

Difficulties in Care and Unmet Needs from the Perspective of Patients with Lung Cancer and Stroke – A Qualitative Study in Germany

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Background: Organizing healthcare becomes ever more complex for people with chronic conditions. Additionally, a distinct separation of inpatient and outpatient care makes it even more difficult to provide coordinated and continuous care across sectors in Germany. Our interview study aimed to identify difficulties and unmet needs along the care continuum of patients with lung cancer and stroke in Germany.

Methods: Data were collected by qualitative interviews. A total of 40 participants with lung cancer (n=20) and stroke (n=20) were interviewed in the metropolitan region of Berlin, Germany. Data were interpreted through thematic analysis.

Results: We identified five main categories of difficulties and unmet needs: 1. Bureaucracy, 2. Unmet information needs, 3. Feeling left alone, 4. Difficulties and unmet needs in healthcare institution settings, and 5. Psychological and emotional stress. Results of our study show a high overlap between the experienced difficulties of both groups of patients. These include, in particular, bureaucratic obstacles, the lack of detailed information, poor coordination of care, and the feeling of being alone with the disease and its consequences.

Conclusion: Patients with complex care trajectories seem to have great need for coordinative, social, bureaucratic, and emotional support and these support topics are largely independent of the index disease. Hence, our research suggests that support offers focusing on social and coordination needs do not have to be disease-specific but can rather cover general needs of people with complex care situations.

Keywords: lung cancer, stroke, patient experiences, qualitative research, complex care, unmet needs

Introduction

Demographic change in western countries is leading to an increasing number of people with age-associated chronic conditions, such as cancer and cardiovascular conditions.^{1–4} Care for chronically ill requires integrated, coordinated, and continuous care usually from various health and social care organizations, but most current healthcare systems are single disease-oriented and thus not adequately responsive to patients with complex care needs.^{5,6} In Germany, this circumstance is reinforced by the strict separation of outpatient and inpatient care. When and where patients enter the healthcare system, and how they navigate through the system when longer-term health care is needed, is an individualized and unregulated process.^{7–10} But coordination and continuity in patient care are of great importance for the quality of health



care and an important principle of patient-centered care.¹¹ Patient-centeredness is a concept that has become a major focus in health policy, health care, and health services research worldwide over the last decades.^{12–14} In 2001, the German Advisory Council on the Assessment of Developments in the Healthcare System called on all actors involved in care to ‘achieve efficient care tailored to the individual patient’.¹⁵ Patient-centered care structures and processes should be designed to take into account patient wishes, provide adequate information, provide physical and emotional support, and also involve family. Despite these demands from politics and research, there are still difficulties in healthcare practice to implement patient-centered care structures and a focus on the patients’ individual needs.¹⁶

Navigation services and programs represent a patient-centered approach to help patients navigating the healthcare system with regard to their individual needs in the healthcare continuum.^{17,18} International studies have shown that patient navigation programs can positively influence timely access to care, patient self-efficacy, and satisfaction with care.^{19–21} Also in Germany, patient navigation is gaining increasing attention and various navigation interventions for different patient populations and diseases have been evaluated.^{22,23} Most of them are targeting specific patient groups or diseases and have guideline-based treatment as a primary goal.^{22,23} In CoreNAVI, we aimed to develop a patient-oriented navigation program that is tailored to the German healthcare context addressing patients’ individual needs and preferences across the entire care continuum and healthcare needs.²⁴ In order to be able to develop a patient-oriented navigation program that can specifically reduce difficulties in care and help patients to better navigate the healthcare system, it is important to understand the difficulties and unmet needs that people with complex care trajectories experience across their care continuum. Hence, the aim of the study presented here was to investigate this topic by in-depth-interviews with people with lung cancer and stroke.

We selected stroke and lung cancer as two prototypical chronic diseases with very different progressions of disease and with increasing number of cases in Germany in the upcoming decades.^{2,3} The 12-month prevalence of stroke or chronic stroke-related symptoms is less than 1% in people under 55 years and then rises disproportionately to around 6% in people over 75 years. Due to demographic change and the ageing of the population, an increase in the absolute number of people affected by stroke in the population can be observed, which is likely to continue.²⁵ Stroke is the second most common cause of death in Germany and one of the most common causes of disability in adulthood. Of the survivors, up to 40% have long-term disabilities in their activities of daily living.^{26,27} In 2020, around 22,600 women and 34,100 men were diagnosed with malignant tumors of the lung in Germany. 17,066 women and 27,751 men died from this disease. Lung cancer is one of the most prognostically unfavorable tumors, which becomes evident in a low relative 5-year survival rate of around 25% for women and 19% for men.²⁸ Both diseases require complex care including medical, therapeutic, nursing, psychological and social interventions. On the other hand, they are characterized by distinct trajectories with different impacts on patients’ lives. Lung cancer patients face a low five-year survival rate and may experience rapidly deteriorating health, aggressive treatments, and regular ambulatory care visits.^{28,29} A palliative care situation may arise early after diagnosis. Patients with stroke need intensive in-patient care after the acute event typically followed by a rehabilitation phase and often long-term aftercare in the ambulatory setting. Many patients face long-term consequences in everyday life that require social care and other support.^{30–32}

Difficulties in care and unmet needs for people with these diseases have been explored in various studies. Patients with lung cancer experience unmet needs, eg poor pain-management and feeling unprepared for the recovery process after hospital discharge, and they report physical burdens and more psychological distress than people with other cancer entities.^{33–37} Patients with stroke are often unaware of services that are available for them and that they are eligible to, and they complain about bureaucratic obstacles. Moreover, studies have shown barriers and deficits in risk factor management and the long-term stroke aftercare.^{31,38–40} A majority of this research used quantitative methods, but individual distressing experiences may not be assessed by standardized questionnaire-based exploration.⁴¹ Some qualitative studies from Germany exist that investigated difficulties and unmet needs in lung cancer and stroke patients’ care trajectory. Results of these qualitative studies show that patients with lung cancer were unsatisfied with communication and continuity of care and missed a coordinating person in their care trajectory.^{42,43} A qualitative study with people with stroke identified decision-making around transfer, discharge and rehabilitation as critical junctures for patient-centered care in hospital.⁴⁴ But these studies usually considered specific care situations or patient groups, for example the palliative care or end-of-life context for people with advanced lung cancer or the acute care setting in hospital for stroke patients.^{42,44–46}

Our aim was to identify and achieve a deeper understanding of difficulties and unmet needs faced by patients with lung cancer and stroke to use these results for the development of a patient-oriented navigation program that focusses on patients' experiences with their care. By choosing two very different chronic conditions that require complex care, we intend to investigate whether difficulties and unmet needs in care are disease-specific or shared between diseases from patients' perspective.

Methods and Materials

Study Design

A qualitative interview study was conducted with 20 individuals with lung cancer and 20 individuals with stroke treated in a metropolitan region of Germany. Participants were invited to take part in three in-depth interviews at baseline, after three and six months (lung cancer) and at baseline, after six and 12 months (stroke). In this article we present results from the baseline interviews.

Ethical approval was obtained from the ethics committee of the Charité – Berlin University Medicine (Registration No.: EA2/095/17).

Sample

All patients diagnosed with lung cancer or stroke were potential participants in this study. Further eligibility criteria were being aged 18 years or older, having no mental disorders and being able to communicate in German language. Having comorbidities was no exclusion criteria. To achieve a diverse selection of participants with different experiences in the healthcare system, we used a purposeful sampling strategy based on criteria as gender, age, time since diagnosis, and comorbidities. Sample size ($n=20$ per disease entity) has been selected based on evidence from other longitudinal qualitative interview studies that have shown that such a sample size is feasible and includes enough patients to achieve thematic diversity in analysis.^{47,48} Demographic data were collected via questionnaires.

Recruitment

Potential participants with lung cancer were approached personally by study personnel at the lung cancer outpatient clinic and the psycho-oncological department of the Comprehensive Cancer Center of a university hospital in a metropolitan region of Germany and in self-help groups. Recruitment sites for patients with stroke were neurological units of a university hospital and several rehabilitation clinics. All patients gave their written consent in accordance with the Declaration of Helsinki before taking part in the interview study. The participants' informed consent included publication of pseudonymized quotations.

Data Collection

Baseline interviews were conducted by the first author (HF) from December 2017 until April 2019. The face-to-face interviews were conducted at a place convenient for the patients (at their home, at the lung cancer outpatient clinic, in rehabilitation clinics, in the interviewing researcher's (HF) office). The interviews lasted on average between 60 and 90 minutes and were audio-recorded and transcribed verbatim. Any identifying details were removed, and participants were assigned pseudonyms. A semi-structured interview guide was used to conduct the interviews. It was developed based on an extensive literature review on the experiences of lung cancer and stroke patients and the expertise of members of the NAVICARE research network. This interdisciplinary project group included physicians, health scientists, sociologists, psychologists, anthropologists, and communication scientists. The interview guide was discussed and adapted in regular project meetings. Two pretest interviews were conducted with one lung cancer patient and one stroke patient to check the quality of the guideline.

All participants were asked to talk in detail about their experiences in navigating the healthcare system as a patient with lung cancer or stroke. Questions focused on care-related issues such as daily practical experiences, current problems, information needs, and general experiences with the healthcare system ([Supplementary table 1](#)). The aim was to identify individual care situations, perceived unmet needs and difficulties patients face during their care trajectories.

Analysis

A thematic analysis of the data was conducted.⁴⁹ The guiding theme underlying the analysis was difficulties in care and unmet needs from the patient's perspective. The codes and categories were derived inductively from the data material. In a first step of analysis, all relevant text passages from the first five interviews per disease were marked. All passages that included the guiding theme were classified as relevant. This was done separately by disease. These passages have then been assigned codes in a second step. These codes were discussed with the principle investigator (CH) and revised by consensus. Then, additional five interviews per condition were analyzed using the same procedure and then discussed again with the principle investigator. At this point, it became apparent that there were many similarities in the code trees of both diseases. The researchers (HF, CH) then merged both code trees and created common main categories for both disease entities. Some main categories contain subcategories that can be assigned to both diseases (disease-spanning subcategory) or apply to only one of the diseases (disease-specific subcategory). The common code tree was then used to analyze the remaining interviews. To ensure the quality of the research process and data analysis, the codes and categories were discussed with the principal investigator in data meeting sessions. Furthermore, both the analysis and the data itself were also discussed regularly within a qualitative research group at the Charité – Universitätsmedizin Berlin.

Results

Participants' Demographic Characteristics

Participants with lung cancer (LC) included twelve women and eight men, aged between 44 and 75 years. People with stroke (S) were between 41 and 81 years old. Nine women and eleven men took part. Table 1 presents the demographic characteristics of the study participants.

Table 1 Participants' Sociodemographic Characteristics

	Patients with Lung Cancer (n=20)	Patients with Stroke (n=20)
Gender		
Male	8	11
Female	12	9
Age in years		
41–50	3	3
51–60	8	7
61–70	6	5
> 71	3	5
Time since diagnosis		
1–6 months	5	15
7–12 months	5	1
1–5 years	8	4
> 5 years	2	0
Health insurance status		
Statutory	16	19
Private	4	1
Household size (persons)		
1	5	8
2	11	9
3 or more	4	3

(Continued)

Table 1 (Continued).

	Patients with Lung Cancer (n=20)	Patients with Stroke (n=20)
Education		
Higher education	7	6
Vocational training	12	11
No vocational training	1	2
n/a	0	1
Employment status		
Employee or self-employed	6	4
Pensioner	7	8
Early ret. / disability pens.	5	3
Unemployed	1	3
Housewife	1	0
Current treatment		
Inpatient	0	11
Outpatient	20	9
Co-morbidities		
Yes	12	11
No	8	9

Difficulties in Care and Unmet Needs from Patients' Perspectives

Analysis of the interview data showed that there are perceived difficulties in care and unmet needs that were similar from the perspective of both patient groups. These are presented in the following five main categories that are common for both groups: 1. *Bureaucracy*, 2. *Unmet information needs*, 3. *Feeling left alone*, 4. *Difficulties and unmet needs in healthcare institution settings*, and 5. *Psychological and emotional stress*. Main categories 1–3 have no subcategories, whereas main categories 4 and 5 are divided into subcategories. The subcategories show disease-spanning commonalities between the two diseases, but also reflect disease-specific facets of the main categories.

Bureaucracy

Bureaucracy was a frequent theme in the interviews. Participants complained about difficulties with public authorities and insurance companies. Such obstacles were especially difficult to handle for seriously ill and physically impaired people. Dealing with bureaucracy takes a lot of energy, which some patients do not have during their illness and therefore feel overwhelmed and frustrated.

So, in the beginning I had so much on my plate with this bureaucracy. I didn't have the strength either, so it was probably more and more mountains of paper, yes? And I couldn't respond to letters. So, it wasn't easy. Now I really have, without exaggeration, at least 500 euros in credit with the health insurance company, because I don't get my travel expenses paid. Because I didn't turn in those prescriptions, or whatever they're called, on time. Bureaucratic stuff and you don't get your money. And because I don't hand in a paper, I get the problem, right? (LC, m, 60-70 years, diagnosis 3 years ago)

Because all this paperwork, well that's my weakness anyway with all the paperwork and then this concentration to stay on it. First, I get sick pay, then the insurance pays, then sick pay again and back and forth. Why not have it all in one place? Why do they make it so complicated? (S, m, 50-60 years, diagnosis 6 months ago)

Unmet Information Needs

Education and information about the disease was described by some interviewees as very poor. Some patients lacked in-depth knowledge transfer by treating physicians and thus did not feel well informed about their disease and health status. Time pressure in care institutions was mentioned as a major reason for this lack of education. Brochures containing information were considered

by some study participants to be too general and not relevant enough to their own individual case. Additionally, they felt that information was available but that they would need to know where to seek it and what to request.

You want to know, what do you have? What does this value mean now? What do these classifications of cancer say? What does small cell mean? And so on. So, I would like to know in any case, in order to be able to deal with it. And that's why I needed this stupid internet. Because I had no one to explain it to me, no one. Because the doctors don't have time for that, that's clear to me. ... Well, there are brochures and so on everywhere. You take a look, but it's all information for the general public. This is not information that concerns me, that answers my specific questions or facts. Rather, it is all global. (LC, m, 70-80 years, diagnosis 2 years ago)

So, you probably already have options. You just have to know them or be brave enough and ask for them. (S, m, 50-60 years, diagnosis 6 months ago)

Feeling Left Alone

A prominent theme in the interviews was the feeling of being left alone. Organizing care and navigating the healthcare system alone is particularly burdensome for seriously ill people. Interviewees complained that they had to take care of many things themselves (eg getting and coordinating appointments, obtaining information), which they found very stressful and exhausting. Both help with organizational matters and psychological support (in the meaning of: there is someone there for me and listening to me) are lacking from their point of view.

So, you are left alone a lot, I would say. Because you have the disease and then you just get the appointments and then you just have to see how you get along. You really have to question everything and run after everything, and I find that a bit exhausting. (LC, f, 40-50 years, diagnosis 2 years ago)

I feel let down. I do everything on my own. I had to do everything on my own, all the applications I had to make. For example, I had to apply for unemployment benefits here now, so as not to look stupid. Or collect information, because the money is simply not enough at the back and front. (S, f, 40-50 years, diagnosis 6 months ago)

Difficulties and Unmet Needs in Healthcare Institution Settings

Study participants reported multiple difficulties and unmet needs they experienced in healthcare institution settings. Some of these difficulties were reported by participants of both diseases and some only by participants with lung cancer or stroke, so this main category is divided into disease-specific and disease-spanning subcategories.

Lack of Empathy (Disease-Spanning Subcategory)

Study participants sometimes felt that they are not perceived as human beings in the care system, but only as a number. Some patients missed empathy from providers, especially when the diagnosis was delivered, which was a shock to many interviewees. Some study participants would like to have someone by their side who takes care and have time for them in this difficult situation. But instead, they felt left alone and lost. Interviewees mentioned a lack of personnel and time in care facilities as the main reason for this lack of attention and empathy.

And you just often feel like a number and not like a patient. That would certainly be nicer, if things would work better. Well, you see, they cut, they save and... the human being falls by the wayside. (LC, f, 50-60 years, diagnosis 11.5 years ago)

Well, what can one say about that. There is simply not enough staff to deal with everything, so you feel put in a corner somewhere. So, now you are sick and now you are old. No one explains, I mean, they try in part, but they can't do everything. Yes, and somewhere there is the point where you should perhaps respond more to the people because somewhere and you feel abandoned, somehow left alone. (S, f, 40-50 years, diagnosis 2 months ago)

Lack of Time, Hectic Care (Disease-Spanning Subcategory)

Interviewees feel pressured to "work through" everything as quickly as possible because of the setting (eg crowded waiting rooms, conversations with physicians in the hallway) in which they find themselves for their treatment. Some patients

therefore prepare notes before their visit to the doctor with questions they would like to ask, because they are afraid of forgetting the questions in this hectic setting. One patient complained that there was not even time for a discharge interview with a physician before he was discharged from the hospital, which is mandatory in Germany. The study participant then insisted on a discharge discussion with a physician despite time pressure in the hospital setting.

And then you have the [doctor] again between door and door and that's this hectic thing that you always have the feeling that under pressure you then let everything out like that and 'quickly, quickly' and then you're sitting at home again: 'Ah, I forgot to say that again.' And then you remember it at home - that's why I say I sometimes start making notes beforehand. So that I can work through them when things just go too fast for me. (LC, f, 40-50 years, diagnosis 2 years ago)

They needed the beds in no time. Yes, they took me off the plugs and sent me home. And the last time, with my third [stroke], a nurse discharged me. Where I said, 'You can't discharge me at all. I want to talk to the doctor.' 'Yes, he doesn't have time now.' I said: 'Yes, then you can't discharge me either. That's my right, that I have a discharge talk with a doctor first, and I won't leave here before that.' Yeah, they were a little bit, I don't know, pressed for time or something. But I mean, after all, we have rights, right? (S, m, 50-60 years, diagnosis 6 months ago)

Poor Coordination and Continuity of Care (Disease-Spanning Subcategory)

Study participants experienced that due to the complex nature of the disease (eg, involvement of multiple disciplines for treatment) their care was poorly organized and coordinated sometimes. Above all, the proactive communication of important information regarding the further course of action was missed. Study participants were informed too late or were traveling to appointments that were then cancelled on short notice, which made them dissatisfied with their treatment organization. Continuing treatment in the outpatient setting was also sometimes difficult to organize. Interviewees complained about having to take care of appointments themselves, which was perceived as stressful shortly after discharge from acute care in hospital. Uncertainty about when therapies would start and how arrangements were made, left some participants feeling abandoned.

And finally, they sent me here. By then I was already on the road with a toothbrush. And then they sent me home again in the evening. Therefore, I was supposed to come back the next morning at nine. Then I went home again. Had no money, because my husband had driven me here, because I thought I would stay overnight. Well, I more or less drove without ticket to get home. And then next morning I came back here and then they explained to me that they're not going to operate on me. They've now decided that I'm going to have chemo. I say, 'Why doesn't anybody call me? I come all the way here. Why doesn't anybody call me?' (LC, f, 50-60 years, diagnosis 6 months ago)

But that somehow went wrong with the woman [social worker]. I first have to see how I can get a phone number there. It has to go on somehow. Somehow, I need the therapy, the exercises. That's important. But I don't know, I don't have a phone number or anything. I have to ask the doctor if he has a number and call him. But time is running out. Now I also do not know. With huge effort first ask in the hospital. I can't go there myself, it's too long, too far, too difficult. I don't really know any advice in the sense that I continue to live like this without therapy, which would actually be important. And every day is lost in the process. (S, m, 60-70 years, diagnosis 1 month ago)

Lack of a Fixed Contact Person in the Care Continuum (Disease-Spanning Subcategory)

In the interviews, it was particularly criticized that overall care lacks someone who is continuously approachable in the long term and has an overview of all treatment steps. Here, study participants wanted a constant contact person who has time, listens to them, and answers their questions during the course of the disease. Some patients wished they could get information important to them in one place. That would save them a lot of work and effort.

But you're left alone overall. Well, I don't know, so sports - is there such a thing? Pulmonary exercise, who prescribes it? Stories like that. But it's difficult because of all the different contacts you have. Here a doctor, there a doctor. You don't have a fixed contact person who you can ask questions to or who coordinates everything. And I would like to have something like that. (LC, f, 50-60 years, diagnosis 6 months ago)

That would be helpful: a place where you can get all this information - so you don't have to stand there and do everything on your own. That saves a lot of energy and nerves. (S, f, 40-50 years, diagnosis 6 months ago)

Frequent Change of Personnel (Lung Cancer-Specific Subcategory)

Some of the participants with lung cancer found it difficult to have constantly changing physicians and contact persons in the outpatient clinic where they are treated. This makes it difficult for them to build trust with their providers. In addition, there is also the feeling that physicians are not as well acquainted with the individual's medical history, but only know him or her from the file.

What I absolutely don't like is that they have changing doctors here every time you are here. I would find it much better to have a constant attending physician who basically knows the whole process not only from the file, but also from daily practice. Because a patient is not a dead object, is not a file, but is a living person. (LC, m, 70-80 years, diagnosis 2 years ago)

Lack of Accessibility to Healthcare Providers (Lung Cancer-Specific Subcategory)

Study participants with lung cancer complained about how difficult it is to reach providers outside of an appointment. They perceived this lack of accessibility to providers as a major deficit in care, especially during emergencies.

Well, try calling here. You won't get through. The first time, I think I pressed redial for at least half a day. And the other time I couldn't get through at all. It's simply because they can't answer the phone here because they're understaffed and can't operate the phone. And that, in my opinion, is very bad. Because there are also emergencies. And try to get through here in an emergency. If you go through the central number, it's the same problem, the line is not answered. (LC, m, 70-80 years, diagnosis 2 years ago)

Unclear Responsibilities (Lung Cancer-Specific Subcategory)

Because various care providers are usually involved in the treatment of lung cancer, it was sometimes difficult for study participants to understand who is responsible for them. Hearing conflicting information from different care providers can cause uncertainty, despair, and overburden in patients.

In the beginning, it was also difficult to understand who was actually responsible for you. I was once asked, 'Who is your doctor?' And I say, 'I don't know who my doctor is or if there is such a thing.' Because you're treated in different disciplines, right? (LC, m, 40-50 years, diagnosis 2.5 years ago)

I would like to hear from those responsible, from those who know about it. They should tell me what I should do. I can't know. And one says, 'Don't take it!' The other says, 'Take, by all means!' They also insist, they really fight each other. And I'm supposed to decide. How is this supposed to work? (LC, m, 60-70 years, diagnosis 3 years ago)

Transport to Therapy Appointments (Lung Cancer-Specific Subcategory)

Interviewees with lung cancer reported problems with the transport to appointments. In Germany, cancer patients can arrange a transport service to chemotherapy appointments. Study participants who are dependent on a transport service cannot accept appointments at short notice because they cannot get this transport organized in such a short time. This sometimes clashes with the short notice scheduling of appointments with providers.

Then the doctor: 'Yes, you have to be here first thing in the morning.' I say, 'How can that be done? I don't have a car here.' The transport, you must order it a few days in advance, the ambulance transport. Not overnight. (LC, m, 70-80 years, diagnosis 3 months ago)

Psychological and Emotional Stress

Interviewees of both diseases reported feeling psychological and emotional stress during the course of the disease. Some reasons for these fears and stress were similar for both patient groups, but some were reported only by participants with lung cancer or stroke, so this main category is divided into disease-specific and disease-spanning subcategories.

Uncertainties and Fears Due to Illness (Disease-Spanning Subcategory)

Study participants of both diseases felt psychological and emotional stress due to the illness and death in front of their eyes. Especially the experience of uncertainty after receiving the diagnosis was hard to handle for them: living in fear and not knowing if there is a cure or not or will there a further stroke occur or not.

I was shot about that because I was so in the dark. What is really going on here now? How long am I allowed to live now? And how long not? Uncertainty has been driving me around for a long time. Because I didn't get any information. Whether I can start ordering a coffin now or not? (LC, m, 50-60 years, diagnosis 2 years ago)

Then, of course, very big fears have built up along with it. Where with every little twinge in me: 'Oh, stroke again'. Always phone nearby. 'Do I have to call the fire department now; don't I have to call them? Is it a stroke now or is it just a false alarm or am I just imagining it?' So, really had such horror scenarios in my head. (S, m, 50-60 years, diagnosis 6 months ago)

Difficulties in Getting Psychological Support (Lung Cancer-Specific Subcategory)

Some interviewees with lung cancer utilized psycho-oncological support to cope with their emotional stress. These study participants considered it helpful to receive professional advice. Other participants were so weakened by the disease that they were physically unable to take advantage of this psycho-oncological support. Finding psychological support outside of a treatment center's psycho-oncology service has been difficult for patients because, despite an intensive search, no psychologist with available appointments could be found on short notice.

There were other, more important things. I could not move my arms. I couldn't see. And things like that, those were bad things. Then also these side effects and so on. So, psychologists, I didn't even think about that. It was out of the question. Everything else was so important, psychologist was a luxury gift. But it would be good, I think so. So, there is a necessity, but other things are more necessary. (LC, m, 60-70 years, diagnosis 3 years ago)

I looked around elsewhere and asked for therapists. For example, after the coma I had an extreme need, because I had to get a lot of things straight first. And that was really hard. And I know that we are in a pretty shitty position in the psychological field. Excuse me if I put it so clearly. So, you don't get any appointments. And I searched really hard for a while. I canvassed them all, called them, asked for appointments. (LC, f, 40-50 years, diagnosis 9 years ago)

Treatment Time Pressure (Lung Cancer-Specific Subcategory)

Some study participants with lung cancer feel pressed for time because from their point of view treatment steps must be taken very quickly. Sometimes they do not have the time to think about it or to consider what is actually happening to them. Especially directly after the diagnosis, this time pressure is perceived as stressful. In addition, the treatment of lung cancer is usually very complex, and many treatment steps are necessary, so that the treatment itself combined with many different appointments with different specialists can be perceived as very exhausting and stressful.

And I can't do it like I did with the intervertebral disc or something: 'I'll think about it for another two months and then look again later.' But I **have to** and I have to **now**. And of course, I found that quite stressful or burdensome. So, you always have this pressure. But that is something that comes with the disease. (LC, m, 40-50 years, diagnosis 2.5 years ago)

I used to have five doctor's appointments every day, right? I'd be out of the house here at eight, and I'd be back by seven. That's incredible, right? All kinds of doctors and every day. I had no break, no time for myself. It was terrible. (LC, m, 60-70 years, diagnosis 3 years ago)

Financial Worries Due to Illness (Stroke-Specific Subcategory)

In one case, the anxiety and stress were specifically related to the financial situation after the stroke. The study participant lost her job after the stroke and it took a long time to apply for unemployment benefits, so the patient had great financial difficulties, which caused stress and anxiety in her.

These financial fears, existential fears, they wear you down. And in January it even went so far, because the money was not enough from sick pay, that I had to open an overdraft facility, which is now fully exhausted. And should there now nothing arise with the pension insurance agency because of the financials, or should the job center not come out of the fold, then I cannot pay my rent in March. That gives me a headache and sleepless nights! (S, f, 40-50 years, diagnosis 6 months ago)

Discussion

Our interview study aimed to identify difficulties and unmet needs in the care trajectory of patients with lung cancer and stroke. Five main challenges and domains of unmet needs could be identified: Bureaucratic obstacles, unmet information needs, feeling left alone, difficulties in healthcare institution settings, and emotional distress. The results of our study show that there are many common difficulties that both groups of patients experience during their care trajectory. These include, in particular, bureaucratic obstacles, the lack of detailed information and the feeling of being alone with the disease and its consequences. Additionally, poor coordination and continuity in care as well as the lack of a contact person that feels responsible was criticized by interviewees of both diseases.

Studies investigating these diseases individually have previously shown that stroke and lung cancer patients experience difficulties in their care: Lung cancer patients experience difficulties for instance regarding hospital discharge or the take-up of supporting services^{33,36} and they report physical and emotional burden and more psychological distress compared to people with other cancers.^{50,51} Stroke patients are often unaware of the benefits and services available to them and furthermore reported struggling with bureaucratic procedures related to obtaining health and social services.^{31,52,53}

Interestingly, our qualitative results showed a high overlap between described unmet needs for both, apparently very different, diseases.

Most of the research on this topic used quantitative methods, but individual distressing experiences may not be assessed by standardized questionnaire-based exploration.⁴¹ Only few qualitative studies exist for the German healthcare context. For example, Villalobos et al (2018) reported insufficient communication and a lack of continuity in care as main barriers from lung cancer patients' perspective.⁴² Another qualitative study from Germany showed that people with lung cancer felt uncertain about their role in the coordination of care across healthcare sectors and that they wished to have a coordinator in the overall treatment process.⁴³ This is in line with our study results. Patients with lung cancer reported that it was difficult to understand who is responsible for them. The fact that different physicians and therapists were often involved in providing care led to uncertainty among those affected about who was responsible and was exacerbated by the fragmentation of the German healthcare system. Continuing treatment - especially in the outpatient setting - was sometimes difficult to organize. The wish was expressed for a long-term contact person who has an overview of the overall care. Both lung cancer and stroke patients also criticized the fact that the organization of outpatient care is very stressful and exhausting for them. Results from Busetto et al (2020) show that post-procedure communication after thrombectomy, the patients' stay at the stroke unit and decision-making around transfer, discharge and rehabilitation were identified as critical junctures for patient-centered care in hospital.⁴⁴

These studies focused on specific care situations, for example palliative care or end-of-life context for people with advanced lung cancer or the hospital care setting for stroke patients. With our open procedure of including patients at different points of their care path and in different care settings we were able to capture a wide range of difficulties that are experienced by patients with different chronic diseases that require complex care (lung cancer and stroke). Interestingly, similar difficulties and unmet needs emerged in the interviews between diseases and settings. Already during the analysis of the interviews, it became obvious that the similarities regarding the difficulties and perceived unmet needs strongly overlap which includes topics like coordination of care, communication with providers and the need for emotional support. This suggests that these topics appear to be overarching difficulties and unmet needs in chronically ill people. Only few other studies investigated the perspectives of patient groups with multiple chronic diseases in Germany. Vennedey et al (2020) included participants with at least one chronic condition (eg, mental health problems, oncological, metabolic, and neurological diseases) in their qualitative study to investigate facilitators and barriers to patient-centered care. Barriers experienced by participants mostly related to disrupted treatment processes during which the patients are

left on their own or a lack of coordination of care. Patients also complained about overburdened staff members in healthcare institutions and that appointments were cancelled at short notice in hospitals.⁶

These findings are in line with our results. Both lung cancer and stroke patients in our study reported difficulties such as excessive bureaucracy, lack of continuity of care or feeling left alone in the healthcare system. This is an important finding to be considered in the discussion on how to better support patients along their care trajectory. From our results, we suggest that there are difficulties and unmet needs that are disease-independent and hence new support services may be developed in a disease-spanning way to address the reported difficulties. Although many support offers already exist in Germany, they are not centrally coordinated and often unknown by patients and providers.⁵⁴

To overcome the shortcomings in the fragmented German healthcare system and support patients to get the help they need, navigation models are currently tested and evaluated in Germany.^{22,23,55} Most of them are guideline-oriented rather than patient-oriented and investigate disease-specific clinical impacts of the navigation like recurrent events or re-hospitalizations. The question that arises from our findings is whether there should not be overarching navigation services to dismantle difficulties in care that can be used regardless of a specific disease, for example, when it comes to need of bureaucratic or emotional support. Other studies also suggest that there appears to be a lack of a coordinating contact person, especially for people with complex care situations.⁴² Such a person could also help to better manage the unregulated access to outpatient care for individual patients and help those affected to better navigate the fragmented German healthcare system. To date, there has been no nationwide navigation model in Germany, but mainly project-based models that vary in their aims and that are used in specific regions or in cooperation with individual health insurance companies. The NAVICARE research project developed a patient-oriented navigation model that has been tested in the metropolitan area of Berlin and in rural areas of Brandenburg.²⁴ At the center of our model was a social worker as navigator, who - depending on the individual needs of the patients - mainly focus on bureaucratic, organizational and coordinating aspects in the outpatient care sector, which is characterized by strong fragmentation. Results on the effectiveness of this navigation intervention have not yet been published.

Limitations

We only considered people from one metropolitan region for our interview study. Experiences with healthcare of patients in rural areas are likely different due to an often low density of support offers. Furthermore, we recruited people with lung cancer mainly in one university outpatient clinic where the principle of personnel rotation is carried out with doctors due to educational reasons. This could be an explanation for the fact that changing personnel was an important topic in the interviews. Lung cancer patients perceived the frequent change of staff very negatively. This might be different if treatment was provided by an oncologist in other ambulatory care settings. The research question of difficulties and unmet needs in care from the patients' perspective represents a broad range of topics. A certain prioritization of key topics cannot be avoided when analyzing and interpreting qualitative data. The prioritization was guided by the study's overarching goal of gaining insights into the areas of care in which patients experience difficulties and have particularly strong support needs that can be used to develop a patient navigation model.

Strengths

We were able to include patients of two very different chronic diseases in our study. This way we were able to capture a broad range of experiences and to compare them with each other. Interviewees had diverse backgrounds in terms of disease and treatment experiences, including acute and chronic disease care.

Conclusion

Our research provides important findings about specific difficulties that people with lung cancer and stroke experience in their care trajectory in Germany. It should be emphasized that very similar difficulties and unmet needs were reported (eg bureaucratic and organizational obstacles) despite the very different courses and impact on daily life of these two chronic diseases. Nowadays, very specific, disease-related support services are often implemented. Our findings, on the other hand, indicate that there should be placed greater emphasis on the provision of disease-spanning support offers that focus

on general issues and difficulties faced by people with complex care trajectories. Therefore, we developed a patient-oriented navigation program to dismantle such disease-spanning difficulties.²⁴

Abbreviations

LC, lung cancer; S, stroke.

Data Sharing Statement

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Consent to Participate

Ethical approval was obtained from the ethics committee of the Charité – Berlin University Medicine (Registration No.: EA2/095/17). All patients gave their written consent in accordance with the Declaration of Helsinki before taking part in the interview study. All methods were performed in accordance with relevant guidelines and regulations.

Acknowledgments

We would like to thank all patients who participated in the interview study. We also thank Anke Desch, Marion Grimberg, Lea Rebecca Minow and Fabienne Janisch for their work as student assistants in the project.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

The present work is part of the research consortium “NAVICARE – Patient-oriented health services research”. NAVICARE is funded by the German Ministry of Education and Research (01GY1601). Funded by the Brandenburg Medical School publication fund supported by the Ministry of Science, Research and Cultural Affairs of the State of Brandenburg.

Disclosure

The authors declare that they have no competing interests.

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