ABSTRACT

Objective  To identify key observable indicators of person-centred care (PCC) from interviews with patients, relatives and professionals with experience of receiving or working with PCC.

Design  A qualitative interview study using deductive content analysis.

Setting  Primary and hospital care settings in Western Sweden.

Participants  Twelve participants with extensive experience of receiving or working with PCC were interviewed: two patients, two patients representative with long-term conditions, one relative and informal carer, three registered nurses, one physician, two occupational therapists and one social worker/researcher.

Results  Nine observable indicators were identified and subsumed under three predetermined categories: initiating, working and safeguarding the partnership. The first category comprised three subcategories: welcoming, interested and courteous reception; agreeing on structure and aims of the conversation; and eliciting patients’ wishes for involvement of significant others. The second category comprised four subcategories: attentive, empathic and encouraging manner; promoting mutual understanding; promoting patient engagement; and encouraging and friendly body language. The last category consisted of two subcategories: collaboration and transparency in documentation and verifying that patient’s and professional’s views, goals and wants are correctly documented.

Conclusion  Our results underline the need for health professionals to actively and conscientiously convey to patients their interest in and respect for the patient as a person and their willingness to collaborate as partners in their care from the very outset of the interaction. Non-verbal behaviours were seen to play a major role in shaping patients’ impressions of health professionals. Given that patients’ first impressions were considered to impact the content, course and outcomes of the interaction, more research attention should be given to this aspect of health professionals’ communication.

Strengths and limitations of this study

► There are few interview studies documenting how person-centred care (PCC) is actually performed in practice.

► The qualitative design may also be seen as a strength of this exploratory study, as it uncovers lived experiences and descriptions of PCC.

► Although our study included a range of key stakeholders, that is, patients, health professionals and relatives, we did not include children or representatives from several health professionals, such as physiotherapists and licenced practical nurses.

BACKGROUND

Recognised as a vital component of quality healthcare, person-centred care (PCC) has been widely endorsed by professional bodies as one of a set of core competencies needed by health professionals to effectively meet the complex challenges facing today’s healthcare systems. Such endorsements, together with research results showing benefits of PCC for patients, professionals and healthcare systems, have spurred calls for implementing PCC in healthcare practice. For example, WHO, The Health Foundation and international patient organisations have been done to tease out a set of fundamental PCC components emphasising the patient’s perspective and various conceptual frameworks have been proposed, with dimensions ranging in number from as few as to as many as . Nonetheless, implementing PCC has proven challenging and efforts to date have been hampered by a number of factors, including lack of a consensus definition of PCC, professional’s attitudes, time constraints and opportunities to participate in training and continuing education.

The bulk of research on PCC to date has focused on patient experiences of the effects and outcomes of PCC, evaluated either through individual or group interviews or standardised questionnaires. Less attention has been directed to evaluating the process of PCC, that is, the way care is
provided and the extent to which the principles of PCC are applied.

A common method for assessing care providers’ competence in the delivery of PCC is the use of direct observation of clinicians’ behaviours as they perform patient care and clinical activities. Although direct observation methods are labour intensive, they have the advantage of providing a direct window for assessing many aspects of ongoing patient–clinician interactions.\(^\text{24}\) A number of direct observation tools that have been designed, adapted or repurposed for assessing PCC are currently available. These tools differ in their coverage of common PCC domains, seldom included patients in their development and, importantly, often lack a clearly defined conceptual framework.\(^\text{25}\)

In an effort to advance and facilitate PCC implementation in healthcare, Ekman \textit{et al} at the University of Gothenburg Centre for Person-Centred Care (GPCC) proposed a PCC framework comprising an overall theme of partnership embodied in three core routines for implementing PCC in daily practice: initiating the partnership by listening to the patients’ narratives, working the partnership by mutually formulating health plans, and safeguarding the partnership by documenting the health plan and making it accessible to both parties.\(^\text{16}\) The framework has been evaluated in several conditions and contexts and has been shown to improve patients’ self-efficacy,\(^\text{26}\) shorten hospital stays,\(^\text{27}\) be associated with increased job satisfaction among health professionals\(^\text{28}\) and to be cost-effective compared with usual care.\(^\text{29}\) The GPCC framework has been widely implemented throughout Sweden in hospitals and primary care centres.\(^\text{30}\)

Although carefully outlined, these routines were not described in detail regarding how they should be performed in daily practice.

The present study is part of a larger project aiming to develop a direct observation tool for assessing PCC in clinical interactions. With the GPCC framework as its point of departure, this study aimed to identify key behavioural indicators of PCC for inclusion in this tool through interviews with patients, relatives and professionals with experience of receiving or working with PCC. (see table 1). The initial question asked to the participants who were unfamiliar with the GPCC model was: Please think about a care situation that you considered the research question to be answered in full. In total, twelve participants were recruited including two patients, two patients representative with long-term conditions, one relative representative and informal carer, three registered nurses, one physician, two occupational therapists and one social worker/researcher (see table 1). Two of the patients were hospitalised at the time of the interview and resided on a ward that worked according to principles of PCC and two were patient representatives who, along with the relative, had been actively engaged in the development and implementation of PCC. The practitioners represented different health professions and had theoretical knowledge and practical experience of delivering PCC. All of the practitioners and patient representatives were schooled in and practised this model.\(^\text{16}\) and had previously participated in seminars and workshops organised by GPCC.

### Data collection

The interviews were conducted between February and November 2018 by the first author (NE).

A letter explaining the purpose of the study was mailed to the participants before the interview. Before starting the interview, the interviewer further clarified the aim of the project and encouraged the interviewees to ask questions about the project so they would feel comfortable and clear about its purpose. During the interviews, the participants were encouraged to freely talk about their experiences of receiving or practising PCC. The three routines comprising the GPCC model were used as a frame during the interviews and questions related to each routine were asked when needed to supplement information given spontaneously by the interviewees (see online supplemental table). The initial question asked to the participants who were unfamiliar with the GPCC model was: Please think about a care situation that you felt that you received particularly good care and please describe what happened during the situation that made it

### METHOD

**Study design**

This is a qualitative interview study with persons having experience of receiving or working with PCC. A deductive content analysis approach inspired by Graneheim and Lundman was used. Content analysis is a method to analyse qualitative data, and which can be used at varying levels of abstraction and interpretation.\(^\text{31, 32}\)

**Participants**

Participants with experience of receiving or working with PCC were recruited using purposeful sampling and selected to include a broad sample of experiences of PCC. The interviews were conducted until the authors considered the research question to be answered in full. In total, twelve participants were recruited including two patients, two patients representative with long-term conditions, one relative representative and informal carer, three registered nurses, one physician, two occupational therapists and one social worker/researcher (see table 1). Two of the patients were hospitalised at the time of the interview and resided on a ward that worked according to principles of PCC and two were patient representatives who, along with the relative, had been actively engaged in the development and implementation of PCC. The practitioners represented different health professions and had theoretical knowledge and practical experience of delivering PCC. All of the practitioners and patient representatives were schooled in and practised this model.\(^\text{16}\) and had previously participated in seminars and workshops organised by GPCC.

### Table 1 Gender and role of interviewees

| N=12 | Gender     | Representing                             |
|------|------------|-----------------------------------------|
| Male | Patient    |                                         |
| Male | Patient    |                                         |
| Female | Patient/patient representative |                              |
| Male | Patient/patient representative |                               |
| Male | Patient/relative representative |                                 |
| Female | Occupational therapist |                               |
| Female | Occupational therapist |                               |
| Male | Social worker/researcher |                                    |
| Female | RN |                               |
| Female | RN |                                    |
| Female | RN |                                    |
| Male | Physician |                                      |

RN, registered nurse.

\(^{29}\)
stand out. All other participants were asked: What do you think are observable indicators of patient–clinician interactions? The interviewer followed up with probing questions, such as Could you please tell me more or give some more examples? The interviews varied in length from 30 min to 1 hour and 20 min and were conducted at the participants’ choosing, either in a room in the hospital ward where the participant and interviewer could be undisturbed, by phone, or at the place of work by the first author (NE). Eight interviews were conducted face to face and four interviews were conducted by phone. The interviews were made in parallel with the analyses in order to be able to include more interviews if issues and questions arose that needed further clarification and more data. The interviews were tape recorded and transcribed verbatim.

**Analysis**

An explorative qualitative deductive content analysis, inspired by Graneheim and Lundman, was used in the present analysis. The analysis was based on the PCC framework proposed by the GPCC. Hence, the three GPCC routines were used as main categories in the analyses.

All interviews were first read through by the first author (NE). Subsequently, meaning units comprising behaviours and actions deemed to be directly observable as person centred were identified and placed into the above three categories. In the next step, three authors (NE, AF and EB) condensed and coded the different meaning units and the codes were grouped into subcategories based on their similarities and differences. During the analysis, discussions were regularly held with the whole research group to identify and reconcile conflicting interpretations until consensus was achieved.

**Table 2** Categories, attributes and example behaviours

| Categories                  | Subcategories (indicators)                                         | Example behaviours                                                                 |
|-----------------------------|---------------------------------------------------------------------|------------------------------------------------------------------------------------|
| Initiating the partnership  | Welcoming, interested and courteous reception                       | Introduces oneself, smiles, eye contact, head nodding, hand gestures, open body posture |
|                             | Agreeing on structure and aims of the conversation                  | Discusses an agenda for the meeting                                                |
|                             | Eliciting patients’ wishes for involving significant others         | Asks the patient if he/she wants to involve someone else                           |
| Working the partnership     | Attentive, empathic and encouraging manner                          | Gives short summaries of patient’s narratives, uses open-ended questions            |
|                             | Promoting mutual understanding                                      | Uses a common language                                                             |
|                             | Promoting patient engagement                                        | Shares communication time                                                          |
|                             | Having an encouraging and friendly body language                    | Does not have arms crossed                                                         |
| Safeguarding the partnership| Collaboration and transparency in documentation                     | Cocreates and invites the patient to review or write the health plan him/herself   |
|                             | Verifying that patient’s and professional’s views, goals and wants are correctly documented | Asks for final approval                                                            |

**Patient and public involvement**

The study was conducted within the GPCC, where patient and public involvement is essential. Several patient representatives were involved in the present study.

**RESULTS**

The analysis resulted in three categories divided into nine attributes (subcategories) and illustrated by example behaviours, see table 2 below. In the quotes illustrating each subcategory, the patient representatives are referred to only as patients to ensure their anonymity.

**Initiating the partnership**

The category initiating the partnership emphasised the importance of first impressions made by the health professional as crucial for engaging patients and gaining their trust and confidence. The category comprised three subcategories: welcoming, interested and courteous reception; agreeing on structure and aims of the conversation; and eliciting patients’ wishes for involvement of significant others.

**Welcoming, interested and courteous reception**

The interviewees underscored the fundamental importance of greeting the patient in a welcoming and courteous manner for developing a personal, trusting connection with the patient. First impressions were considered by the interviewees to impact the content, course and outcomes of the interaction. Verbal and non-verbal behaviours, such as knocking on the door and waiting for a response, introducing oneself and smiling, were seen to signal respect and warmth for the patient as a person. Performing simple acts of courtesy, such as introducing oneself and looking in the patient’s eyes, being attentive
and responding appropriately to the patient’s emotional state was considered vital.

It’s personal chemistry. I know right away if it feels right, you can just feel it... You see from their eyes, whether it’s a soft or hard look. If she doesn’t look welcoming, by not smiling, is a quick sign. Patient

First, it’s about how you present yourself in the room, paying attention to the person’s state-of-mind. It requires listening and reading the person. Is this person someone who is vulnerable, afraid or distressed? Right there, you need to... well... be courteous and attentive by knocking on the door and waiting for a response, making eye contact, introducing yourself. Patient

The doctor draws conclusions and observes, but you do that yourself as a patient also about the doctor. It affects how the conversation goes. If the doctor just sits there or seems stressed or so, I can’t trust him. That determines how you behave, which is what in the end what the doctor judges. There are some things you can’t change, like stress, but you need to clarify for the patient that right now there’s a lot to do. Patient

Agreeing on structure and aims of the conversation

Time constraints were described as a major obstacle to delivering PCC. The interviewees stressed the need for allotting time to establish an agenda for the meeting to ensure that the patient’s and health professional’s most prioritised concerns can be addressed in the time available.

The structure is important, you may only get one chance to have a good conversation. The best way is practice. Occupational therapist

You have to change the current structure, because the fact is that short meetings are really a thing in today’s healthcare, quick and easy it should go. Unfortunately this problematize the interaction. Occupational therapist

Eliciting patients’ wishes for involving significant others

The interviewers stressed the importance of respecting patients’ wishes about involving significant others in their care and decision-making. Although significant others were considered potentially valuable partners in the care team, the professionals expressed concern that they may in fact ‘take over’ decisions from the patient. In such cases, they saw their role as an advocate for the patient, ensuring that the patient’s own wishes and preferences for care and treatment are respected.

Relatives can take over. You must be observant during the interaction between the patient and the significant other. RN

Working the partnership

The category working the partnership involved the enactment of behaviours, attitudes and skills that foster free and open communication between patients and staff. Fundamental was that both partners, particularly the health professionals, acknowledge and respect each other’s knowledge and expertise in managing different situations in the care process. Especially, important aspects were that both parties endeavour to: identify resources in the other person, find a common language, and encourage each other to actively participate in the dialogue. The category comprised four subcategories: attentive, empathic and encouraging manner; promoting mutual understanding; promoting patient engagement; and encouraging and friendly body language.

Attentive, empathic and encouraging manner

The interviewees underscored the need to convey to the patient that what he/she says is important. Use of active listening skills, such as paraphrasing and summarising, was mentioned as ways to signal this and to verify understanding. Showing empathy and genuine interest in the patient’s concerns were considered essential for partnership building.

Show that you are interested, be aware of how you ask questions, and see the story in relation to the patient’s illness. Patient

To tell the patient that I see and understand you. You do not always have to fix everything, but just let them know that you see them... Just show kindness and acknowledge the feelings and stress that the other person is experiencing, for example, feeling powerless or irritated. Occupational therapist

Asking open-ended questions and respecting pauses, non-verbal behaviours such as nodding, an open body posture, eye contact, as well as refraining from judgmental comments and interrupting the patient was stressed.

I listen carefully, even if the patients have a type of illness which could affect how the narrative is presented, to the whole story. And then I make sure that I have understood them correctly by summarizing what they’ve said, because even if there seems to be a lot of strange things in their narrative, it is true for them, they don’t make up these things. Physician

It is very important to listen, especially to what resources the person tells you she/he has. The art, as I see it, is to get a person to tell the narrative so they themselves discover their story. It is not certain that they know that this story is within them. RN

Promoting mutual understanding

The ability to actively listen to what the other person says and reflect on it was crucial. The informants expressed the importance of communicating with patients using a language appropriate to the patient’s level of health literacy. Communicating in this way reflects respect and equality in care.

One RN was very skilled, for example, by translating from the medical language to plain language. It’s about translation. Patient
I think it is good for the patient to participate and when the patient tells you something, you write and then you show him/her, is this what you said, and then the patient understands that his/her words really had some meaning. RN

**Promoting patient engagement**

The subcategory promoting patient engagement comprised behaviours and attitudes that motivate patients to become actively involved in their care and treatment. Professionals have to find a balance between acting in a competent, professional manner and revealing themselves as persons behind their professional role in order to build personal trust.

It is an art to be able to communicate about things that matter and ask how the conversation was experienced in terms of comfort, not only facts. RN

If I look at a person-centered conversation, I actually measure the time between the patient and the caregiver. What is classical in today’s care is that we talk much and listen so little. RN

Your professional role must always exist, but it’s about how much you dare to go show yourself as a person. Occupational therapist

**Encouraging and friendly body language**

Having an encouraging and friendly body language was underlined as important and exemplified by listening attentively, avoiding interrupting and making good eye contact.

Not having arms crossed, quiet, but still shows interest. Occupational therapist

The healthcare professionals have to make room for building a partnership, it is about how you engage the patient, but also what you do with your body, stand or sit down next to the patient. Patient

**Safeguarding the partnership**

The category safeguarding the partnership emphasised the importance of reaching and formalising agreement on and coauthoring health plans. Cocreation and documentation of the health plan was seen to ensure that it acknowledges and validates patients’ concerns and perspectives, is understandable to the patient, that the patient–professional interaction is transparent, and that continuity in care is facilitated. Patient access to health plans was stressed. It consisted of two subcategories: collaboration and transparency in documentation and verifying that patient’s and professional’s views, goals and wants are correctly documented.

**Collaboration and transparency in documentation**

The interviewees stressed that patient records should be jointly formulated, written in a language that the patient understands and approved by both parties. It was considered important that patients should not only be given access to their records but also to make changes and additions. Using the patient’s own words when documenting was seen as a way of validating patients’ concerns and perspectives and of showing respect. Examples of behaviours that contribute to collaboration and transparency included: sitting next to the patient so that both can see the paper or screen and the patient can check that what is written is relevant and correct; and either documenting together or allowing the patient to do so by themselves with support from the professional. Documenting in this way was seen to reduce misunderstandings between the parties and foster equal partnership.

It has to be a two-way communication when writing the record, the health-care professionals put in the test result and the patient writes how he feels, if he is tired, vomits, etc. Patient

I always use a laptop, so when I write the care plan I show the patient and says, ‘I’ve written this, what do you think, is it ok, have I understood you correctly? RN

**Verifying that patient’s and professional’s views, goals and wants are correctly documented**

This subcategory emphasised the importance that both parties agree on and are equally acknowledged in the documentation. Example of behaviours are to ask for final approval and ask if there is anything more to add or to explain.

It is important to ask how the patients experienced the conversation, not only in terms of how well the facts were covered, but also how comfortable they felt. Occupational therapist

You have to be quiet and give the patient time to speak, the pauses have to be much longer than you first think. And after a while you can ask questions like, ‘is there anything more you want to say… anything that you missed in our conversation?’ And then more often comes. One has to practice it. Social worker/researcher

**DISCUSSION**

In the present study, we found that observable indicators of PCC were possible to describe by patients and health professionals. The main finding was the importance of the professionals’ non-verbal behaviours for instilling trust and demonstrating a willingness and interest to collaborate throughout the care process, and thereby reducing the power asymmetry between the patient and the professional. Non-verbal behaviour has been described as a variety of communicative behaviours that do not carry linguistic content and include facial expressivity, smiling, eye contact, head nodding, hand gestures, voice tone and body posture and lean. Its importance for conveying affective information is widely recognised and is highlighted by studies indicating that non-verbal behaviours account for as much as 93% of inferred meaning and...
are as much as four times more influential than verbal messaging.\textsuperscript{36, 37} The importance of non-verbal behaviours is also reflected by their inclusion in a number of existing observation-based methods.\textsuperscript{17, 38–43}

We found that non-verbal behaviour was particularly important in our first category initiating the partnership. The core function of this GPCC routine is to gain an understanding of patients’ personal illness experience through their illness narrative. Our informants underscored that patients actively monitor the healthcare professional’s behaviour from the very outset of the encounter for cues thought to signal whether he/she is welcoming, respectful and sincerely interested in listening to their narrative in order to gauge what and how much they will share. In particular, they emphasised that healthcare professionals should be forthright with the patient and explain the reasons for their negative feelings, for example, why they are stressed or irritated; otherwise, patients may wrongly assume that they are the cause. This is in line with findings by Alharbi \textit{et al} that patients wait for an invitation to partnership and that healthcare professionals need to be perceived as genuinely curious and interested in the patient.\textsuperscript{44} McCormack and McCance also emphasise that having a sympathetic presence is central to the practice of PCC,\textsuperscript{15} which may be seen as the professional attempting to take on an ‘insider’ approach.\textsuperscript{45}

First impressions are durable and were described by the informants to be influenced by behaviours respecting accepted social norms, such as knocking on the door and waiting for the patient’s response before entering the room. Similarly, it is important that professionals are aware of their own risk of making quick assumptions about the patient. Emotions, moods and feelings commonly accompany illness and are largely expressed through non-verbal behaviour and thus non-verbal behaviour has a significant role in care.\textsuperscript{33} The ability to distinguish, understand and respond appropriately to the affective aspects of illness requires not only cognitive skills but particularly emotional and bodily competence from professionals and a sensitivity to their own vulnerability and to that of the patients. A welcoming body language includes smiling, maintaining eye contact and an open body posture. The patient must also sense the professional’s respect and humility. An open mind and body should characterise the professional’s approach towards the patient; arms crossed when asking the patient to relate their illness narrative will obviously not create a safe and welcoming atmosphere.

Observable attributes of our second category, working the partnership, were attentive and encouraging manner, promoting mutual understanding and patient involvement, and having encouraging and friendly body language. Examples of behaviours characterising this category included an open body posture when discussing and writing a care plan together and respecting the patient’s wish to sit down or stand up during their conversation. An observational study of patient and health professional interactions found that when doctors do not behave in a positive manner, patients felt less satisfied, less enabled and had greater symptom burden.\textsuperscript{46} Research also indicates that eye contact may enhance listening skills in professionals and thus their ability to decode verbal and non-verbal cues.\textsuperscript{33} Similarly, Bensing \textit{et al} have shown that professionals who demonstrated greater eye contact with patients were better at interpreting emotional cues of psychosocial distress.\textsuperscript{47} Other observable and very concrete aspects in working the partnership were to conduct the meeting in a place where no one else can listen (a room) and to write the documentation together. During the process of working the partnership behaviours that accompany words are particularly important as they give words meaning, for example, by amplifying or contradicting the verbal message. As noted by the informants, a verbal message of agreement (‘sure, that’s fine’) may be interpreted differently depending on whether the statement is accompanied by a frown or a smile or a blank expression.

Our third category, safeguarding the partnership, which involves cocreating care plans and making them accessible to patients, challenges current positions for both healthcare professionals and the patient as it requires new power positions for both the professionals, the patients and relatives.\textsuperscript{48} Changing to these new roles places a variety of demands on both professionals and patients, but the care is experienced as more meaningful.\textsuperscript{18}

Operationalising person-centred ethics in healthcare is not something that is easily and quickly accomplished, but rather a process of developing the professional role and changing the clinical mindset through reflection on theory and practice.\textsuperscript{49} McCormack has described the importance of health professionals being aware of patients’ beliefs and values, of being engaged and of striving towards agreement in care actions, which we see as congruent with safeguarding the partnership.\textsuperscript{13, 16} The mutual respect and reciprocity were mirrored in the present study by activities such as jointly summarising and documenting the health plan. In traditional care systems, goals are rarely set; when they are, the professionals formulate them alone with no or little involvement by patients and they are often formulated to comply with guidelines and recommendations for the specific diagnosis.\textsuperscript{50} Directly involving the patient in writing patient record entries, writing them in a language that the patient understands, for example, avoiding abbreviations, and whenever possible using the patient’s own words may help to ensure that patients’ views, goals and wants are correctly documented.\textsuperscript{31} In PCC, both parties need to go beyond traditional work tasks and behaviours in order for patients to become active partners, which might be met with scepticism and conservative attitudes by professionals.\textsuperscript{39} On the other hand, a recent scoping review of the effects of PCC on healthcare provider outcomes reported positive associations between PCC and job satisfaction, burnout, stress of conscience, job strain and intent to leave.\textsuperscript{32}
The observable indicators identified in our study may be of value in the ongoing process of implementing PCC for appraising the degree to which health professionals are person-centred in their practice. Some of the identified observable attributes in this study can be found in existing observation-based methods, such as eye contact and body language. The new knowledge that this study adds to the literature is the importance of how non-verbal communication is manifested, particularly in the initiation of PCC but also throughout the whole process of working and safeguarding the partnership. In addition, many existing observation-based tools lack defined conceptual frameworks of PCC, while the present study had its point of departure in a tested and practised framework. The results of this study may serve as a basis for developing a new direct observation tool.

Limitations
This study has some limitations. First, the number of informants representing each of the stakeholder categories, that is, patients, relatives and health professionals, was small. It is conceivable that adding informants might have improved the depth and richness of our data; however, we found considerable agreement between these key stakeholders regarding what health professionals should do and how they should be in person-centred clinical encounters and noted that little new information was derived from later interviews. Second, because we did not include representatives from several health professionals, such as physiotherapists and assistant nurses, and the study was conducted in a particular context (urban Sweden), our findings may not be transferable to other patient or professional groups, or to other settings.

CONCLUSION
A core finding was that first impressions that patients form of health professionals are crucial for determining the content, course and outcomes of the interaction and more research attention should be given to their impacts in future studies on PCC. The descriptions of PCC by the informants were clearly dominated by expectations of a respectful and welcoming approach, which was manifested to a large degree through the health professionals’ body language. This indicates that healthcare professionals need emotional and bodily competence to be able to fully appreciate and respond appropriately to the patient’s vulnerability and at the same time to recognise and manage their own vulnerability in order to create a sympathetic presence in their interactions with patients.

Contributors
NE, PM, CT, EB and AF contributed to the conception and design of the study. NE conducted the interviews and had primary responsibility for drafting the manuscript. NE, AF and EB contributed to the interpretation and analysis of the data. All authors were responsible for the revisions of the manuscript and approved the final version. AF acts as a guarantor for the manuscript.

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Competing interests
None declared.

Patient and public involvement
Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication
Consent obtained directly from patient(s).

Ethics approval
This study involves human participants and was approved by the Swedish Ethical Review Authority. Reference number: DNr 1004-17. The participants gave their written consent, were informed that their participation was voluntary and that they had the right to withdraw. All of the informants were informed that their information would be used in research and any published quotes from the interviews would be anonymised.

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Data may be obtained from a third party and are not publicly available.

Supplemental material
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