

# Patient perspectives and experience on the diagnostic pathway of lung cancer: A qualitative study

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## Abstract

**Objectives:** Lung cancer is one of the most common types of cancer, with high mortality rate and a significant burden of symptoms. It is therefore important to assess patients' perceived quality of life during the diagnostic process and treatment. Knowledge of and attention to patients' perspectives, experiences, and expectations in relation to lung cancer diagnostic pathways is limited. The aim of the study is to contribute with patients' and relatives' experiences with and their assessment of the quality of a hospital-based lung cancer diagnostic pathway.

**Methods:** A qualitative study was conducted, comprising participant observation with 20 patients and semi-structured interviews with further 19 patients referred to the Lung Cancer Package, which initiates a fast track diagnostic pathway in a hospital setting. Data were obtained over a period of 9 months and analysed in collaboration with an interdisciplinary team of health professionals. The purpose was to further develop existing management strategies of the fast track diagnostic pathway based on patient's perspectives.

**Results:** Patients associated the fast track diagnostic pathway with high levels of anxiety due to the immediate risk of a lung cancer diagnosis. Although patients experienced the fast track programme as very challenging, they still wanted to move through the diagnostic pathway as quickly as possible. The patients expressed a need for support from relatives and repeatedly required information in multiple formats from health professionals throughout the diagnostic pathway.

**Conclusions:** The study provided insight into the need for developing the fast track diagnostic pathway with a focus on patient anxiety, network involvement, and information strategies. The results qualified clinical practice with an increased focus on managing patients' anxiety, raised awareness to involve relatives in the diagnostic process, and relaying information in dialogue with patients and their relatives, including management strategies to support patients through diagnostic investigations in the fast track programme.

## Keywords

Lung cancer, patient perspective, diagnostic pathway, qualitative research, patient involvement

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## Introduction

Lung cancer is among the most common types of cancer worldwide.<sup>1,2</sup> In Denmark, approximately 4600 new cases are diagnosed per year.<sup>3</sup> Mortality is high and burden of symptoms significant. Lung cancer is often characterized by symptoms such as persistent cough and sputum (possibly mixed with blood), breathing difficulties, hoarseness of voice, chest pain, fatigue, weight loss, and frequent pneumonias.<sup>4,5</sup> The diagnosis of lung cancer is based on diagnostic imaging examinations (chest X-ray, chest and upper abdominal PET/CT scan) and biopsies (guided by ultrasound or CT scan, or carried out by laparoscopy (i.e. bronchoscopy or less frequently thoracoscopy)). A pre-defined

fast track diagnostic pathway known as the Lung Cancer Package (Figure 1) was introduced by the Danish Health Authority in April 2008.<sup>6</sup> The Danish lung cancer package aims to ensure the rapid assessment and diagnosis of

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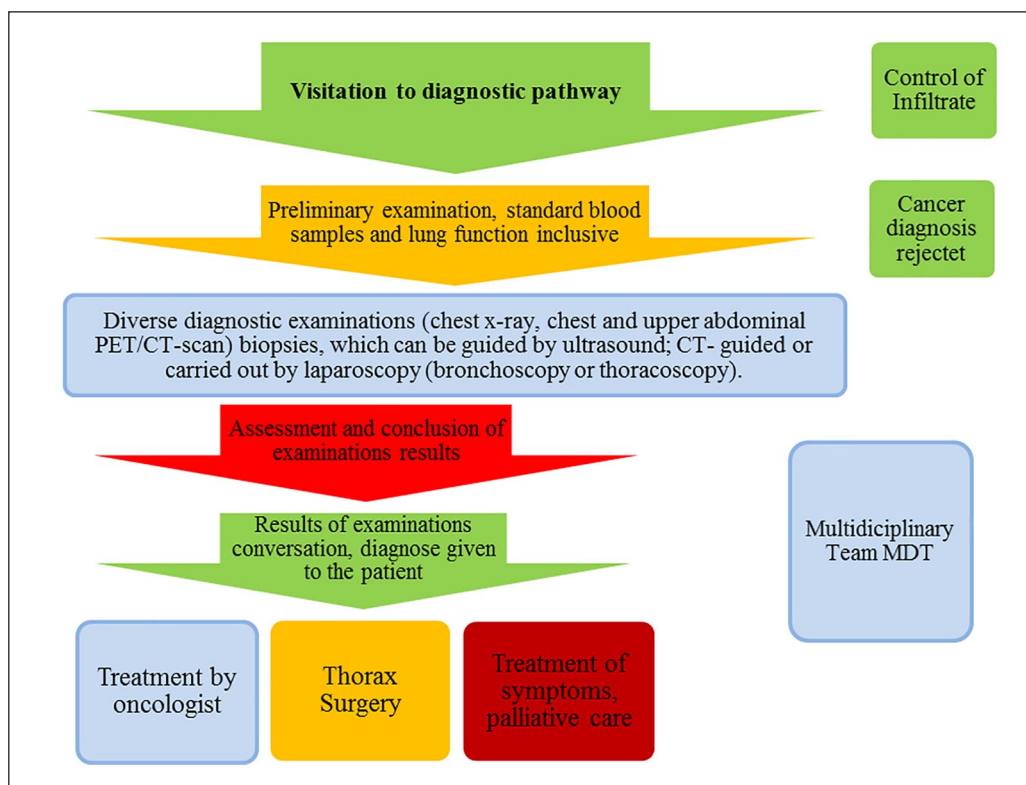
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**Figure 1.** The Danish Lung Cancer Package.

patients with suspected lung cancer, and their prompt treatment to improve prognosis and quality of life.<sup>6</sup> Evaluations of the lung cancer package show that there has been considerable focus on the organizational aspects of the fast track diagnostic pathway in clinical practice.<sup>6</sup> However, knowledge of and attention to patient's perspectives on, experiences with, expectations, and quality assessment of diagnostic pathways related to lung cancer are limited. The fast track diagnostic pathway is very intense with diagnostic investigations on a daily basis. As the emotional burden of being examined for lung cancer can be considerable for the individual patient, assessment of the patient's experience of the quality of the organization of the fast track diagnostic pathway is an important component in developing best practice. Likewise, insight into and knowledge of patients' perceived quality of everyday life during the diagnostic process is important, as patients are faced with the possibility of having a type of cancer with a high mortality rate.

Patients' and relatives' experiences of the healthcare system, care, and treatment are increasingly viewed as important to inform and improve quality of care, patient safety, and treatment efficacy.<sup>7</sup> Likewise, there is increasing focus on the positive impact of user involvement in care, treatment, and research in health. For example, users can contribute to the prioritization in daily clinical practice and the optimization of quality of care delivered to individual patients.<sup>8,9</sup>

Thus, patients' and relatives' assessment of the quality of the fast track diagnostic pathway for lung cancer is perceived by health professionals as an additional source of knowledge to clinical measurements and assessment by clinicians. A literature search in PubMed, PsycINFO, CINAHL, and Cochrane revealed 20 studies describing patient's experiences of everyday life with lung cancer. The search included two studies on patients' and/or relatives' experiences and attitudes towards diagnostic pathways in relation to lung cancer.<sup>10,11</sup> Rankin et al.<sup>10</sup> focus on general practitioners' and patients' perspectives. Their study shows that systemic interventions, such as a formal pathway to diagnosis, are important. Walton et al.<sup>11</sup> focus on factors that lead to delays in arriving at diagnosis in primary and secondary care. The study shows that it is necessary to inform patients about symptoms and when to seek medical assistance. Furthermore, the study suggests the implementation of cancer coordinators to support the patient.

### *Aim of the study*

To contribute knowledge of patients' and relatives' perspectives on, experiences with, and expectations and quality assessment of the Danish lung cancer package.

To further develop clinical management strategies of the fast track diagnostic pathway in Denmark based on user knowledge.

## Methods

The study's qualitative research design draws on the theoretical and methodological framework of critical psychological practice research.<sup>12,13</sup> Well rehearsed in the areas of psychology and pedagogy, practice research is now also being applied in healthcare research.<sup>14–16</sup> The authors of this article have both conducted practice research involving patients with chronic obstructive pulmonary disease. In both studies, the aim was to involve patients' perspectives in research and development of clinical practice with hospital-based non-invasive ventilation<sup>17,18</sup> and with home-based self-monitoring of symptoms.<sup>19</sup> In the present study, the framework was chosen to (1) focus on first-person perspectives of patients and relatives and (2) integrate patients' and relatives' perspectives into the development of the organizational aspects of the fast track diagnostic pathway and of clinical practice at the Center for Lung Cancer more broadly.<sup>12,13</sup>

Critical psychology is grounded in historical and dialectical materialism.<sup>12,13</sup> As a consequence, subjects and their actions are viewed as dialectically interacting with structures of social practice.<sup>12</sup> The concept of first-person perspective calls for an investigation of how subjects reason about their actions in specific circumstances in relation to what these circumstances mean to them and to their conduct of everyday life.<sup>12,13,20</sup> According to this research tradition, it is important to explore perspectives, experiences, and reasons for actions as they play out in everyday practice.<sup>21</sup> In addition, practice research is characterized by engaging co-researchers in developing and exploring research questions. In the present study, a group of health professionals contributed with clinical experiences and concrete concerns arising in their clinical practice pertaining to the lung cancer package. Furthermore, the principal investigator (PI) (first author) contributed to the joint process with data about patients' perspectives on the fast track diagnostic pathway, together with knowledge of the chosen theoretical and methodological research approach. An exchange of different kinds of knowledges, approaches, and perspectives contributes to form a shared understanding of a research problematic and specific research questions aimed at qualifying and developing clinical practice.<sup>22</sup> Practice research is described by Dreier<sup>21</sup> as a way to bridge the gap between generating knowledge and developing practice. Through systematic investigation, description, analysis, and the identification of possibilities for development, this participatory approach to knowledge production aims to provide insights into particular problems as they occur in specific action contexts in order to work towards solutions.<sup>20,21</sup> The research design of the present study involved regular meetings in a research group consisting of multidisciplinary health professionals and the PI. During meetings organizational and clinical problematics were brought up to inform the investigation of patient perspectives on the fast track diagnostic pathway. Preliminary insights from participant observation and interviews with patients were presented by the PI, and

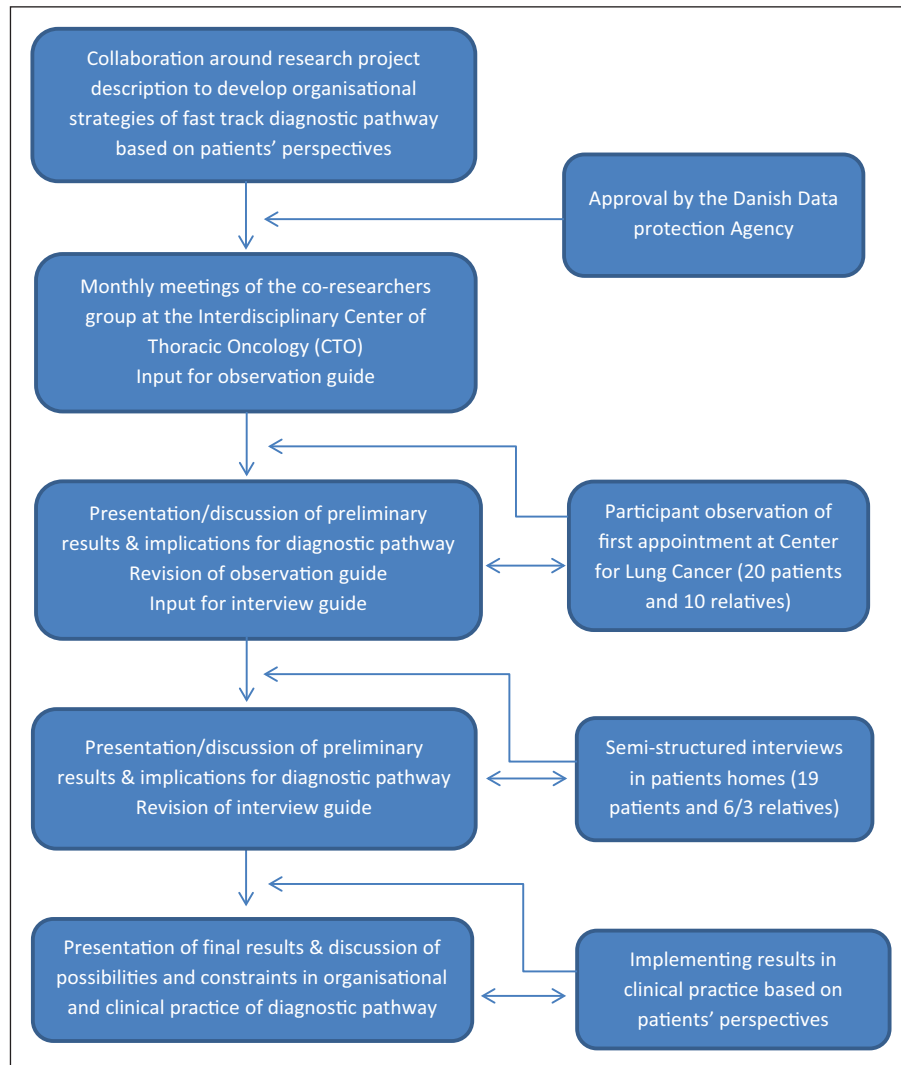
analysed and discussed further in relation to clinical and organizational practice (see Figure 2: flow chart).

### *Design of the study*

This study was carried out at the Center for Lung Cancer, Odense University Hospital (OUH), Denmark, in 2016–2017. Within this centre, a multidisciplinary team of lung cancer experts, employed in several specialist departments, collaborate in what is termed the Center of Thoracic Oncology (CTO). Members of the CTO include medical oncologists, radiation oncologists, thoracic surgeons, pulmonologists, pathologists, and radiologists. The CTO team meets once a month to ensure a continuous focus on professional quality of diagnostics, treatment, care, rehabilitation, and palliative care. At the beginning of the study, the PI was invited to join the multidisciplinary team at the CTO. The PI, based at the department where the study was carried out, is an experienced clinical research and nursing specialist within respiratory medicine, with prior experience of researching patients' perspectives. At the time of initiating the study, the PI had 10 years of experience on conducting semi-structured interviews and participant observation. The multidisciplinary team decided on an iterative research process, beginning with participant observation of 20 patients attending their first hospital appointment of the lung cancer diagnostic pathway. Data from these observations were continuously analysed and discussed at the CTO team meetings to inform changes to clinical practice and the content of the subsequent interviews with patients and relatives.

### *Co-researcher group*

The CTO accepted the study after an in-depth introduction to practice research as the overall approach, the purpose of the study, and the research activities, including the role of the multidisciplinary team as a co-researcher group. The PI participated in CTO meetings over a period of 2 years, and the study was part of the agenda at each meeting. During this time, the PI also carried out participant observation at the Center for Lung Cancer and conducted semi-structured interviews with patients and relatives in their homes, with the aim to shed light on patient perspectives and experiences with the fast track diagnostic pathway (further details below). Based on ongoing data analyses, the PI presented preliminary findings concerning patient perspectives at the multidisciplinary CTO meetings. The observation and interview guides were revised and expanded during the study in order to include further questions aimed at qualifying clinical practice. The co-researchers contributed to the research process with experiences from their specific clinical contexts, as well as reflections on possibilities and constraints for the development of clinical practice based on user knowledge. In the process, co-researchers raised questions for further investigation in relation to their clinical experiences and everyday practices: To what extent were patients aware of the purpose



**Figure 2.** Flowchart of study design.

of the hospital appointment before arriving? If patients were not aware of the purpose, what were the reasons? Has knowledge of treatment scenarios from the responsible physician influenced the perceived quality of the organization of the diagnostic pathway? Did the patients use the opportunity to contact health professionals during the diagnosis process?

### *Inclusion of patients*

This qualitative study of patients' and relatives' perspectives on and experiences with the fast track diagnostic pathway of lung cancer included a total of 39 patients and 16 relatives; of these, 20 patients and 10 relatives agreed to participate in participant observations and 19 patients and six relatives agreed to participate in semi-structured interviews. All patients asked agreed to participate and none withdrew during the study. To reflect different ages, gender, and civil status, the patients were purposefully sampled from medical

records at the Center for Lung Cancer. All patients in the study were approached by the PI face-to-face at their first appointment of the lung cancer package. Relatives participated based on the patients' choice. Inclusion criteria were the following: (1) Patients referred by the Center for Lung Cancer to the lung cancer package. (2) Patients and relatives able to approve of and sign the consent form to participate in participant observation or semi-structured interview. Exclusion criteria were the following: (1) Patient needing an interpreter. (2) Significant comorbidities. (3) Inability to understand information about the research project.

### *Participant observation*

Twenty patients referred to the lung cancer package were included consecutively in the observational part of study during April–June 2016, together with 10 cohabiting partners (Table 1). Data were generated through participant



**Table 1.** Patient characteristics (field observations).

Characteristics	No.
Male/female	10/10
Age median [min; max]	66.5 [49; 85]
Relatives participating in first consultation	10
Performance status (0/1/2/3)	10/6/2/1
Smoker/ex-smoker/smoking stop/never smoker	8/7/2/3
Aware of purpose of first consultation (yes/no)	13/7

observation following the patients at their first appointment at the Center for Lung Cancer, initializing the fast track diagnostic pathway. The first appointment consisted of a pulmonary function test and a consultation with a physician. During the consultation, results of a chest CT scan were conveyed and the patient was informed of additional diagnostic investigations necessary to arrive at a diagnosis. The patient was asked for consent to proceed with further diagnostic measures. The patient was then seen by a nurse who followed up on the information given by the physician, prepared for diagnostic investigations, and offered help of how to manage the fast track diagnostic pathway. The PI carried out participant observation inspired by Spradley<sup>23</sup> with the aim to obtain knowledge of the daily clinical routines and patients' experience of their first appointment of the fast track programme. Observations were recorded in structured fieldnotes, following Emerson et al.<sup>24</sup> During participant observation, attention was directed at describing clinical practice during the first appointment along with patient participation, responses, and reactions during the visit. The fieldnotes were systematized, analysed, and presented by the PI at CTO meetings for further analysis and discussion. Through discussions of the preliminary findings at the CTO meeting, it became apparent to all members of the co-researcher group that some patients did not realize why they were being referred, that emotional reactions were affecting patients' ability to receive information during appointments, and that many participants came to the appointment unaccompanied. These issues were explored further during the semi-structured interviews.

### Semi-structured interviews

The PI conducted semi-structured interviews inspired by Kvale and Brinkmann<sup>25</sup> over a period of 9 months. The aim of the interviews was to obtain in-depth knowledge of patients' and relatives' perspectives on, experiences with, expectations, and quality assessment of the lung cancer package. Nineteen patients referred to the lung cancer package were included consecutively for semi-structured interviews from August 2016 to May 2017 (Table 2). All semi-structured interviews were conducted in patients' homes. Nine patients chose to include a relative in the interview; six relatives were present during the whole interview, and three were present part of the time. The interviews took place after the diagnostic tests had been completed and before receiving the results of

**Table 2.** Patient characteristics (semi-structured interviews).

Characteristics	No.
Male/female	11/8
Age median [min; max]	74.53 [63; 85]
Relatives participating in interviews	6 (3 partially)
Performance status (0/1/2/3/4)	6/9/1/2/1
Smoker/ex-smoker/smoking stop/never smoker	5/13/1
Fev1 median [min; max]	76 [31; 107]
Co-morbidities (0/1 or more)	3/16

the diagnostic investigations, including a possible cancer diagnosis. This timing was chosen, in order to investigate patients' and relatives' perspectives on the fast track pathway at a time where a possible cancer diagnosis had not yet been confirmed or rejected. Each interview lasted between 25 and 65 min and followed an interview guide. The guide contained open questions to enable the patients to talk about their experiences from a first-person perspective. The interview guide was structured around three broad themes: (1) Patients' conduct of everyday life and related sub-themes. (2) Patients' experience of the fast track diagnostic pathway. (3) Patients' quality assessment of the organization of the diagnostic pathway. Attention was directed at informant's conduct of everyday life, including issues related to health and disease, and their life circumstances at the time before and while going through the diagnostic process. In this context, patients' and relatives' experiences and understandings of the fast track diagnostic pathway were explored. Interviews were audio-recorded and transcribed verbatim.

### Data analysis

Field notes were taken during participant observation, and patients' interviews were audio-recorded and transcribed. Preliminary thematic analyses of field notes and interview transcripts were theoretically informed by critical psychology and carried out with inspiration from Kvale and Brinkmann's<sup>25</sup> procedural suggestions. Both field notes and transcripts were read several times by the PI in a search for meaning units.<sup>25</sup> The meaning units were identified drawing on critical psychological concepts such as first-person perspectives, conditions of everyday life, meaning, agency, possibilities, and constraints. The main meaning units arising from the preliminary analyses were discussed consecutively in the co-researcher group of the CTO, and notes from meetings (recording, for example, health professionals' experiences and understandings) were included in further analysis. The analytical activities during meetings directly informed the development of clinical practice in relation to the fast track diagnostic pathway. The ongoing analysis also informed further purposive sampling of patients and added to the progressive development of the interview guide. Main themes from the analysis were later presented and further analysed by interdisciplinary health professionals at CTO

meetings. This allowed to qualify and continue the analysis and discussions of possibilities and constraints in developing clinical practice regarding the lung cancer diagnostic pathway based on all participants' perspectives. The collaborative efforts of the CTO made it possible to investigate, develop, and convert the knowledge of patients' perspectives and experiences of the diagnostic pathway into management strategies in clinical practice.

## Ethical considerations

All study procedures conformed with the Helsinki Declaration<sup>26</sup> (<https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>). The study was approved by the Danish Data Protection Agency (J.nr. 2016-41-4656).<sup>27</sup> Currently, the Danish National Committee on Health Research Ethics does not require the approval of research projects with qualitative methods (such as participant observation and interviews). To ensure anonymity, all patients have been identified by numbers only and are represented by numbers in this article. Before data collection all patients and relatives were informed of the content and aims of the study and of their right to withdraw at any time. Written informed consent was obtained. In addition, participants received details about the PI's relation to the department.

## Results from participant observations and interviews

Results were generated through analyses of data from participant observations and semi-structured interviews. Four main themes emerged: (1) Being in the spotlight of suspected lung cancer. (2) Patients' first appointment: 'What am I here for, doc?' (3) Management strategies during the diagnostic process. (4) Patients' reflections and assessment of the quality of the fast track diagnostic pathway. All themes are interwoven, but will be presented separately below. Quotes are translated from Danish by the authors with the assistance of an English language editor.

### Being in the spotlight of suspected lung cancer

Prior to their first appointment at the Center for Lung Cancer, all patients had been referred for at least one chest X-ray by their general practitioner or another health care agent. The Department of Radiology at OUH assessed the need for further investigation on the basis of a thoracic X-ray and, if deemed necessary, referred patients for a CT scan within 1–4 days. Patients were contacted by the Center for Lung Cancer immediately after these procedures and given a first appointment for the following day. Participant observation revealed that most patients described being nervous about the results of the CT scan. They did not know what to expect

from the consultation and described being affected by the sign at the door of 'Center for Lung Cancer'. This emotional reaction seemed to impact the appointment, such as asking the same questions more than once, and furthermore having trouble understanding or taking in all the informations given by the health professionals. The co-researcher group analysis of fieldnotes from these observations resulted in the stated need for knowledge about the emotional reactions during the first visit, in order to develop clinical management strategies. The interviews revealed that referral to the Center for Lung Cancer had an immediate impact on all patients' well-being. Referral invoked anxiety and a sense of shock at the prospect of having lung cancer. Patients explained their fear about a diagnosis of lung cancer, with knowing that cancer, especially of the lungs, has a high mortality rate. One patient searched for the word 'lung cancer' on the Internet, whereby he envisaged himself as dying. He subsequently chose to completely avoid Internet-derived information. Equally, everyday life and relations with close family members were affected by the sudden threat of serious illness. In some families, the information caused great emotional upheaval.

I don't even know what to expect, because you don't know anything after all. It might be different, if I had been for several consultations [ . . . ], but we don't expect anything. (P2)

Patients generally expressed concern about the response from their relatives. Concerns were about both the well-being of relatives and relatives' abilities to manage their own fear and grief. Other concerns focused on the way relatives might behave towards the patient and about possible changes in interpersonal relationships. At the same time, patients expressed a need for help to be able to get through the waiting until receiving the final results of the diagnostic investigations.

Well we [pointing to his wife] can talk about it and try to think of something else, but if a patient is sitting alone and has no one to talk to, then a week is a long time. (P13)

### Patients' first appointment: 'What am I here for, doc?'

Seven of the observed patients (out of 20) did not appear to have a clear sense of why they had an appointment at the Center for Lung Cancer when they arrived for their first appointment. Patients could tell from the information letter sent to them in advance or received when arriving at the department, and also from the sign at the door of the department, that their appointment was at the Center for Lung Cancer.

I was told I was going to . . . , what they wrote to me was, investigations [CT scan] show changes, we offer you further diagnostic investigations of changes through the lung cancer package, so I've got it there on paper, in the letter there, yes. (P19)

Half of the patients observed did not bring relatives along to the first appointment. Reasons stated for coming on their own included (1) not wanting to worry relatives unnecessarily, (2) not knowing that the appointment was for the lung cancer fast track diagnostic pathway, or (3) not having anyone to bring.

Semi-structured interviews revealed that the lack of a clear sense of purpose influenced patients' reactions at the first appointment.

It was like a mental stand still, no, well he [the physician] did talk about a spot on the lung, so of course the thoughts were immediately racing, but I just couldn't take it in. (P15)

These patients described being overwhelmed with shock and anxiety about the possibility of a cancer diagnosis which, in turn, meant that they found it difficult to concentrate and remember the information provided by the health professionals. Those patients who seemed to have been well informed of the purpose of the appointment by their general practitioner also expressed being pre-occupied by thoughts of a possible lung cancer diagnosis. The patients mentioned that they could only remember two or three important aspects of the information given at the first visit.

Yes, it's all of it, everything is spinning around for me, I can't really remember the order of things, I cannot remember. (P7)

By contrast health professionals expected patients to be well informed about the purpose of the appointment by the general practitioner or other agent of referral prior to the appointment at the Center for Lung Cancer, as revealed during CTO meetings. Instead, health professionals often had to spend time dealing with patient's feelings of shock and anxiety, in order to establish a good dialogue and provide the necessary information.

### **Management strategies during the diagnostic pathway**

Interviews revealed that after the first appointment at the Center for Lung Cancer, patients expressed not being able to carry out everyday activities, as they had spent their energy in their efforts to complete all the investigations of the diagnostic programme. Patients expressed an increased need for help from their social network due to decreased ability to manage information and investigations. This was explained as a result of the emotional reaction. For example, a patient who had routinely used a computer and phone for many years was suddenly unable to do so while going through the fast track diagnostic pathway, as he explained:

We [the informant and his computer] . . . We don't really get along, so I stopped [using it] completely, both that and also my phone. (P11)

All the patients shared how they used their relatives and closest social network for managing anxiety. The social

network also helped most of the patients to keep track of the preparations for the diagnostic investigations and the information provided by health professionals. Patients also used the network to have someone to share and help manage anxiety while waiting for biopsy results. Hard copy patient information was used as a practical guide for handling one diagnostic investigation at a time and as a shared point of reference between patients and relatives. Furthermore, such patient information was important in planning, keeping an overview, and conducting everyday life to get through the numerous investigations that make up the diagnostic pathway. Interviews revealed that it was important for most of the relatives to be part of both the practicalities and the emotional process, and patients expressed that they relied on being able to involve their relatives.

We have been incredibly pleased about this piece [of patient information]. It says, in black and white, what will happen and as we say, we cannot remember it all. I have followed it slavishly. (P3)

Most patients in the present study had very little experience with the use of computers and other electronic devices; they used such items occasionally or not at all in their conduct of everyday life prior to the diagnostic process. After the first visit at the Center for Lung Cancer, anxiety and a focus on completing the fast track diagnostic process resulted in patients being unable to use a computer or similar devices, even if no demands were made that exceeded their previous IT skills. Patients described an experience of decline in cognitive abilities during the preparation for and progress of the diagnostic investigations.

Most patients revealed during the interviews that they experienced the 4 days of waiting between the completion of the diagnostic investigations and the diagnosis as the worst part of the diagnostic process.

Waiting time, but that's the worst part. (P18)

The patients were managing this waiting time with strategies such as taking one day at the time, trying not to worry in advance, and engaging in everyday activities to distract thinking about the possibility of a cancer diagnosis. Some patients highlighted the importance of having someone to share their thoughts and anxieties with during this time, particularly between the last diagnostic investigation and receiving results.

### **Patients' reflections on and assessment of the quality of the fast track diagnostic pathway**

Prior to the present study, the interdisciplinary group of the CTO, as part of qualifying the diagnostic pathway, had decided that all patients should be assigned a physician responsible for their treatment. The patients were informed in writing of what they could expect from this physician. The

analysis of notes from the co-researchers group highlighted the need for the health professionals to know whether patients experienced this approach as useful. When exploring this issue during interviews, all the patients confirmed that knowing that one person was responsible for the progress of the diagnostic investigations was considered important. All the patients also evaluated the possibility of an easy way to contact a health professional, should problems arise, as positive. Even though patients and relatives considered the possibility of contacting a health professional to be an important option, none of the patients in present study made use of it.

The goal of the fast track diagnostic pathway is to arrive at a diagnosis within 24 calendar days. The fast track pathway therefore entailed a dense diagnostic investigation programme for each patient, which they found difficult to cope with; all expressed difficulties in taking in and handling all the information and found it challenging to relate to new diagnostic investigations on a daily basis. As management strategies, all the patients used hard copy patient information as a schedule planner, sharing it with relatives in order to be able to get through one day at a time. By contrast, electronic information was perceived as not useful. Even though all patients considered the fast track schedule difficult to manage, they also expressed satisfaction with it. In particular, they thought of the fast track as high-quality care, due to the importance of receiving a diagnosis, and hence possible treatment, as soon as possible.

A lot of thoughts that're passing through, [I] think it has been all right, if the answer is ready on Friday, I think it has gone fast. If that's so [if the diagnosis is ready], then I think I'm extremely satisfied. (P19)

The waiting time of approximately four working days from the last biopsy taken until receiving the results of the biopsies and final diagnosis was expressed as particularly difficult. To cope with the anxiety about the result, some patients expressed a need for talking to somebody. Commonly this 'somebody' was a relative or a close friend. All the patients had a person close to them in their social network. The patients who did not have close relatives talked to neighbours or friends.

## Results from the practice research project

The analysis of both field notes and interview transcripts in the co-researchers group resulted in several changes in clinical management strategies for the diagnostic pathway of lung cancer. Members of the co-researcher group (CTO) and other health professionals at the Center for Lung Cancer considered it important that patients during the fast track diagnostic pathway were able to participate in all relevant diagnostic investigations in order to obtain clarification of diagnosis as soon as possible. Not only arriving at a diagnosis

fast was considered important, but also that patients should experience high quality of clinical practice and good quality of life throughout the process.

During the research project, preliminary analyses of observations and interviews were part of the agenda at the monthly CTO meetings. This resulted in discussions of the possibilities and constraints in clinical practice of management strategies to address the following issues:

1. Approximately 1/3 of the patients arriving to the first appointment did not have a clear sense of the purpose of the visit before arrival. For that reason, it was deemed important to schedule time during the first appointment so that a physician and a nurse could inform patients about the purpose and process of the fast track diagnostic pathway for lung cancer. Furthermore, time was scheduled to enable patients to raise any questions.
2. The insight that patients' anxiety about a potential lung cancer diagnosis affected their ability to receive and remember information was considered important. In order to support patients in managing the considerable amount of diverse and anxiety provoking information, more focus was on providing information in different ways. Three informational videos about previous patient's experience and the process of the diagnostic investigations were produced. Patients and relatives could also watch these at home. Oral and written information were given in dialog with the patient and their relatives, including a discussion about individual management strategies of how to participate in all diagnostic investigations. Given the lack of ability or desire to use computers or other devices, clinicians focused on providing the same kind of patient information as given in the videos in hard copy format. It was decided that it was important to produce further patient information in hard copy format in order to support patients in keeping track of and attending the individual diagnostic investigations on a daily basis.
3. Increased attention focused on raising awareness of patients to involve relatives or friends in the process. A smartphone app with patient information and videos of the diagnostic investigations was developed, facilitating the involvement and sharing of information with relatives and friends.
4. Results of the study showed a need for patients to have a person supporting them in order to be able to complete the investigations of the fast track diagnostic pathway. If patients had no relatives or close friends, health professionals in clinical practice should pay particular attention to the ability of these patients to complete the diagnostic investigations in the pathway process. Health professionals should, in the information provided to these patients, pay particular attention to how and when patients can



contact departmental staff, should they feel insecure; in some instances, patients should be offered the possibility to stay overnight at the hospital-based patient hotel between the diagnostic investigations.

## Discussion

The study has a number of strengths. First, participant observation at the department and shared data analysis involving health professionals at the Center for Lung Cancer qualified the research agenda, questions, and analytic process. Second, the co-researcher group confirmed the main themes that resulted from the PI's preliminary analysis of the data from the semi-structured interviews with patients and their relatives. Third, the emerging management strategies that resulted from the involvement of the co-researchers were gradually integrated into daily routines and discussed further during the research process.

### *Limitations of the study*

The semi-structured interviews were conducted after the patients had been through diagnostic investigations and before receiving a diagnosis. At this particular point in the process, most of the patients were still recovering from the shock of their first appointment, still waiting for results, and were reporting high levels of anxiety. If interviews had been conducted after a cancer diagnosis was either confirmed or rejected, the assessment of the fast track diagnostic pathway might have included additional or different aspects. The high level of shock and anxiety was also the basis for the decision not to return transcripts to participants for comment and/or correction.

We were not able to include patients who did not keep their initial appointment at Center for Lung Cancer upon referral. Also not included were patients who decided not to participate in further diagnostic investigations after having received information at their initial appointment at the Center for Lung Cancer. The study did not take into account any differences between patients with and those without a previous cancer diagnosis.

According to a European Respiratory Society (ERS) statement on harmonized standards for lung cancer registration and lung cancer services in Europe, standards differ across the European countries, making for different diagnostic pathway for lung cancer.<sup>28</sup> A harmonized standard is in progress, and in Denmark a fast track programme is implemented. The results of the present study must be understood in this context.

### **Results in relation to other studies**

As far as the authors are aware, few studies have explored patients' perspectives on the pathway of lung cancer

diagnosis. Most studies of pathways of lung cancer diagnosis have focussed on the identification of symptoms and the development of a fast track diagnostic programme. Rankin et al.,<sup>10</sup> however, explored the perspectives of patients and general practitioners during a pathway of lung cancer diagnosis and showed that patients experienced a sense of urgency and uncertainty which resulted in an increased need for psychosocial support.

In contrast to other studies, the research approach of the present study ensured a continuing process, involving multidisciplinary health professionals in the investigation and development of new management strategies in clinical practice. In the study by Walton et al.,<sup>11</sup> data was produced on patients perspectives and experiences with the pathway towards lung cancer diagnosis. Focus in this study was on factors within primary and secondary care that resulted in delay of the diagnosis of lung cancer. One of the conclusions was that fear of a cancer diagnosis and treatment resulted in a delay in help-seeking and attending the general practitioner.

## Conclusion

Results showed that focusing on user perspectives in a practice research design that engages a co-researchers group composed of key health professionals contributes to bringing about knowledge that is useful in developing and implementing additional management strategies in clinical practice. Preliminary analysis of participant observations and semi-structured interviews were presented and evaluated continuously in the co-researchers group which strengthened the clinical application of the study results and thus supported the overall aim of the research project. Results from participant observation and interviews were partly in concordance and partly supplementary, and on no counts conflicting. The participatory approach of critical psychological practice research enabled an ongoing analytic process and continuing reflections on practice development by involving participants from the healthcare setting in the research process. Through collaboration in a practice research design, new questions for investigation, analysis, discussion, and implementation continued to develop throughout the study period. Given the continuous development of the fast track diagnostic pathway and the diagnostic process, there is a future need to regularly explore patients' perspectives to qualify the organizational development of clinical practice.

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