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Fugemann, H.; Goerling, U.; Godde, K.; Desch, A.K.; Muller-Nordhorn, J.; Mauckisch, V.; ...
; Holmberg, C.

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BMJ Open What do people with lung cancer and stroke expect from patient navigation? A qualitative study in Germany

Hella Fügemann ^{1,2} Ute Goerling,³ Kathrin Gödde,¹ Anke Kristin Desch,^{1,2} Jacqueline Müller-Nordhorn,⁴ Verena Mauckisch,¹ Bob Siegerink,⁵ Nina Rieckmann,¹ Christine Holmberg ^{1,2,6}

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ABSTRACT

Objective This qualitative study investigated patients' needs and wishes in relation to patient navigation.

Design A qualitative interview study was conducted. Participants were invited to take part in three in-depth interviews over a period of 6–12 months. Thematic analysis was used.

Setting Interviewees were sought in the Berlin metropolitan area of Germany in academic university hospitals, in rehabilitation clinics and through self-help organisations.

Participants The sample consisted of individuals diagnosed with lung cancer (n=20) or stroke (n=20).

Results From the perspective of interviewees, patient navigators should function as consistent contact persons, present during the whole care trajectory. Their role would be to guide patients through an often confusing healthcare landscape, offering practical, advisory and emotional assistance corresponding to patients' needs. The study shows that—independent of the disease—participants had similar expectations and needs regarding support from navigators.

Conclusion For chronic and complex diseases—as is the case with lung cancer and stroke—it appears less important for navigators to fulfil disease-specific tasks. Rather, they should ensure that patients' more general needs, in relation to social, practical and emotional support, are met in a way that suits their individual wishes. Following these results, patient navigation programmes might be designed to include generic elements, which should then be adapted to the infrastructure in a particular healthcare region and to the particularities of a specific healthcare system.

INTRODUCTION

The demographic development towards an ageing society represents one of the greatest challenges to healthcare systems in industrialised countries worldwide, including Germany. Age-related diseases such as cancer and stroke have either stagnated at high levels or will continue to rise in the coming decades.^{1–4} Additionally, because medicine is continuously differentiating into further specialities, healthcare for older adults and

Strengths and limitations of this study

- Interviewees had diverse backgrounds in terms of disease and treatment experiences, including acute and chronic disease care.
- The implementation of in-depth interviews over time permits a comprehensive and multifaceted collection of knowledge regarding the expectations and support needs of patients in relation to navigation.
- The sample comprises only participants from a single metropolitan region in Germany—support needs and expectations regarding patient navigation may be different in rural areas or indeed elsewhere in the world.

people with chronic diseases is becoming ever more complex and it is becoming more difficult to ensure coordinated, consistent care across all sectors.^{5–8} This trend is exacerbated by the German healthcare system that traditionally has a distinct separation of outpatient and inpatient care, with no coordination along a patient's care trajectory between these different care sectors.^{6 8–10}

These challenges have led to the development of patient navigation programmes in several countries.^{11–15} Patient navigation has been suggested as a model for care delivery for complex and chronic health conditions in particular, to guide patients as they handle increasingly complex healthcare systems or treatment regimens.^{11 14} The model of patient navigation was originally developed in the USA to improve and expedite access to healthcare for vulnerable populations and minorities after an abnormal screening finding or a cancer diagnosis.¹⁶ Since then, many patient navigation models, which are quite diverse with regard to navigator characteristics and programme structure, have been developed for different patient populations.¹⁷ Common navigation tasks include the provision of information, guidance, advocacy, emotional



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For numbered affiliations see end of article.

Correspondence to

Mrs Hella Fügemann;
hella.fuegemann@charite.de

and practical support, as well as education and empowerment.^{11 18–20} Patient navigation aims to support patients to organise their healthcare according to their individual needs and to optimise their care trajectory.^{13 14 21–25}

Patient navigation programmes may be particularly well suited to overcoming the shortcomings in the German system. In order to investigate such an assumption, we carried out a qualitative interview study to investigate patients' needs in relation to navigation programmes. To be able to assess needs across a spectrum of diseases that are particularly relevant in older age groups, we selected lung cancer (LC) and stroke. We used these two diseases as prototypical examples of age-associated chronic diseases with very different progressions; additionally, the number of cases for both diseases in Germany is high.³ Both LC and stroke are characterised by often very complex healthcare needs and we therefore view them as particularly suitable for patient navigation. The two diseases are, furthermore, characterised by different trajectories with very different impacts on patients' lives.^{26 27} This ensures that a broad range of diverse needs can be captured when developing a navigation model for Germany. Patients with LC face a low 5-year survival rate and may experience rapidly deteriorating health with aggressive treatments and regular visits during ambulatory care.^{25 28} A palliative care situation may arise early after diagnosis. In contrast, patients who have experienced a stroke often face long-term consequences in everyday life, including new social care and support needs, while co-morbidities are common.^{29 30} In addition to direct medical care, studies show that patients with age-associated chronic diseases often have a further need for social work and administrative and informational support when handling their new health and living situation.^{31–33}

In this article, we present patients' views on navigation, with the aim of understanding the kinds of support people with LC and stroke want from navigators, and what requirements such a care model should fulfil from their point of view.

METHODS

Study design

A longitudinal, qualitative interview study was conducted in the metropolitan region of Berlin, Germany. Participants were invited to take part in three in-depth interviews: at baseline, after 3 months and after 6 months for patients with LC, and at baseline, after 6 months and after 12 months for patients with stroke. We chose shorter intervals between follow-up interviews with participants with LC because they were expected to experience a more rapid deterioration in health than participants with stroke. Patient eligibility criteria included being aged 18 years or older, having a diagnosis of LC or stroke, having sufficient command of the German language, and being physically and mentally willing and able to complete the interviews. Purposeful sampling was used to achieve a diverse sample of patients who were likely to have

different experiences in the healthcare system. Selection was based on age, gender, time since diagnosis, comorbidities and selected treatments. Demographic variables were collected via a self-report questionnaire before each interview. Sixteen persons with LC (of 20 at baseline) and 18 persons with stroke (of 20 at baseline) also completed the first follow-up interview (n=34). We present results from the baseline and first follow-up interviews, because these were the two interviews (out of three) when participants had the possibility to express their own ideas and wishes for a patient navigation programme.

Recruitment

Patients with LC were recruited at the LC outpatient clinic of a large academic university hospital in the Berlin metropolitan region and through self-help groups and the psycho-oncological department of the comprehensive cancer centre of the university hospital between December 2017 and May 2019. Patients with stroke were recruited from neurological units of the university hospital and in different rehabilitation clinics between January 2018 and October 2018. Potential participants were approached personally by study personnel. All participants provided written informed consent before participating in the interview study.

Data collection

Baseline interviews were conducted from December 2017 to April 2019, and the two follow-up interviews were completed by November 2019. These face-to-face interviews were conducted in German and at a place convenient for the patients (at their home, at the LC outpatient clinic, in rehabilitation clinics, in the researcher's office). The interviews lasted on average between 60 and 90 min, and were audiorecorded and transcribed verbatim. Any identifying details were removed and participants were assigned pseudonyms. The in-depth interviews at baseline and first follow-up had a section focusing on expectations, suggestions and support needs regarding patient navigation. In the baseline interviews, study participants were asked to describe their own ideas of navigation and navigators, if possible without any previous explanation of the concept of navigation. In the first follow-up interviews, questions focused on specific aspects of navigation, that is, the mode and structure of interactions with navigators, the tasks of navigators, and participants' ideas of the target groups for navigation. We used primarily open-ended questions in the interviews so that participants had the opportunity to speak freely and openly about what was important to them in their care, including positive and negative experiences with healthcare. Interview questions from the baseline and first follow-up interviews regarding patient navigation are presented in online supplemental table 1.

Analysis

To capture study participants' views on navigation, most importantly on the kind of support they were looking

for from a navigator, we used a descriptive qualitative approach.^{34–36} In a first step, we identified all answers to the following questions from the interview guide that asked about navigation: what do participants imagine is meant by the term navigator, what kind of tasks should navigators fulfil and how should interactions take place from their point of view (see also online supplemental table 1). We then coded the data corpus according to deductive codes: Patients' definition of navigators, tasks of navigators, communication and interaction modes, and target groups.^{11 18} These predefined codes were chosen to fill core components of the navigation programme with content based on patients' wishes and ideas (see online supplemental table 2). Then the text passages under each code were used for inductive, thematic analysis. This analysis was done separately for both patient groups and then compared with each other in order to condense content of the deductive codes. Similarities in content across codes between both data sets became apparent. After finalising the thematic content of each deductive code, components of a navigation model were defined in line with the inductive thematic analysis.^{37 38} In this process, initial deductive codes were renamed when necessary to align them with interviewees' views and wishes (see online supplemental table 2). The entire analysis process was conducted by HF and CH through regular data session meetings to discuss the data material and determination of codes and categories. Additionally, the analysis process and the data itself were presented and discussed regularly within a qualitative research group at the Charité-Universitätsmedizin Berlin to ensure grounding of analysis in the data throughout. In these research meetings, coding was scrutinised by reading the coded text passages and discussing the associated code and its fitness.

Patient and public involvement

Representatives of self-help groups (LC and stroke) were regularly invited to participate in our project meetings to consult on the research questions and to identify existing resources and gaps in the healthcare system.

RESULTS

Participants' demographic characteristics

The sample consisted of 20 patients with LC and 20 patients with stroke at baseline (n=40). Individuals with LC included 12 women and 8 men. For the baseline survey, patients were between 44 and 75 years old. Patients with stroke (S) included 9 women and 11 men, and at the time of the first interview they were between 41 and 81 years old. The demographic characteristics of the participants are summarised in tables 1 and 2. Reasons for drop-out after baseline were severe progression of the disease (LC=3; S=1) or the death of patients (LC=1; S=1).

Expectations and support needs

The results pertaining to the interviewed patients' ideas and support needs regarding navigators were similar for

Table 1 Participants' sociodemographic characteristics at baseline interview (lung cancer)

	Patients with lung cancer (n=20)
Gender	
Male	8
Female	12
Age in years	
41–50	3
51–60	8
61–70	6
71–80	3
Time since diagnosis	
1–6 months	5
7–12 months	5
1–2 years	4
2–5 years	4
>5 years	2
Health insurance status	
Statutory	16
Private	4
Marital status	
Single	1
Married/living with partner	15
Divorced	3
Widowed	1
Household size (persons)	
1	5
2	11
3	4
Education	
University degree	4
Polytechnic degree	3
Training	12
No vocational training	1
Employment status	
Employee or official	5
Pensioner	7
Early retirement/disability pension	5
Unemployed	1
Self-employed	1
Housewife	1
Current treatment	
Inpatient	0
Outpatient	20
Comorbidities	
Yes	12
No	8

**Table 2** Participants' sociodemographic characteristics at baseline interview (stroke)

	Patients with stroke (n=20)
Gender	
Male	11
Female	9
Age in years	
41–50	3
51–60	7
61–70	5
71–80	4
81–90	1
Time since diagnosis	
1–6 months	15
7–12 months	1
1–3 years	4
Health insurance status	
Statutory	19
Private	1
Marital status	
Single	3
Married/living with partner	7
Married but separated	2
Divorced	5
Widowed	2
n/a	1
Household size (persons)	
1	8
2	9
3	2
4	1
Education	
University degree	2
Polytechnic degree	4
Training	11
No vocational training	2
n/a	1
Employment status	
Employee or official	4
Pensioner	8
Early retirement/disability pension	3
Unemployed	3
n/a	2
Current treatment	
Inpatient	11
Outpatient	9
Comorbidities	
Yes	11
No	9

n/a, not available.

both diseases. Overarching categories were *patients with support needs*, *tasks and support needs*, and *role of navigators*. The deductive code *target groups* was changed to the overarching category *patients with support needs* because inductive thematic analysis showed who—from study participants' point of view—urgently needed help and support from navigators. This included primarily older individuals and/or those with impairments, but also patients without a social network, and patients' relatives or informal caregivers. The code *tasks of navigators* was renamed to the overarching category *tasks and support needs* because the thematic analysis showed that from the patients' perspective these two things belong together thematically. The overarching category *tasks and support needs* refers to all combined desires and expectations that the interviewed patients could imagine as supportive; for example, the wish for information, for help in coordinating their care as well as for bureaucratic issues. Patients could also envisage pursuing leisure activities together with the navigator. Emotional support in the form of 'having someone to talk to' was also mentioned. After the thematic analysis, the deductive codes *patients' definition of navigators* and *communication and interaction modes* were merged into one overarching category named *role of navigators*. This overarching category describes how and where navigators could be best integrated into the healthcare structure. Above all, patients wished for navigators to be available as a consistent, long-term contact person, that they should not have to travel long distances or make additional efforts to meet their navigator, and that there would be no conflict with other participating professional caregivers. Interview quotes illustrating each particular theme and category can be found in [tables 3–5](#).

Patients with support needs

When asked who, in their view, had a more urgent need for a navigator, patients mentioned various groups, including older people and/or individuals with impairments, but also patients without a social network and patients' relatives or informal caregivers. They tended to outline fewer of their own experiences, and rather referred to other patients whom they had observed during the course of their disease. The interviewed patients agreed that the use of a navigator might be valuable, though not all of them would use a navigator themselves; for example, because they felt adequately cared for within their own social network.

Patients who are elderly or have physical/cognitive impairments

According to the interviewees, older patients, but also persons who, for example, have impaired mobility or cognitive limitations after a stroke, would have a particularly urgent need for a navigator.

Patients without a social network

The interviews show that patients without a supportive social network appear to have a particularly difficult time organising their care; either because they are

Table 3 Characteristic quotations from the interviews illustrating the overarching category *patients with support needs*

Overarching category	Codes	Quotes
Patients with support needs	Patients who are elderly or have physical/cognitive impairments	<p><i>Because many people who are older are discharged from the hospital and no one worries about whether they are eating, or cared for, right? So, all of that gets lost somewhere.</i> (LC, f, 50–60 years, diagnosis more than 10 years ago)</p> <p><i>For example, those individuals sitting in a wheelchair or who actually have memory difficulties.</i> (S, m, 50–60 years, diagnosis less than 1 year ago)</p>
	Patients without a social network	<p><i>Exactly. I do that all by myself. I had to do everything alone. All of the applications that I had to make. For example, I should now have to apply for unemployment money here, so as not to be caught short. That is nerve-racking for me, to tell the truth. And no one provides the information on their own, what you can apply for, what is available to you.</i> (S, f, 40–50 years, diagnosis less than 1 year ago)</p> <p><i>First, I need to see how I can even get a phone number. Life needs to keep going somehow. I need to get the therapy somehow, that is surely important. But I don't know, I have no phone number or anything. It is difficult now. I am more or less at home now for the first day. That is, without help I am a bit beat. I am more or less reliant on family or the hospital now. That is my external world. Otherwise there is no one around who takes care of things and worries about me.</i> (S, m, 60–70 years, diagnosis less than 1 year ago)</p> <p><i>For example, for single persons. Then such a thing would be absolutely recommendable. That there is some reaching out in support. Many people in this case are entirely alone. And I think that is independent of age.</i> (LC, m, 50–60 years, diagnosis less than 1 year ago)</p>
	Relatives and informal caregivers	<p><i>But that anyway, maybe someone will also include the relatives. Perhaps also make a phone call once in a while.</i> (LC, f, 60–70 years, diagnosis less than 5 years ago)</p> <p><i>No, he [the husband] was not at all in a position to manage. He did not know at all what he should attend to.</i> (S, f, 60–70 years, diagnosis less than 1 year ago)</p>
No needs	<p><i>I don't know at the moment what someone external could do for me. Because what everyone can do is allocated.</i> (LC, f, 60–70 years, diagnosis less than 1 year ago)</p> <p><i>But otherwise, taking me by the hand and such, no. Until now I have everything together, I think. After all, I didn't fall on my head. In that sense, that someone is constantly telling me what to do, I am not in favour of that.</i> (LC, m, 70–80 years, diagnosis less than 1 year ago)</p> <p><i>I do not need it, thank God, I do not need it. Those people who really rely on it, they should use it then.</i> (S, f, 60–70 years, diagnosis less than 1 year ago)</p>	

overwhelmed by the number of tasks they find themselves presented with, or lack the necessary knowledge, resources or competencies to arrange for their care. Study participants described this based on both their own experiences as well as on observations of other patients. Patients with support from their social network perceived less need for support from professional navigators for themselves.

Relatives and informal caregivers

The offer of support by navigators should, from the interviewees' point of view, also be available to relatives and informal caregivers. Patients had the feeling that, in the current system, relatives and informal caregivers have too little support and are not adequately integrated into the caregiving procedure. Interviewees were aware of the burden that the disease presents for relatives and informal caregivers and that they can feel partially helpless.

No needs

The interviews show that not all of the study participants had a need for or would like a navigator. The reasons for this were, for example, that all tasks had already been assigned, that the interviewees would rather control the

situation themselves, or that they thought other patients would need a navigator more than they did.

Tasks and support needs

This category refers to the wishes for and expectations of support that participants could imagine. In the interviews, five topics could be identified as particularly important to the participants: the wish for consultation and information, the need for help with organising and coordinating care, support with bureaucratic and administrative obstacles, help with housekeeping and leisure activities, and the wish for emotional support.

Consultation and information

The study participants clearly placed an emphasis on consultations and the relaying of information—whether very generally pointing out opportunities for support or specifying consultations on particular topics such as social issues, social regulations and financial topics, but also, for example, related to sports and nutrition. They would find it very valuable to obtain all of this information from one source and not to have to tediously gather it by themselves.

**Table 4** Characteristic quotations from the interviews illustrating the overarching category *tasks and support needs*

Overarching category	Codes	Quotes
Tasks and support needs	Consultation and information	<i>That they [navigators] sort of show the patient where things are headed and what needs to be considered. Someone who will explain exactly where they can ask for something and where they can obtain financial support.</i> (LC, f, 50–60 years, diagnosis less than 1 year ago) <i>That would be helpful: an office where you could get all of this information as a stroke patient.</i> (S, f, 40–50 years, diagnosis less than 1 year ago) <i>There is much one doesn't know. And you have to worry about everything yourself. And it shouldn't be like that.</i> (S, m, 50–60 years, diagnosis less than 1 year ago)
		Organisation and coordination
	Support with bureaucracy	<i>For all of the applications. Because all of this paperwork, that is my weakness.</i> (S, m, 50–60 years, diagnosis less than 1 year ago) <i>That is, when you are totally alone, to really fight your way through, so to speak. As I said, as I saw it last summer, when I was just overwhelmed with the entire stuff. I am not going to fill in any application then.</i> (LC, m, 40–50 years, diagnosis between 1 and 5 years ago)
	Help with housekeeping/leisure activities	<i>These are issues that are very banal for me: making beds, putting things together, hanging things up. Or going for a little stroll.</i> (S, f, 50–60 years, diagnosis between 1 and 5 years ago) <i>For example, shopping could be done... And then I would also like to go to the soccer stadium. And I watch the game, that person drives me back. Would be quite nice. Or simply go to the movies, then back again.</i> (LC, m, 60–70 years, diagnosis between 1 and 5 years ago)
	Emotional support	<i>The main thing is to have someone you can talk to: about problems, anxieties and such.</i> (S, m, 50–60 years, diagnosis less than 1 year ago) <i>That is, even if they were not going to do anything: they arrive, sit around, leave after an hour – that would help. For me, that is. To fight this loneliness a bit, you see?</i> (LC, m, 60–70 years, diagnosis between 1 and 5 years ago) <i>And in third place, definitely emotional support. In the form of actually having someone put at your side. Someone who just comes at regular intervals and has a look around: 'How are things? What's new?'</i> (S, f, 40–50 years, diagnosis less than 1 year ago)

Organisation and coordination

A further important area of activity that interviewees saw for navigators was the organisation and coordination of their care; for instance, in the form of support to make appointments with physicians and therapists. The endless phone calls required to arrange outpatient care was especially criticised in the interviews. Additionally, not all study participants had a computer and it became obvious how difficult it is in this case to even find the address of potential caregivers. In this regard, the assistance of navigators—by contacting caregivers for patients or directly relaying existing support opportunities—was viewed as potentially very helpful.

Support with bureaucracy

Bureaucracy was a big topic for the patients interviewed. They wished to have consultation and support when filling in forms and applications, such as for rehab, pensions, cost coverage, etc. It was these administrative issues in particular that the interviewees described as additional

obstacles and burdens, on top of their serious disease; this was especially the case for those without social support.

Help with housekeeping/leisure activities

Some study participants also named tasks in the area of housekeeping and leisure time. Especially for those with limited mobility or patients weakened by therapy, dealing with housekeeping (shopping, making beds, etc) was a topic. Leisure activities, such as going to a soccer game or taking a walk, were also mentioned as something that could be conducted together with a navigator.

Emotional support

Interviewees had the expectation that navigators could offer them and their families emotional support by responding to emotional distress, listening supportively and providing comfort. They expressed the desire to have someone such as a navigator at their side, who would care for them as a human being and who would regularly ask about how they feel and how things are going. Some study

Table 5 Characteristic quotations from the interviews illustrating the overarching category *role of navigators*

Overarching category	Codes	Quotes
Role of navigators	Consistent and long-term contact person who has time	<p><i>Because it is difficult with the contact persons that you usually have, who are always changing. Here a doctor, there a doctor. There just doesn't seem to be a fixed contact person.</i> (LC, f, 50–60 years, diagnosis less than 1 year ago)</p> <p><i>Sure, having a contact person with time and the inclination, yes? So that you don't get the feeling that you are bothering them. But rather someone who takes the time and is concerned with the anxieties and questions that the patient has.</i> (S, f, 70–80 years, diagnosis less than 1 year ago)</p>
	Flexible mode of interaction and outreach	<p><i>For me, in my case, depending on need. If I had a problem I would very gladly reach out to them (the navigators).</i> (S, f, 40–50 years, diagnosis less than 1 year ago)</p> <p><i>If you are feeling that bad, then you surely would wish that someone would come and approach you.</i> (LC, f, 60–70 years, diagnosis between 1 and 5 years ago)</p> <p><i>I think there are few who would dare to request this. I think that if someone approaches from the outside, the reaction is different from when you have to be active externally. First of all, you don't know where to go, and then the problems already start. Who do you call? That is, it has to come from outside.</i> (S, f, 60–70 years, diagnosis less than 1 year ago)</p>
	Integration into existing healthcare structures	<p><i>That you go one floor lower and can knock on the door or that the [navigator] actually comes to the ward. That you have that readily in-house. Or only a short distance away, not always those long distances.</i> (LC, f, 40–50 years, diagnosis between 1 and 5 years ago)</p> <p><i>Right after the stroke in the hospital. Very important. 'Someone is going to come. Someone here will help me.' Just that thought alone already provides strength.</i> (S, f, 40–50 years, diagnosis less than 1 year ago)</p> <p><i>At the start, I think, that is the most important point, that you also get a bit of guidance. Because you are just sort of thrown into it then. Well, all of this at the start is like, 'What do I do now? What does this actually all mean?' And you can hardly think straight on your own.</i> (LC, f, 40–50 years, diagnosis between 1 and 5 years ago)</p> <p><i>The only problem would be my health. Because I lacked the strength, you see? That was so bad, that I would have probably found a navigator too bothersome. Most probably, I don't know.</i> (LC, m, 60–70 years, diagnosis between 1 and 5 years ago)</p> <p><i>Here I certainly think that it is important, if you now put another person in the mix, that doing that also fits into the procedures then. Because I think what would be worse for a patient is if they have a navigator who tells them one thing and the nurse tells them something different.</i> (LC, m, 40–50 years, diagnosis between 1 and 5 years ago)</p>

participants stated that they would appreciate the presence of navigators to help combat loneliness.

Role of navigators

Participants wished for navigators to be available as consistent contact persons along their entire care trajectory. A navigator programme would require a high level of flexibility in regard to delivery mode or interaction intervals from patients' perspectives and should be implemented within existing care structures in order to be easily reachable for patients.

Consistent and long-term contact person who has time

Study participants expressed the desire for a consistent contact person who would have time for them, and who would be available along their entire care trajectory. In their view, there was no one who had an overview of their care history and who could hold together the threads that made up their care. They envisaged that navigators could fill this gap, in that they could be available for patients as early as diagnosis and would act as a regular contact person during the course of the care trajectory. An important aspect would be that the navigators would not have any time pressure, as is the case for many other

caregivers in the healthcare system, but would rather be able to take enough time for each individual patient.

Flexible mode of interaction and outreach

A strongly emphasised request was that, in the interaction with the navigator, there should be consideration for patients' individual needs. Study participants wished to have the opportunity to be able to reach the navigator flexibly and through various communications channels, including phone, email, in person, etc. Home visits were also mentioned, such as for those with mobility impairments or for patients who have been weakened by treatment. Interviewees also considered it important that navigators would not only be available at agreed appointment times, but sometimes also on short notice, such as for acute questions or problems, and without great obstacles. Regarding the offer of possible support from navigators, many study participants said that they would like to be informed proactively; that is, they would like to have someone actively approach them and offer support, rather than having to search for help themselves. Others reported that the question of whether they would like to be proactively contacted by a navigator, or rather reach



out to a navigator themselves, would depend on their health status.

Integration into existing healthcare structures

Interviewees requested that they should not have to travel long distances or make additional efforts to meet their navigator in person. Rather, these meetings would optimally take place at the same location as their therapy. It was also important to many study participants that the offer of help be made available at the same time as diagnosis; that is, right at the start of the treatment process. One patient, however, expressed the fear that a navigator might potentially have overtaxed him at such an early stage, as it had been particularly bad for him at the start of his disease. Individually, interviewees expressed their thoughts on how the navigators could be integrated into the existing structures and procedures without there being discrepancies or competency overlaps with other caregivers. For example, one participant expressed the worry that navigators—as an additional person in the care processes—might have different opinions or recommendations than other professional caregivers (eg, nurses or physicians), so that from their point of view there would be a risk of misunderstandings or miscommunication.

DISCUSSION

The aim of our interview study was to investigate patients' perspectives on navigation, in particular what kind of support people with LC and stroke want from navigators and how a navigation programme should be best integrated into their care trajectory.

Interviewees perceived navigators as potentially valuable, though not all study participants would want to use a navigator themselves, because in their view all of their needs were already being addressed by other resources. Navigators should provide emotional ('being there') and practical (such as with applications, the organisation of care) support, give advice on social care issues and refer to existing support services. A navigator programme should offer patients a consistent contact person who has sufficient time to identify the individual support needs of patients and their informal caregivers as well as already existing support services. The programme, according to study participants, would require a high level of flexibility (for instance, with respect to delivery mode, interaction intervals) depending on patients' preferences, and should be implemented to easily reach patients within existing care structures.

Regarding the tasks to be fulfilled by the navigators, these included many currently unmet needs of patients with LC and stroke, as have been shown in other studies. For example, patients with LC experience unmet needs both throughout their care trajectory and on hospital discharge, and report physical and emotional burdens and even more psychological distress than people with other types of cancer.^{39–45} A qualitative study with people with LC and their informal caregivers in the USA revealed

topics like insurance coverage, appointment scheduling and provider-patient communication as organisational barriers to receiving quality care.⁴⁶ A qualitative study from Germany showed that patients with LC were uncertain about their role in the coordination of care across healthcare sectors and that they wished to have someone as a coordinator in the treatment process.⁴⁷ This latter finding is in line with our results, where participants expressed the desire for a consistent contact person who would have time for them, and who would be available along their entire care trajectory. Previous studies have reported that patients with stroke are often unaware of the benefits and services available to them and whether or not they can access services again after they have been discharged; patients furthermore reported struggling with bureaucratic procedures related to obtaining health and social services.^{33 48–50} Our interview results confirm that currently there seems to be an unmet need in Germany for better social support in outpatient care for patients with chronic diseases such as LC and stroke.

Participants generally preferred their personal networks for care delivery to a navigation programme, even when they had little support from others. They did, however, suggest that people without social networks may be the ones who benefit most from a navigation programme. This is in line with other studies showing the importance of social networks for providing healthcare in the German healthcare context.^{51 52} It remains to be investigated if navigation programmes manage to reach those patients without sufficient informal support and if their services are adequately tailored to effectively support them.

Patient navigation has been shown to improve cancer-related health outcomes and satisfaction, and to decrease concerns and anxiety.^{53–55} In Germany, navigation models for cancer and stroke, as well as for a number of other conditions, are currently being evaluated.⁵⁶ Most of these models are oriented to be target group-specific and disease-specific and have guideline-based treatment as a priority goal.^{57–59} These navigation models often focus mainly on clinical outcomes such as recurrent events or rehospitalisation. To our knowledge, in no cases were the perspectives of patients systematically integrated in the development of these programmes.^{55 56}

In contrast, our qualitative study was conducted in order to help develop a navigation model that is based primarily on the needs and ideas of patients; in other words, our model considers patient needs that have been identified in advance and is thus primarily patient-oriented. For example, the finding that study participants would prefer their contacts with a navigator to be available as and when needed, and not according to a predetermined schedule, is now being considered in the design of our patient navigation programme, to offer a needs-adapted, flexible appointment and contacting concept. Additionally, the desire was expressed in the interviews that relatives and informal caregivers should also receive professional support, because they are also heavily burdened and seem to have unmet needs according to interviewees. Relatives

and informal caregivers perform an immense body of care for patients with chronic diseases, ranging from nursing care to all tasks involved in care coordination. High burden, psychological distress and perceived helplessness of personal caregivers of patients with chronic diseases has been demonstrated in numerous studies.^{33 60–63} Often, this poses additional strains on the interpersonal relationships. Despite the differences in navigator tasks and roles that existing navigation programmes have devised, the common ground is that patient navigators are professionally trained and their roles are aligned with a professional distance in performing their tasks. In Germany's outpatient care system, little assistance is provided to navigate the healthcare system. Existing services such as community-based patient counselling services are rarely centrally coordinated and do not accompany patients and their caregivers along healthcare sectors. Thus, many patients critically depend on informal caregivers in organising their healthcare, and these informal networks have shown to be an important factor for good care delivery in Germany.⁵² However, as the demographic change progresses, the number of patients without functioning and reliable informal care networks increases, and there is a need to establish formal care structures within the medical system that are accessible to these patients in order to avoid significant care gaps. Whether professional patient navigators with formal training in medical and social care issues have the potential to improve care coordination for patients and whether this type of service is effective and cost-effective, remains subject to further empirical investigation.

A strength of the study was that participants were encouraged to express their ideas and wishes as openly and freely as possible in the interviews—without any explanations regarding the concept of patient navigation by the interviewer. The aim was to minimise any influence on the study participants through prior information and details regarding patient navigators, so that they could express their own suggestions and expectations. As a result, participants also mentioned requests for support that do not fit the professional role of healthcare navigators, such as leisure activities. A navigation programme that aims at delivering patient-oriented care has to carefully negotiate the possibilities a healthcare system can offer. For example, the disease may progress leading to strong frustrations and unrealistic expectations to care and thus to requests to the navigator what needs to be done. Other situations, such as unsatisfying personal family relations regarding support, all have the potential to set unrealistic expectations towards navigators. To handle such situations, a navigator training programme should include a communication module as well as a module in which the limits of navigators' tasks are developed during training. Similarly, supervision is often a recommended element.

We sampled according to a purposeful sampling in order to achieve a diverse sample of patients who were likely to have different experiences in the

German healthcare system. Unlike many studies investigating the effectiveness of existing navigation programmes,^{14 19 25 53 54 56} we placed no restrictions in terms of comorbidities or limitations to a certain disease stage. In our sampling characteristics used to achieve a broad variety of experience, we had not selected study participants based on social support. We only had used married/living with a partner as a selection criterion. However, social support turned up as a crucial characteristic for a potential vulnerability to receive suboptimal care. This in turn, we now argue, is a factor in determining the target group for navigation within the German healthcare system. The sample is not diverse enough to include many people without a support network. It remains open whether and how people who lack social support during their disease trajectory would imagine a navigation programme to look like.

A limitation of our study is that the sample comprises only participants from a single metropolitan region in Germany. Support needs and expectations regarding patient navigation may be different in rural areas and indeed in other countries. However, the selection of patients did take place according to the principle of 'maximum variation' of lived experiences, and thus included participants living in the outskirts of the metropolitan region, which could ameliorate some of this urban focus. Nevertheless, most were treated and lived within the boundaries of the city.

This qualitative interview study shows that LC and stroke are quite similar in terms of expectations about navigation support, despite the differing courses and functional limitations of the two diseases. Navigators certainly need to have disease-specific knowledge in order to be able to provide information and recognise patients' unmet critical care needs, yet the types of needs identified and the types of services needed were very similar for both patient groups and concerned predominantly social, practical and emotional support. Above all, interviewees considered it important that someone would be there for them as a consistent contact person and that the navigation model be designed to be flexible and thus able to focus on individual patient-specific, instead of disease-specific, needs. Both patient groups wished for navigators to proactively approach them and offer support right after diagnosis. Both groups complained about discontinuity and the absence of a fixed contact person in their care trajectory, and they requested support for improved coordination of their care. In Germany, many resources such as community care points, self-help groups, travel and mobility support, home care support, or social counselling exist to support patients to navigate and manage their own healthcare trajectories.⁶⁴ However, they are often fragmented and not connected in a visible and optimally accessible manner, especially for patients. Navigators could, therefore, act as a connector between the fragmented, poorly coordinated German healthcare system and the needs of patients with chronic diseases.

CONCLUSION

For chronic and complex diseases that have a significant impact on everyday lives, and where a range of therapists and institutions are involved in care—as is the case with LC and stroke—it appears to be less important for navigators to fulfil disease-specific tasks. Rather, they should ensure that patients' more general needs, in relation to social, practical and emotional support, are met in a way that suits patients' individual wishes and goals in relation to their health. This would also include paying attention to the mode, frequency and availability of navigator contacts, and the ways in which navigators would fit into the already-existing individual support system. Following these results, patient navigation programmes could be designed to include generic elements, which should then be adapted to the infrastructure in a particular healthcare region and to the particularities of a specific healthcare system, rather than to disease-specific aspects.

Author affiliations

¹Institute of Public Health, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

²Institute of Social Medicine and Epidemiology, Brandenburg Medical School Theodor Fontane, Brandenburg/Havel, Germany

³Charité Comprehensive Cancer Center, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

⁴Bavarian Health and Food Safety Authority, Bavarian Cancer Registry, Nuremberg, Germany

⁵Dept clinical epidemiology, Leiden University Medical Center, Leiden, The Netherlands

⁶Faculty of Health Sciences, Brandenburg Medical School Theodor Fontane, Neuruppin, Germany

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ORCID iDs

Hella Fügemann <http://orcid.org/0000-0001-7920-7351>

Christine Holmberg <http://orcid.org/0000-0002-8852-4620>

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