of time to think about it, since I have a lot of things to do. I haven't been thinking about it, but I'm focused on the stuff I'm planning to do. I'm going to do this and that, I'm going there and here

I am with my wife, we go to the store, visit friends, and go for walks sometimes. We talk together, cook dinner, watch TV, and read the newspaper. I do what I always do, and live as I always have

Others took on a more passive role and stated that whatever happens I will have to wait and see what the results of the examinations are.

I take things as they come, because there's not always anything you can do about it other than just deal with it. Even though it's difficult and challenging, you have to try to find a solution. You can't go around thinking about it all the time, I have to wait and see what happens

Some talked about coping strategies that entailed discussions with their family, spouse or others close to them.

I talk a lot with my wife, who is a good person who supports me. She is the one I lean on. She is good to talk to. I also have good friends who I talk to and meet. So, I keep myself a little busy with socializing with friends and family. When I feel that I am thinking a lot about it, I try to talk to my wife. I feel that helps me a lot when the thoughts start. She is very patient and kind

For other participants it was difficult to act like “normal” in daily life. They felt their lives were put on hold and that they had to wait before they could live normally again.

“*I'm trying to stay busy and doing things. I tried to go to work, but it didn't work. So it was really just pointless, I wasn't there*”.

“It was pretty horrible for both me and my wife. We were sad and kept ourselves busy all the time. We tried to talk about it…we had to postpone all our future plans because of it. We didn’t know what the future would be like. Life was put on hold”.

Patients noted the stress associated with waiting periods between tests and receiving results. Most participants didn´t have any symptoms, but some patients had either psychological- or physical symptoms or both.

“I was walking around and feeling nervous all the time, every day. Yeah, it wasn't a good feeling. Walking around with a bad feeling in my stomach. It affected me, but I had to make the days go by. Work and try to do what I usually do”.

They could overthink daily, cancel plans, isolate themselves and be depressed even though they had someone to talk to. Some explicitly expressed a need for integrated psychological support during waiting periods. Several patients explicitly expressed that psychological counseling should be incorporated as a standard component of the diagnostic pathway due to high levels of anxiety. Others point out the importance of getting an opportunity to talk to someone that is or has experienced the same thing that you are going through.

“While I was waiting, I spoke to two people who were in the diagnostic pathway, and it was good to talk to someone who was in the same situation”.

Everything happens so fast and not knowing what you get into

Participants frequently reported the rapid onset and intense nature of the diagnostic process once they are referred to the standardized pathway. Some patients appreciated the swift and structured process.

Everything happened so quickly. I went to the doctor on Tuesday, took images and on Thursday I had new blood tests done and was sent to the hospital. Then they were going to empty my lungs and do a CT on

Friday. Then on Wednesday I was called back again, because that was when the report was ready. Then I found out how serious it was, and at the same time I found out when treatment would start, which was on Friday. I was really happy. It went quickly! I was very impressed!

Then I was actually told that it could be cancer, and I was shocked. There was a doctor and a nurse who talked about cancer. They told me what to do and the various tests that would come in the next few weeks. It was actually good, but it was sudden to get that news. It was a good conversation with them, and they explained it well

Others felt overwhelmed by its rapid progression, describing it as stressful and anxiety-provoking. Some even talked about being unprepared for what kind of pathway and diagnosis they were facing.

No, I didn't know what I was going to do, and I didn't really have anything to compare it to. I hadn't been told that cancer was suspected, so it came as a surprise to me

"I was very anxious, and I didn't understand why I was being referred. I was nervous, and it all went very quickly, so I didn't really have time to think much "

Many participants had no or minimal expectations regarding the diagnostic process prior to their enrollment. However, once engaged, their experiences typically exceeded initial expectations in terms of speed and thoroughness. Nevertheless, some participants experienced a gap between expectations and experiences, particularly related to communication and emotional support during the diagnostic process.

Discussion

This qualitative study has identified several themes that can add new insights into an underexplored phase of the lung cancer trajectory. This gives health professionals clear guidance to what they should focus on in their interactions with the patients and their relatives.

Participants consistently highlighted the importance of clear, honest, and timely communication and information. An Australian study also shows the importance of honest and clear communication and information (3). The findings in our study showed that patients had different information needs. Some wanted detailed information, while others were satisfied with a minimum of information. This tells us that information and communication should be person centered, coordinated, and consistent throughout the entire diagnostic lung cancer pathway, also in the early phases. Meaning that the individual's information preferences is a topic that should be explicitly addressed, not just assumed, from early on in their pathway. Many patients did not know they were referred to the fast-track pathway for lung cancer, until they received a phone call from the hospital.

Patients were often stressed and anxious when referred to a diagnostic lung cancer pathway. The study by Tod et al. (10) showed that patients who worried about their prognosis and thought about how long they potentially had left to live, found peace when they were given clear information about treatment

options, because it gave them hope. Although clear information provides reassurance and promotes hope, sometimes it is not easy for health professionals to know how patients and families cope with receiving the information that is provided. We know that sometimes healthcare professionals shield patients, with good intensions, because they are worried that they cannot take in so much at once or are uncertain about what will overwhelm them. Sometimes this is counterproductive for patients themselves because they may already be thinking about it and are worried about topics that are not being thematized. It is important to acknowledge that healthcare professionals may think these conversations are difficult, and that we therefore need to do something to support healthcare professionals in dealing with this.

While most described positive encounters with healthcare professionals, fragmented communication and frequent changes of responsible physicians created insecurity for some. Previous studies have similarly emphasized that trust, empathy, and continuity are central to patient experiences in cancer care (2, 3, 10). Our findings confirm that also within a well-structured pathway, relational aspects of care remain decisive for patients' sense of safety.

The diagnostic process was experienced not only as an individual journey, but as a shared family challenge. Patients often relied on spouses, children, or close friends for support. Some deliberately shielded family members from distressing information. This aligns with previous literature showing that cancer diagnosis affects family systems, with both supportive and potentially burdening effects (3). Recognizing the family as part of the care unit may therefore be essential when designing supportive interventions. In general, not many patients or family members know what the diagnostic pathway is and how it could affect them. Helping both the patients and their family with clear information and showing support can help them to help each other.

Patients adopted diverse coping strategies while waiting for diagnostic results. Some maintained routines and sought distraction, while others reported life being "on hold," accompanied by anxiety, sleep problems, or depressive symptoms. The psychological strain associated with waiting has been well-documented (2), and our findings reinforce calls for systematic psychosocial support during the diagnostic phase. Notably, several participants explicitly suggested that psychological counseling should be offered as part of standard care.

The fast-track pathway was appreciated by many participants for its efficiency and structure. Yet, others felt overwhelmed by the rapid pace, especially when little preparatory information was given. This duality efficiency as both reassuring and stressful, illustrates the paradox of fast-track systems. While medically advantageous, they may limit patients' opportunity to process information and prepare emotionally. Similar findings have been reported in studies from other healthcare systems (3).

Our findings point to an unmet need for supportive interventions early in the patient pathway. As mentioned in the introduction, prehabilitation programs may help address these needs by integrating physical activity, nutrition, smoking cessation, and psychological support (4). However, effective implementation requires that programs are tailored to the lived experiences of patients in the diagnostic

phase. By mapping these experiences, our study provides an empirical foundation for designing patient-centered prehabilitation services in a Norwegian context.

The study's strength lies in providing first-hand insights into patient perspectives on the Norwegian lung cancer diagnostic pathway, an area previously lacking research. The sample included men and women at different stages of the diagnostic process, which strengthened variation in perspectives. Telephone interviews, while practical, may have limited the depth of interaction between interviewer and participant compared to face-to-face interviews.

Conclusions

Patients experience the diagnostic phase for suspected lung cancer as emotionally intense, shaped by communication quality, family involvement, coping strategies, and the speed of the pathway. While the fast-track system ensures timely diagnosis and treatment initiation, patients face significant psychological strain, and to implement structured prehabilitation can play a role in addressing these challenges. We see a need for the patients and the caretakers to get more involved and give them more knowledge and tools to help them prepare and cope.

Declarations

Conflict of interest:

The authors have no conflicts of interest to declare.

Ethics

The project was approved by Regional Committees for Medical and Health Research Ethics (#632356) and by the Data protection officer of the hospital (#2023_140).). All methods in this study were performed in accordance with the relevant guidelines and regulations.

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Author Contribution

SCRP - interviews, transcriptions, main manuscriptKJØF - methodologyKN - prosject management and supervisionAll authors - data analysis and manuscript review and editing

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Data Availability

The data presented in this article is not readily available to general public due to restrictions. Please contact the corresponding author for any requests regarding the data from this study.

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