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Understanding the Needs and Perspectives of Patients with Incurable Pulmonary Disease at the End of Life and their Relatives: Protocol of a Qualitative Longitudinal Study

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Abstract

Background: Although patients with COPD sometimes have lesser physical, social, and emotional functioning than those with lung cancer, they rarely receive specialised palliative care support at the end of life. To date, specialised palliative care is not common for patients with non-malignant disease but should be adapted according to the patients' special health-care-related needs with regard to specific illness trajectories. This longitudinal study aims to get a deep insight into the needs and perspectives of patients suffering from progressive lung diseases, i.e. lung cancer and COPD, over a period of time.

Methods: The design of this study is divided into three phases: (1) Qualitative prospective longitudinal study conducting four semi-structured repetitive interviews with a total of 40 patients over a period of 12 month. Data will be analysed content related as well as interpretative using Grounded Theory (2) Four group discussions with bereaved people whose relatives died from COPD or lung cancer. Data will be analysed using documentary method. (3) A one-day multidisciplinary workshop with representatives of different health related fields to derive implications for daily practice.

Discussion: By integrating different diseases, the study contributes to shift the focus of palliative care to patients with non-oncologic diseases. As this is the first German study on this issue, results will enrich the current international discussion with a German perspective.

Keywords: Patient needs; Relatives; Chronic obstructive pulmonary disease (COPD); Lung cancer; Palliative care; End of life care; Qualitative longitudinal study

Background

Diseases of the respiratory system are the second leading cause of death in Europe. In Germany, 43908 patients (5.2% of all deaths) were dying of lung cancer and 26018 patients (3.1% of all deaths) were dying of chronic obstructive lung disease (COPD) in 2011 [1]. Patients with severe COPD and those with advanced non-small-cell lung cancer experience similar health-related quality of life and therefore probably have a similar need for and will benefit equally from palliative care. Although patients with COPD sometimes have lesser physical, social, and emotional functioning than those with lung cancer, they receive less specialised palliative care support at the end of life [2-6]. Moreover, invisibility of breathlessness, especially in COPD, was identified to be a major cause of low access to health care services in general [7].

Despite the fact that the prognosis of a specific disease and the experience of being ill differ among individuals, some common patterns of experiences, symptoms, and needs exist. Strauss und Glaser first described different dying trajectories: expected swift death (because of an accident), expected lingering while dying (typical for cancer patients), and entry-reentry (changes between phases of relatively wellbeing and crisis with hospitalization, and unpredictable death point) [8]. Depending on different diseases and consequent limitations, Lunney et al. defined three trajectories of dying of illness, based on the work of Strauss and Glaser: terminal illness (i.e. as the last phase of incurable cancer diseases), organ failure (which is characteristic for non-malignant diseases like heart failure or chronic obstructive lung disease), and frailty/dementia (as a typical course for old and frail people or dementia) [9]. On the background of an increasing life expectancy and the growing amount of elderly people living with chronic conditions, the focus switched from dying trajectories to illness trajectories. Murray et al. adapted typical illness trajectories for people with progressive chronic illness, originally developed by Lynn and Adamson in 2003: (1) Short period of evident decline (mostly incurable cancer, including lung cancer): steady progression and usually clear terminal phase with decline over a few month, specialised palliative care input available at the beginning of decline, (2) long-term limitations with intermittent serious episodes (e.g. severe respiratory disease, including COPD, heart failure): gradual decline over a period of two to five years, punctuated by episodes of acute deterioration and a sudden, seemingly unexpected death, (3) prolonged dwindling (e.g. frail people, dementia): gradual decline over a period of six to eight years, with limitations in functional capacity, speech or cognition at the onset [10]. Awareness for the COPD disease trajectory has changed during the last decades and is well described now [11]. To date, specialized palliative care is not common for patients with non-malignant disease [12], but should be adapted according to the patients' special health-care-related needs with regard to the specific illness trajectories.

To enable appropriate care for patients at the end of life, this longitudinal study aims to get a deep insight into the needs and perspectives of patients suffering from progressive lung diseases, i.e. lung cancer and COPD, over a period of time.We aim to learn more about strengths and limitations of end of life care from the patients' perspective that not

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necessarily correspond with the professional perspective, i.e. we hope to identify health service related gaps to improve end of life and palliative care. We also aim to identify differences and similarities of care needs regarding two of the above-mentioned trajectories: *short period of evident decline* and *long-term limitations with intermittent serious episodes*. To know more about these characteristic illness trajectories and the associated patients' needs may improve palliative care [10].

The following research questions will be explored:

- What are the major needs of patients with COPD or lung cancer at the end of life (including medical, nursing care or psychosocial needs) and to what extent could these needs be satisfied?
- How do the perspectives and needs change over the last phase of the illness trajectory?
- Which differences, depending on the respective illness (oncological: lung cancer, non-oncological: COPD), can be identified?
- What are the relatives' perspectives and needs and how do they differ from those of the patients?

Definitions

To date, the definitions of the terms *end of life* and *palliative care* as well as *hospice care* and *terminal care* are not yet clear and they are often used interchangeably [13]. Even the official position paper of the European Association for Palliative Care (EAPC), the "White paper on standards and Norms for hospice and palliative care in Europe: part 1 - Recommendations from the European Association for Palliative Care" could not develop consistent recommendations for a common terminology [14].

Historically, palliative care was often the last stage of care, in the terminal phase especially for cancer patients. At least since Temel et al. showed that integration of palliative care early in the therapeutic process can lead to both better quality of life and life prolongation [15], palliative care needs to be understood as a care option in an early phase of an incurable disease. In this study, we therefore define palliative care according to the current definition of the WHO. It emphasizes the importance of symptom management at an early stage of the disease and suggests expanding palliative care beyond terminal illness to become an integral part of care for patients with a severe disease, sometimes starting at the time of diagnosis alongside potentially curative treatment [16]. Consequently, especially patients with non-malignant diseases or frailty, who receive less specialised palliative care, should be included and could benefit from palliative care at any point in the illness trajectory. To define a patient's end of life is difficult, and to date specific indicators for an end-of-life time frame are lacking [13], as this phase mainly depends on the underlying disease and the illness trajectory [17]. As a practical definition, the State-of-the-Science Panel of the National Institutes of Health State-of-the-Science Conference suggests defining end of life according to the evidence of (1) the presence of a progressing chronic disease with pronounced symptoms of functional impairments and (2) the presence of symptoms or impairments resulting from the underlying conditions leading to death, that require care [17].

Methods/Design

The design of this study is divided into three phases, with the main focus on the first phase:

Phase 1: Qualitative prospective longitudinal study with repetitive interviews with patients and their relatives (if preferred by the patients).

Phase 2: Group discussions with relatives of deceased patients to get insight into experiences and needs of bereaved people.

Phase 3: Multidisciplinary workshop to discuss empirical results of the interviews and the group discussions with experts of different fields, and to derive implications for daily practice.

Phase 1: Interviews with patients

Design: To get a broad as well as deep insight into the perspectives and daily needs of patients, we chose a prospective longitudinal design referring to the methodical work of Murray et al. [18,19]. Contrary to qualitative cross-sectional studies, a qualitative longitudinal design provides the chance to gather patients' and relatives' experiences according to the dynamic process of the course of the illness. It also allows to timely analyse change, wherefore a series of qualitative interviews implies the possibility to better understand and describe the daily life and daily needs of seriously ill and dying people.

Participants: This study focusses on patients with a limited life expectancy. Inclusion criteria are: (1) Patients with diagnosed lung cancer in a progressed stage (small cell lung carcinoma or non-small cell lung carcinoma, stage III/IV); no further inclusion criteria are defined for these patients, because the prognosis is usually clear for this advanced stage of illness (see above). (2) Patients with a diagnosed severe COPD (stage III/IV according to GOLD [20]). The prognosis for patients with COPD is uncertain compared to those with lung cancer. Therefore, additional clinical parameters were defined to identify patients with a poor prognosis [21] and to ensure optimal clinical-prognostic comparability of the patient groups: self-reported breathlessness at rest or under slight physical activity, symptomatic heart failure, body mass index <21, and frequent hospitalization because of acute bronchopulmonary infection or breathlessness.

We use a purposive sampling strategy including heterogeneous demographic variables (e.g. sex, age, social status/rural residency) and aim to recruit 40 patients in total (20 patients per disease), which is an appropriate sample size for qualitative studies. According to the experiences of Murray et al. [18] and Pinnock et al. [19], we expect a drop-out rate of about 50-60% because of death, withdrawal from the study or inability to be interviewed (Table 1). Each participant will be interviewed by the same person in order to ensure continuity.

Field access takes place in cooperation with specialized hospitals in Lower Saxony, Germany. Resident physicians address potential study participants during their ambulatory or inpatient hospital stay (e.g. before starting chemotherapy in an outpatient clinic or because of acute crisis intervention) according to the inclusion criteria and provide them with information about the study. If they show general interest in participation, the researchers further inform the participants regarding details of the study.

Data collection: After written informed consent is given, four serial semi-structured interviews with eligible patients will be conducted four-monthly over a period of 12 month (t_0-t_3). Initial interviews will be conducted at the participants preferred place: initially usually during the hospital stayright after recruitment (if the patients are willing and

	Number of participants	**Number of interviews**
Baseline (t_0)	40	40
4 month (t_1)	32	32
8 month (t_2)	24	24
12 month (t_3)	16	16
Interviews in total:		**110**

Table 1: Expected number of patients and interviews over the course of study

able to); succeeding interviews will take place at the patients' home. During our previous end of life research we experienced patients wishing to have their close relatives by their side wherefore a combined interview will be tolerated [19]). During the first interview (t_0), patients will be encouraged to narrate their illness story from the occurrence of first symptoms until present. With these first interviews we aim to gain insight in the individual experiences and needs if being diagnosed and living with a progressive lung disease. The additional interview guide which focuses on care-related issues, is a modified version of the interview guide developed by Pinnock et al. [19].

The interview guide covers the following issues using open-ended questions:

- Daily practical experiences, possible problems, and structural support available,
- Current problems and issues,
- Communication and information needs, and
- Suggestions/wishes.

Although questions are pre-formulated, the interview guide should be used flexible according to the patients' individual thematic priorities and relevancies (full topic guide shown in Table 2).

The follow-up interviews (t_1-t_3) address these issues in order to get insight of treatment and care- and needs-related changes from the patients` perspective. Field notes subsequent to any interview will complete data collection. These memos encompass impressions of the interview situation, the patients' condition, possible disturbances, first hypotheses et cetera.

All interviews will be audiotaped and transcribed verbatim (Table 3).

Data analysis: According to the research question and the design of the study, we aim to develop a theory about the meaning of being ill by systematically considering the illness trajectory, the patients' health related needs and possible gaps in healthcare provision using grounded theory [22,23]. Grounded theory is an appropriate method as it allows both systematically integrating established concepts (e.g. trajectories of dying) in the analysis process, and gaining new insights in the patients' illness experiences by following abductive reasoning [24]. The aim of grounded theory is to "uncover relevant conditions" and "to determine how the actors […] actively respond to this conditions" [22]. Further, a continuous analysis process, as suggested by Glaser and Strauss [23], enables the interviewer to make reference to interim findings during the follow-up interviews. The core activity in the analytical process is the iterated comparison of data in search for similarities and differences

Introduction and opening question

- How do you feel today? Is there anything you want to tell before we start the interview?
- We are interested in individual experiences of people diagnosed with severe lung diseases and aim to contribute to improve care related needs for these patients.
  Invitation to tell: Please tell me what happened, when the disease was diagnosed and what happened in your life since that time. May be you could elaborate on all details that seems relevant for you. Please take as much time as you want.
  Stage direction: While you tell, I will restrain requesting, but listen to your story. I will just make some notes and come back to them later. We have sufficient time. If you need a pause, please tell me.

Additional questions
(as long as they were not yet mentioned, or to deepen the issue)

Daily practical experiences, possible problems, and structural support available

- Please tell me a typical daily routine
- Please tell me a typical weekly routine, including weekend
- Thinking about your daily or weekly routine: where do you need daily support? Do you get this support? What kind of changing do you wish to have? May be you remember some situations you could tell me?

Additional (if required)

- What kind of support do you receive presently?
- How was your present support be arranged? Did you know, what kind of support exist for a person suffering from a severe lung disease? Did anybody help you with that?
- Please think: What kind of further support could help you?

Current problems and issues

Symptoms, discomfort

- What kind of symptoms, discomfort or concomitant effects of the disease or the therapy are currently problematic for you? How are they treated?
- What kind of examination and treatment do you currently receive and what are they for?
- What do you feel, to what extent these examinations and treatment impair your daily life? (How do you perceive this?)

Social contacts

- Please tell me something about your social contacts, your relationship to your friends and family. How were they before you were diagnosed and how are they now? May be something has been changing over time? Please tell me single situations that stick in your mind.

Personal issues

- What personal issues currently bother you? (worries/fears)
- What are you doing to solve these issues? How did you get the idea to do this?
- When you look back: In the context of your disease, what did surprise you most

Communication and information needs

- Do you remember the encounter, when the diagnosis was told you? What happened? How did the following initial clinical interviews rsp. intake interviews with doctors and nurses or other involved personnel after diagnosis?
- With whom do you speak currently about your disease, prognosis and therapies? What happens during these encounters?
- What kind of experiences did you make in facilities that you had to visit during your disease (hospitals, emergencies, rehab clinic, therapy center)? Please tell me about positive and/or negative experiences you have made.

Suggestions/wishes

- Please imagine optimal care: How should this be organized and constituted? Which wishes do you have? What should remain unchanged, what should be changed?

Closing the interview

- Is there anything you want to tell me, may be something that is important to you, and we didn't have talk about?
- How do you feel now? How did you experience the interview?

*This is a translated version of the German original for the purpose of publication.

Table 2: Interview guide for serial interviews with patients*

,	*Comma*: short brake, short pause (maximum one second)
(3)	*Parentheses with a number*: pause, length of time in seconds
|_	*Pipe and underscore*: beginning of an overlapping talk of two or more people; also marker of a rapid turn taking
bad=experience	*Equal sign*: rapid repetition, contraction with no gap of silence
no	*Bold*: accentuated speaking
MAY BE	*Capitals*: loud talk
‘may be’	*Single quotations marks*: quiet talk
noooo	*Attached vowels*: drawl; the more vowels attached, the longer the drawl
becau-	*Hyphen*: break-up
b e c a u s e	*Spaces between the letters*: slow talk
?	*Question mark*: distinct raise of the voice
.	*Point*: Distinct climb down
((laughing))	*Filled double parentheses*: commentary of the transcriptionist to an event, sound, detail, that is not easily transcribed
/	*Slash*: beginning and length of the commented phenomenon
(sure)	*Filled single parentheses*: doubt about the spoken words
( )	*Empty single parentheses*: speech is not to decode; the length of the parentheses shows the length of the speech
//mhm//	*Double slashes*: short reaction of the interviewer; external (third) persons are signed as //EP: mhm//

Table 3: Transcription convention adopted in this study

within and between the two patient groups (COPD and lung cancer). Coding process will be conducted and synthesised mainly by four researchers of different disciplines (sociology, health care research and medicine), and, in addition, discussed and revised within periodical interdisciplinary qualitative research workshops.

Subsequent comparative cross-sectional analysis will contrast the differences and similarities in patients' health related needs. Additionally, for case related longitudinal analysis we will consider the individual illness experiences over the time course.

Analysis will be conducted in three steps, which are carried out concurrently: open, axial, and selective coding. *Open coding* is the process of labelling phenomena (e.g. specific experiences) within the course of illness and end of life care by answering the questions ‘what is this?’ and ‘what does this represent?’. Subsequently, the developed concepts within the phenomenon are categorized (i.e. concepts are grouped). *Axial coding* is the procedure connecting a category (phenomenon) and its subcategories. This means to specify the context of the phenomenon considering the coding paradigm (What are the causal and context conditions related to that phenomenon, the actions and interactional strategies, and their practical consequences?) [22]. *Selective Coding* is the process of selecting the core category and systematically relating it to other categories which develops a Grounded Theory (system of categories) based on the data. The whole analytic process will be accompanied by successive memoing hypotheses and theoretical thoughts. MAXQDA will support data analysis.

Phase 2: Group discussions with relatives

Design: At the final stage of phase 1 (see above) group discussions will be conducted with relatives of recently deceased patients with COPD or lung cancer. We aim to get insights about how they have experienced the last weeks and days before death and what kind of needs they themselves have had during that time and may still have. As people are not always aware of their feelings and needs, a promising way to collect data and understand issues relevant for end of life care involves the method of group discussion for data collection and the documentary method for analysis. Both methods were established by Ralf Bohnsack [25,26] and refer to Karl Mannheim's theory of the specific immanent meaning of a discourse. According to this theory, people with similar biographical experiences are able to understand one another without interpreting what is literally communicated (implicit understanding).

Participants: In this phase of the study, we focus on people who lost a relative to COPD or lung cancer three to 12 month ago. Potential participants will be recruited through interview partners of phase 1 (relatives of deceased participants) or through cooperating hospitals, support groups in Lower Saxony, and the Patientenuniversitaet at Hanover Medical School, Hanover, Germany. After giving informed consent, the potential participants will receive a short questionnaire to collect demographic data. These data will be the basis for group composition (see below).

Data collection: We aim to conduct four group discussions with six to eight participants each. This group size is appropriate for a running discussion [27,28]. Groups will be composed to ensure maximum homogeneity (e.g. illness of the deceased relative, duration of illness, how much time has passed since the death, participants' sex). This is essential for group dynamic and continuous discussion [25] and may motivate participants to “act as co-researchers taking the discussion into new and often unexpected directions” [27].

To encourage discussion at the beginning, the participants will be asked to narrate and then discuss their experiences regarding living with a relative dying of COPD respective lung cancer. Additionally, in the second part of the group discussion, an interview guide, developed from the literature and the results of phase 1, will be used to focus on these topics. Two researchers will moderate each group discussion. The facilitators' role will be nondirective and they will therefore allow and encourage all participants to talk to each other and to frankly discuss the topics. By doing so, the participants will have the opportunity to prioritise, and new relevant aspects may arise. Group methods have proven to be suitable for bereaved people as they are less burdensome than interviews [29].

Group discussions will be audio recorded and transcribed verbatim (Table 2).

Data analysis: While the underlying meaning of communication is often subconscious and therefore non-verbalizable, the documentary method of analysis allows us to analyse these underlying patterns of meaning beyond literal content, using an interpretative approach in addition to the explicit content of the discourse. The interpretative process of analysis requires a two-step approach: the *formulating interpretation* refers to *what* is said, i.e. the relatives' reflected action and thinking; the *reflecting interpretation* refers to *how* and in *what context* the topic is discussed, i.e. the underlying patterns [25]. Analysis will be conducted mainly by two researchers, and additionally discussed and revised within the above mentioned qualitative research workshops.

Phase 3: Expert workshop

Design: As the last step, a multidisciplinary workshop with representatives i.e. in the field of professional medical and nursing associations, health politics, church, patients' organizations, and science will be conducted. The aim of this workshop is to develop strategies in order to specifically improve care for patients with chronic (lung) diseases at their end of life. Targeted issues amongst others are qualification of health care providers, service planning, and organizational and psychosocial support for patients and their relatives.

Participants: Potential participants will be recruited through respective institutions in Lower Saxony, Germany. The expected number of participants is about 15 to 20 including the research workgroup and the national and international cooperation partners.

Data collection: In this one-day workshop, main categories derived from the interviews and focus group discussions will be presented and discussed using interactive techniques (i.e. small group work, meta-plan technique). These techniques are appropriate to motivate a detailed thematic reflection.

Data analysis: The results of the workshop will be transferred into a strategy paper for implications to improve end of life care considering medical, nursing care and social aspects as well as aspects of future structure in end of life and palliative care. The paper will be passed on to policy makers in Lower Saxony and Germany.

Ethics

The study received approval by the ethics committees of the Hanover Medical School (Registration No.: 5896) and the University Medical Centre Goettingen (Registration No.: 19/11/12). Written informed consent will be obtained from all participants. Consent includes the option to withdraw from the study at any time.

Discussion

The necessity and implications of providing adequate palliative care to patients with COPD or lung cancer is nationally and internationally discussed [2,3,5,28,30-32]. Although it is known that progressed COPD and advanced lung cancer bring about similar physical symptoms and psychosocial burden, there is a difference in end of life and palliative care provided for either one or the other disease. In Germany, palliative and end of life care is separated in two coverage areas, primary (general) palliative care and specialized palliative care, which has mostly focused on special needs of patients suffering from progressive malignant diseases, leading to differences in provision of palliative care. Results of this longitudinal study will promote the understanding of patients' and relatives' (resp. the bereaved peoples') care-related needs and wishes, which may change during the course of the respective disease (COPD or lung cancer). As this is the first German study on this issue, results will enrich the current international discussion with a German perspective.

By integrating different diseases, the study contributes to shift the focus of palliative care to patients with non-oncologic diseases. Due to the expert workshop, findings may be rapidly transferred into practice, as the applicability will be discussed with participants working in the field of medical practice as well as stakeholders and policy makers. Thus, the gap between primary and specialized care might be reduced by broadening specialised palliative care as well as deepening primary palliative care in order to enhance end of life care practice for the benefit of patients and their relatives.

Limitations and Strengths

The chosen design (qualitative, prospective longitudinal study) results in a limited time frame for adequate theoretical sampling, which is, according to grounded theory, commonly used for qualitative research. As the analysis process starts right after conducting the first interview, we try to consider first results within the sampling procedure.

The study's greatest strength is the intensity with which the individual experiences of living with a severe lung disease are explored, and the ability of getting an in-depth insight in patients' daily life, health care related needs, expectations, and wishes.

Competing Interests

The authors declare that they have no conflicts of Interest.

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