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What determines patient-centred care? Exploring facilitators and barriers from the patients' perspective: insights from qualitative patient interviews

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Title What determines patient-centred care? Exploring facilitators and barriers from the patients' perspective: insights from qualitative patient interviews

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Keywords

Patient-centred care, care process, patient, patient-provider interaction, qualitative research, chronic illness, interview

Word count: 6,270

Abstract

Objectives Redesigning the health care delivery system towards patient-centred care (PCC) is on the political agenda in many countries. Previous studies examined determinants of PCC primarily from the providers’ or experts’ perspective. The objective of this study was to analyse patients’ understanding of PCC and to identify patients’ experiences of facilitators and barriers towards implementing PCC.

Design We conducted semi-structured individual interviews with chronically ill patients. The interviewees were encouraged to share positive and negative experiences of care in all settings. Interview data were analysed based on the concept of content analysis.

Setting Interviews took place at the University Hospital Cologne, nursing homes, at participants’ homes or by telephone.

Participants Any person with at least one chronic illness living in the region of Cologne was eligible for participation. 25 chronically ill persons with an average age of 60 years participated

in the interviews. Chronic diseases included eg, various mental health problems, oncological, metabolic and neurologic diseases.

Results Patients described determinants of PCC on the micro- (eg, patient-provider-interaction), meso- (eg, health and social care organization, HSCO) and macro-level (eg, laws, financing). In addition to previous concepts, interviewees illustrated the importance of being an active patient by taking individual responsibility for health. Interviewees considered functioning teams within HSCOs a facilitator of PCC as this can compensate stressful situations or lack of staff to some degree. A lack of transparency in financing and reimbursement was identified as barrier to PCC since it can induce distrust towards the health care system or individual providers.

Conclusion Many aspects of PCC as perceived by patients can be implemented by individual providers and HSCOs, but large scale changes such as reduction of administrative barriers, the expansion of care networks or higher mandatory nurse to patient ratios require political action and incentives.

Study registration German Clinical Trials Register DRKS00011925

Strength and Limitations

- Interviewees had a diverse background in disease and treatment experiences, including acute and chronic illness care.
- The open nature of the interviews encouraged interviewees to express various positive and negative experiences resulting in a rich collection of determinants of patient-centred care from the patient perspective.
- Due to self-selection our sample might be biased since probably more involved and active patients participated.

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INTRODUCTION

Health care systems worldwide face the challenge of providing healthcare for an aging population with growing numbers of chronically ill and multi-morbid patients.[1] These patients need integrated and coordinated care over long time periods and usually from various providers including health and social care organizations (HSCO).[2] Often, however health care provision is still designed to primarily meet the challenges of acute care. The effects of the demographic and epidemiologic developments on the delivery system and the resulting necessity to change structures, processes and goals of care (i.e. cure vs effective long-term management) are often neglected. If the requirements to meet the needs of chronically ill patients are disregarded the result is ineffective and inefficient care delivery.[3 4] Societies, health policy makers, health care providers and individual actors in the health care system are invited therefore to find ways to adequately address the needs of all patients. A prominent concept to adapt care to the individual needs of chronically ill, multi-morbid and aging patients is the concept of *patient-centred care* (PCC).

To date no universal definition of PCC exists. In its report “Crossing the Quality Chasm” the Institute of Medicine (IOM now National Academy of Medicine, NAM) defined six core principles of high quality care with PCC being one of them.[5] The IOM established the widely accepted definition of PCC as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”.[5](p. 5) To implement PCC the IOM defines eight guiding principles: respect for patients’ preferences, coordination and integration of care, information and education, physical comfort, emotional support, involvement of family and friends, continuity and transition, as well as access to care.[6] A similar definition as the IOM’s is used by Reynolds who defined PCC as care which “focuses on the patient and the individual's particular health care”.[7]

Previous models and determinants of PCC were based on expert interviews or opinions [3 8-13], patient interviews with a very specific homogenous patient group [14 15], or addressed only specific care settings. Scholl et. al provided a systematic literature review synthesizing all elements of PCC described in the literature.[8] However, none of the existing concepts was developed with and from the patient perspective including a diverse group of patients and referring to a variety of care settings. The aim of this study was to develop a conceptual model of PCC determinants based on the perspective of patients with a broad range of disease and treatment experiences. This model should facilitate the discussion on initiatives, which are necessary to increase the current level and involvement of actors in PCC.

METHODS

The study conduct and reporting is based on the “Consolidated criteria for reporting qualitative research” (COREQ).[16]

Setting: German Health Care System

In the German health care system ambulatory care, hospital care, ambulatory and stationary rehabilitation and nursing care is provided. Ambulatory health care is mainly provided at local physician offices, with general practitioners (GP) usually being the first contact persons. However, patients can opt for an ambulatory specialist visit directly and without additional out-of-pocket costs. Hospital care ranges from regular basic hospitals to centres of medical excellence usually being an academic hospital, which provide care for all indications and levels of disease severity. Ambulatory, intramural hospital care, rehabilitation, and long-term nursing care each have their own mode of financing and reimbursement and are therefore highly separated from a delivery, but also a financial perspective.[17] To overcome this separation, improve chronic illness care and incentivise care integration, disease management programs (DMP) are implemented in Germany for six chronic conditions.[18] The programs consist of regular GP and specialist appointments and self-management trainings for patients.

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Patient and public involvement

This project was conducted within the Cologne Research and Development Network (CoRe-Net), which consists of scientists, patient organizations, HSCOs, municipality representatives and other stakeholders.[12] The data collection for this study took place within the research project OrgValue (Characteristics of Value-Based Health and Social Care from Organizations’ Perspectives), which is one of currently four projects affiliated with CoRe-Net.[19] CoRe-Net members participated in developing ideas on the study conduct. The study results were partly presented at public CoRe-Net events and will be disseminated to all participants.

Participant recruitment & sample

To be eligible for this study, patients had to be 18 years or older and feel cognitively and emotionally able to participate in an interview. They also had to be diagnosed with at least one chronic condition. Participants were recruited via newspaper advertisement, flyers and posters distributed at public places, primary care physician offices, and nursing homes. The diversity of sampling strategies was used for the purpose of reaching maximum variation [20] regarding age, gender, or disease specific characteristics (physical and mental health indications, fluctuating and stable symptoms, life-threatening diseases).

Data collection methods & setting

Data was collected through individual interviews from January until May 2018. Depending on the participants’ mobility or preference, the interviews took place at a meeting room in the University Hospital, in their long-term care institution, at home or by telephone. Prior to the interviews, each interviewee was called to provide explanations of the study. After this phone call participants received informed consent forms describing aims and procedures of the study and a questionnaire on socio-demographic and disease specific data. This data was used to prepare the interviewer for the personal situation of the interviewee and get acquainted with disease characteristics.

The interviews were based on a semi-structured interview guide (supplementary file 1) and conducted by VV. The process of interviewing was regularly discussed in the interdisciplinary research team. Each interview started with a personal introduction of the interviewer including position and research interests. In the interview participants were asked to describe situations, in which they experienced as optimal and suboptimal health care subjectively judged provision. For both situations, participants were encouraged to explain the determinants that made them judge their experiences as optimal or suboptimal. The interviews were finalized by collecting ideas and suggestions, for changes in health care provision, which they perceive of added value. Throughout and after the interviews participants were allowed to ask questions. All interviews were audiotaped and transcribed verbatim according to scientific guidelines.[21]

An iterative process of data collection and analysis was applied. This included listening to audiotapes after each interview, discussing preliminary results in the research team and identifying topics needing more detailed discussions in subsequent interviews. Each participant was offered to contact the researchers after the interview by phone or e-mail to share additional ideas or memories. Field notes were taken after the interview in case any particular observations or a specific atmosphere was noticed. Participants were allowed to access, correct or withdraw their audiotapes or transcripts.

Data Analysis

Data were analysed based on concepts of qualitative content analysis based on Miles et al. [20] The coding scheme was developed in a combination of an inductive and deductive approach. Themes from previous concepts of PCC were complemented by themes emerging from the data. Existing codes related to the categorization of determinants into the micro, meso and macro level.[8] Aspects of care provision which relate to individual interactions between a patient and a care provider or other contact persons were coded under micro level. The meso level included aspects related to one care providing organization (meso level 1) or the cooperation of several

care providing organizations (meso level 2). Laws, regulations, policies, and guidelines shaping health care provision were considered determinants on the macro level. The subcodings were developed, revised and finalized by the team of researchers (KH, HH, and VV) alongside conducting the interviews. Using this scheme, each interview was coded by at least two researchers (KH, HH, and VV in varying teams). Data coding was performed using MAXQDA 12. Prior to data collection and analysis all researchers were trained in qualitative research methods.

RESULTS

Participants & atmosphere

32 persons reported interest to participate in the study of which interviews took place with 25 persons. The remaining could not be followed up, were unable to read and sign informed consent materials or could not be interviewed for other reasons. Participants suffered from diseases such as breast and gastric tumours, diabetes mellitus type 2, asthma, chronic obstructive pulmonary disease, depression & anxiety disorder, hypertension, hypercoagulability with thrombosis and embolism or multiple sclerosis. Additional characteristics of the 25 analysed participants are summarized in table 1. While one interview was terminated after 6 minutes due to cognitive limitations of the participant, the interviews lasted 30-80 minutes with an average of 44 minutes. The variation of interview length resulted from varying amounts of experiences with or ideas for implementing PCC. Participants were open, dared to be critical, and perceived the interview as a good opportunity to share experiences. The interview was very emotional for some participants. Participants also described situations of close relatives or friends to illustrate their understanding of PCC. One participant contacted the researchers after the interview to share additional experiences, which were considered in the analysis. After around 20 interviews no new themes emerged.

Table 1 Participants’ characteristics

Characteristic	Number of patients (%)
Gender	
Male	8 (32)
Female	17 (68)
Age	
18-29	2 (8)
30-39	1 (4)
40-49	3 (12)
50-59	5 (20)
60-69	5 (20)
≥70	9 (36)
Marital status	
Living with partner (married)	8 (32)
Living with partner (unmarried)	1 (4)
no partner, divorced or widowed	15 (60)
Persons within household	
1	12 (48)
2-3	11 (44)
≥4	1 (4)
Education	
No degree	0
Secondary school	5 (20)
High school	6 (24)
College	13 (52)
Other degree	1 (4)
Professional qualification	
Vocational training	11 (44)
University degree	10 (40)
Retired	15 (60)

Net household income	
500-999€	3 (12)
1000-1499€	5 (20)
1500-1999€	1 (4)
2000-2499€	8 (32)
2500-2999€	2 (8)
≥3000€	2 (8)
Degree of disability ^a	
0	13 (52)
1-19	0 (0)
20-39	1 (4)
40-59	6 (24)
60-79	1 (4)
80-100	3 (12)
Nursing scheme ^b	
None	22 (88)
1	1 (4)
2-4	0
5	1 (4)

^a Higher value corresponds to greater extent of impairments; ^b Higher nursing scheme represents a greater need for nursing care; if number of patients ≠ 25, data are missing

Facilitators & barriers of PCC

The determinants as identified from the patient perspective are categorized and summarized for the micro, meso and macro level in figure 1. Citations for the corresponding topics are displayed in supplementary file 2.

Please include Figure 1 somewhere here (Legend: Figure 1 Determinants of patient-centred care)

Micro level determinants of the interaction between patient and clinicians or other contact persons

Responsibilities and characteristics of patients

Interviewees reported their role in establishing a good provider-patient relationship as a facilitator (see also supplementary file 2). It was considered especially helpful if patients share all health problems with the health care provider and treat the provider with respect. Moreover, communicating personal wishes or fears (eg, anxiety disorder) upfront was seen as a precondition for consideration by the provider. Interviewees acknowledged the necessity of being open to take up suggestions of the care provider, also if they require active participation in care (eg, psychotherapy, physical activity, healthy diet). Patients described the responsibility to show a high level of self-initiative and commitment within the current health care system to receive safe and effective care. This included *medical* (eg, regular administration of tablets) as well as *organizational* (make appointments in time), and *informational* (collect and organize medical and non-medical information) duties. Moreover, some patients perceived a *financial* responsibility to save some money for non-reimbursed therapies or co-payments. Patients highlighted, however, that such a high level of self-responsibility cannot be expected from all patients in every situation (eg, in case of mental health problems, bedfastness, lower education, unemployment). Especially patients with mental illnesses felt burdened by coordinating care from different and often unknown providers, and to inform themselves adequately.

Patients differentiated their role as customers in the health care system in comparison to their role as customers in other situations, which implied eg, that waiting times even for scheduled appointments sometimes just need to be accepted since health care cannot be timed exactly. Patients described their and other patients' duty to request existing health care services in an efficient manner, eg, by contacting emergency primary care services instead of the hospital emergency departments whenever possible. Also they consider themselves and other people responsible for treating short-term minor complaints individually without seeking professional

care immediately and thereby using physician time, which might be needed by more seriously ill patients. Few interviewees exclusively considered health professionals responsible for their patients' health status.

Professional skills of clinicians and contact person

Patients expected providers to possess comprehensive medical knowledge to make a fast and accurate diagnosis based on state-of-the-art knowledge; and can offer treatments which are effective, safe, easy to administer and integrate into daily routine, with as few side-effects as possible, while fitting the individual patient's needs. Taking a holistic view on the patient, considering family history (eg, genetic predispositions), the current personal situation and the patient's social environment were mentioned as prerequisites for PCC. Some patients appreciated knowledge and official qualifications on complementary medical therapies, since it broadens the therapeutic scope of a provider.

Finally, continuous trainings and specializations were considered to improve provider skills. Especially, communication skills for interacting with eg, demented or anxious patients were considered valuable. Complementary, expertise and professionalism were considered relevant to assess own professional limits in treating specific patients and, depending on these limits, referring the patient to a specialized colleague.

Personal characteristics of clinicians and contact persons

Individual patients reported a variety of desired care providers' personal characteristics. All were considered necessary to maintain humanity in care, but their degree of importance and expected intensity differed depending on patients and situations of seeking care. Firstly providers must *be present & pleasant*, meaning that they should focus on the patient and should not be distracted or pressured (eg, by time constraints) during patient appointments. Specifically, providers ought to create a friendly and pleasant atmosphere and dedicate a sufficient amount of time to answer questions and explain treatment plans. In addition to being present, providers should also *show interest & understanding* for the patient's complaints,

needs, and fears and take them seriously, even though they seem to be less relevant from a medical perspective. Being understanding towards the patient's needs and use of services, conveyed towards the patient through a positive attitude (eg, reporting personal experiences, emotional involvement) without comparing one patient's health problems to the severity of another patient were considered important determinants. Interviewees expected providers to *show commitment* to the patients' interests and responsibility for pursuing patients' interests within the process of care, irrespective of opposing financial incentives and constraints. Moreover, providers should *be flexible* in making treatment plans since patients seek individualized care based on personal needs and circumstances. This includes actively considering patient preferences (eg, regarding treatment alternatives). Interviewees explained that providers should also be flexible in their behavior and communication depending on the particular patient (eg, child vs. adult, demented vs. non-demented). This was also one reason why participants considered it important that providers are *able to take negative feedback* without feeling personally blamed or challenged by the patient. Participants stated that asking for more information or additional explanation was sometimes misconstrued as affronting professionals. They also reported feeling uncomfortable providing feedback within consultations with limited time frames. Hence, taking criticism seriously was considered a valuable trait eg, to adapt the treatment plan or developing a trustful relationship. A common reported option of expressing negative feedback was to seek health care from another provider. Finally, providers were expected to *be honest & open*. On the one hand this facilitates understanding of clinicians and other person's recommendations and instructions. On the other hand it allows patients to critically think through recommendations and have realistic expectations about their situation. While interviewees considered all these characteristics important, none of them could compensate for low professional skills.

Physical and emotional well-being of clinicians and contact person

Patients generally acknowledged that health care professionals across organizations are facing a high responsibility and workload. Some patients reported that work overload and exhaustion decreased the provider’s ability to provide PCC and increased the risk of errors. Patients also reported that they feel uncomfortable when requesting services from an overburdened staff member and sometimes preferred not to ask for help or information to prevent further burdening.

Interventions

Interviewees expressed several general characteristics of interventions selected during the care process. The major goal of seeking care as stated by participants was improving health or preventing deterioration of their health status by receiving interventions or recommendations, which *effectively* address the individual’s physical or mental health problem. Moreover, interventions were preferred if they have none or acceptable *side effects*, are *easily administrable* and *can be integrated into daily living*. What to consider effective, acceptable side effects or easily administrable differed between patients eg, due to differing perceptions of sensitiveness to side effects and different individual treatment expectations.

Meso level 1 determinants related to health and social care organizations

Patients reported various aspects relevant to PCC provision on the level of HSCOs or separate departments of such organizations (see also supplementary file 2, page 5-8).

Process of care within an organization

Coordination of care

Patients report various deficits, but also positive experiences of related coordination of care. Waiting times were perceived as acceptable if the provider later on also takes sufficient time for patients or if more severely ill patients were prioritized. Nevertheless, patients often

assumed deficits in the coordination of care processes instead of emergencies to be the cause of waiting times.

Interviewees reported that the delivery of documents and information often happens due to the patient's initiative rather than as an institutional process. A joint coordination of the following procedures in care was requested by interviewees. This implied eg, communicating the next diagnostic or therapeutic steps as well as discharges or referrals to another care provider. Related to inpatient hospital care interviewees reported their appointments sometimes to be canceled at short notice or that patients have been forgotten for therapy. This seemed to be a minor problem in nursing homes, where interviewees perceived a regular and predictable schedule. Regarding structured care programs (eg, DMP) interviewees valued the well-coordinated care process, but sometimes also felt controlled if follow-up intervals were not adapted to individual needs, but strictly followed a guideline.

Continuity of care

For patients, PCC implied *continuity of care*. This included *continuity related to the care process*, but also *continuous contact persons*. Interviewees requested eg, aligned and gapless care meaning, that someone oversees and coordinates all steps of care and can guide the patient through the process. Especially at points of transitions or significant interventions interviewees requested a structured check eg, regarding the question whether the patient is able to fulfil activities of daily living or needs help. Interviewees also mentioned that sometimes a longer time frame lies in between diagnostics and start of treatment, implying a disrupted care process during which the patient is left on its own. Continuity of care was perceived as being established satisfactorily within DMPs since regular appointments and continuous contact to necessary care providers is established.

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Continuous contact persons were highlighted as an important determinant of PCC, since establishing relationships of trust and in-depth knowledge of individual medical history takes time. Interviewees explained the importance in particular in relation to GPs. Especially elderly patients, patients with life-threatening disease or with mental health problems reported difficulties in getting acquainted with new people over and over again. Frequent changes in contact person were reported to occur often during hospital care.

Flexibility of care

Next to the individual care provider’s flexibility, patients appreciated flexibility of care processes in organizations in terms of individualized planning of care adapted to the needs of patients and relatives. This included eg, consultation hours, which are feasible for fulltime employees especially those with chronic diseases, who often have medical appointments. Moreover, individually planned transitions, or a flexible change of appointments and a self-initiated appointment allocation (eg, via online systems) were requested. Positively evaluated examples were especially rehabilitation units with individualized therapies and schedules, which is flexibly adapted to the patient’s needs. Also, individual decisions on hospital discharge in cooperation with the patient were positively evaluated, eg, if patients need to organize home modification or nursing services.

Timeliness of access to care

Patients requested waiting times for appointments to be reasonable. This was considered an important criterion of well-organized care. Patients complained that it is difficult to get specialist appointments promptly, especially when being insured with the SHI and that despite appointments they often have to wait a long time in the waiting room. Particularly waiting times for diagnostics or treatments in the course of serious diseases such as cancer was perceived as very stressful. The acceptability of waiting time length for and at appointments varied between

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3 patients eg, in relation to disease severity or depending on whether patients were retired or
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5 working fulltime. Interviewees explained that transparency about processes and reasons for
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7 delays would contribute to higher acceptance of waiting time. Interviewees prefer the GPs to
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9 provide support in finding specialists more quickly. To do so, patients considered GPs who
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11 operate in networks or medical service centers valuable.
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15 *Culture and Climate*

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17 A welcoming *atmosphere* and a feeling of being respected within a HSCO were considered
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19 important for patients' wellbeing. From the patients' perspective, the *atmosphere* is closely
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21 related to the general way of staff members' interaction and communication with each other in
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23 the HSCO. Staff members communicating harshly with each other or negatively about other
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25 patients induced daunting feelings in patients and did not support a welcoming and trustworthy
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27 atmosphere. Communicating calm and friendly despite stressful situations was reported to calm
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29 down patients and supports the feeling of being cared for by a competent and functioning team.
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31 A basic determinant shaping the culture and climate in a HSCO was the infrastructure of the
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33 HSCO (see section "Infrastructure"). Additionally the provision of *non-medical special*
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35 *services* such as magazines, water, coffee or tea made interviewees feel welcome at a HSCO;
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37 and depending on waiting times these were even considered necessary (eg, water).
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44 Interviewees would value *structured feedback options* such as patient surveys on the level of
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46 HSCOs, on the one hand to improve their own care, but also to improve care for future patients
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48 in a particular HSCO. Since structured feedback methods are not common -especially in the
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50 ambulatory care sector- the only way to express negative feedback is seeking care from another
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52 HSCO. This was often considered necessary since other options were unavailable. Patients who
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54 expressed feedback (verbally or in writing) felt disregarded and very disappointed if such
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56 feedback was not replied to either through a dialogue or by implementing suggested
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58 improvements in the HSCO.
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Staffing & Workload

Interview participants described that teams of care providers can only provide good care if the *number of staff* is sufficient in relation to the number of patients. An adequate staff to patient or staff to task ratio, respectively, was regarded as the basis for providing safe, hygienic and effective care. However, not only the total number, but also the *mix of experience and skills* and a sense of *cohesion among staff members* were considered necessary. Interviewees explained that even the most experienced and skilled care providers can only provide PCC if they work closely together, support each other and apply the variety of staff skills as needed disregarding hierarchies. Sometimes interviewees even had the feeling that a well-functioning team can compensate an overall lack of staff members, whereas non-functioning teams do not work well regardless of staff number. Participants perceived a higher level of task separation being potentially associated with negative effects, since care providers would feel responsible for only a minor part in the process of health care provision (eg, task-oriented nursing). In contrast, a lower separation of tasks combined with a continuous contact person (eg, primary nursing) was considered supportive for PCC as long as no specialized skills are needed.

Infrastructure

Interviewees explained the role of *physical* and *technical* infrastructure aspects in facilitating PCC. Especially in the ambulatory care setting providers with a broader range of technical equipment could contribute to faster and more coordinated diagnosis and treatment eg, if patients do not need to arrange specialist appointments for additional examinations. Interviewees expected the technical equipment to be serviced and at best the latest state of technology. This included more calm and less fear inducing devices. Interviewees also explained that the availability and use of *information technology* was important to reduce loss of information between different departments especially in the case of large hospitals. Interviewees also described the influence of the *built environment* on their care. First, HSCO

need to be accessible for all patients, which includes aspects ranging from being geographically close to their homes as well as having wheel-chair ramps and informative signs within the HSCO. Interviewees expectations specifically related to inpatient care included clean and modern facilities with small units in general. Patient rooms, which allow for privacy and recovery, eg, by having only two to three patients in one room or having private rooms for any consultation or examination between patients and care providers or other contact persons were considered valuable. Also sharing bathrooms with less people was considered more comfortable and hygienic. The provision of safe havens such as seating areas away from hallways or waiting areas was considered necessary for private conversations with relatives and friends. While interviewees were appreciated that hospitals do not have to provide hotel-like services, negative experiences such as dirty facilities or confined spaces considerably influenced patients overall impression of the HSCOs.

Meso level (2) determinants related to the cooperation among health and social care organizations

At this level patients considered all factors summarized under *processes of care* described on the level of one organization relevant for the collaboration between organizations as well. Problems experienced by patients mostly related to coordination and continuity of care eg when information was not provided to following care providers, transitions between HSCOs were not planned well or no organization felt responsible, but always another provider is assumed to take responsibility. Also patients reported experiencing repetitive diagnostics, which was considered unnecessary, since all care providers should perform diagnostics at the same level of quality and share their results. Moreover, interviewees considered such diagnostics inappropriate cost drivers and felt that time consumed for repetitive diagnostics could be used in better ways in the care process (eg, explaining procedures). Interviewees reported a lack of information when being referred to a specialist. Receiving specific recommendations for a specialist was

considered helpful in finding qualified providers, but also providers who smoothly cooperate with the patient’s GP.

Macro level determinants related to structural, financial and legal conditions of care provision

On the macro level, interview participants explained the *structures of the health care system*, the *financing & reimbursement* as well as the *laws and regulations* shaping health and social care provision as relevant determinants of PCC (see supplementary file 2, page 9-10).

Structures of the health care system

Participants described the structures of the German health care as very complex and sometimes confusing with its high degree of separation. Interviewees often mentioned that they were sent to other providers since the provider they contacted was not the primarily responsible provider for the particular health problem at stake. This was especially the case for ambulatory out-of-office hour GP-practices, which were meant to be visited instead of hospital emergency departments in case of non-life-threatening conditions. In line with this, interviewees described examples of the fragmentation of care provision eg, by having to contact different providers at different locations of whom none feels responsible for the overall care process. Interviewees they felt not educated well about the structures of the health care system to prevent unnecessary or wrong utilization of health care services.

Financing & Reimbursement

Interviewees considered fairness elements in modes of insurance payment and service provision important. This includes eg, that contributions to the SHI are levied as percentage of actual income or receiving care based exclusively on medical need. Sometimes patients perceive the insurance status (statutory or private) leads to differences in treatment not justified based on medical need. This was illustrated eg, by being asked first about the health insurance when requesting an appointment rather than being asked about the medical condition.

Regarding reimbursement, interviewees often expressed that they do not understand why particular therapies are reimbursed and others are not. Since ambulatory physicians in Germany have a so-called care-budget, which they have available for distribution among patients and interventions, patients often did not know whether eg, medication or therapy is or is not prescribed because it is (not) covered by the insurance in general, whether the physician considers it too expensive to prescribe this from the care budget or whether care providers actually base their recommendation on effectiveness. The same doubts were reported for recommendations regarding out-of-pocket paid interventions. Only few patients were aware of specific reimbursement processes and most were not aware about detailed mechanisms, but in general they perceived reimbursement to be intransparent. Such complexity of payment schemes and non-transparency was reported to induce distrust towards providers and insurances, and a feeling of insecurity regarding trustworthiness of recommendations. Several interviewees also called for the extension of the SHI's benefits catalogue particularly for naturopathy, homeopathy, eurhythmics or other alternative forms of therapies, since they experienced them as helpful in their personal care process and facilitating PCC.

Laws & regulations

Interviewees urged for a more timely reaction to challenges requiring political action. Since challenges such as lack of staff or financing and reimbursement mechanisms require political action, challenges often cannot be addressed flexible, but require long time frames. During these time frames quality and PCC was perceived to decrease eg, not increasing nurse wages was assumed to be one reason for the growing lack of nursing staff. Interviewees perceived the political initiatives to address problems in health care supply as insufficient.

Interviewees also perceived the integration of health care with other social services related to health care as suboptimal. The health insurance is responsible for covering the treatment of patients, while the pension insurance is responsible for the payment of rehabilitation of working

patients. Interviewees perceived that the boundaries between treating patients and re-integrating them into the labour market are not that clear cut in practice, which sometimes lead to health insurance and pension insurance discussing about the financial responsibilities and thereby delaying care initiation. Also rehabilitation was sometimes perceived to be approved by insurances primarily to evaluate whether patients are able to return to work fulltime instead of focussing on recovery, which patients sometimes experienced as degrading.

Interviewees described that they perceive supervising mechanisms of clinical care practice such as regular audits of physicians to be unavailable or implemented insufficiently. These were considered necessary since interviewees themselves felt insecure about judging the quality of medical care by themselves, but require assistance. In the case of perceived medical errors, over- and undertreatment interviewees were unsure how to react. Regular checks of local physician offices by an independent institution were considered to reduce or prevent such problems.

DISCUSSION

This study identified determinants of PCC from the perspective of chronically ill patients. PCC is considered a multidimensional concept with determinants on the micro-, meso- and macro level. The *micro level* was described as having the highest impact eg, through conversations and decisions for the individual patient and the direct experience of behaviours and decision. On the *meso level* patients described a smooth flow of information within and between organizations as well as functioning care teams as important aspects for providing PCC. Interviewees preferred to have continuous contact persons, which enables building trustful relationships, having a complete overview of the medical history, and feeling responsible for the whole care process. Determinants identified on the *macro level* included the structure of the health care system, financing and reimbursement mechanisms as well as laws and regulations. Interviewees described that a lack of transparency and comprehensibility of regulations were

perceived as barriers to PCC since it induces distrust of the patient towards the health care system and care providers.

The two determinants of PCC expressed by all patients were receiving effective interventions and the successful interaction with the health care provider and other contact persons. Both personal and professional skills of providers were considered relevant, with professional skills being even more important. The variety of personal & professional skills facilitating PCC and their different importance in different situations illustrate that behaviours of professionals need to be constantly adapted for the particular situation and patient. Patients also perceived healthy staff members with good working conditions as being better able to provide PCC- an impression supported by other studies.[22 23] The finding from previous studies that well-functioning teams, where members support and communicate friendly with each other and have clear responsibilities facilitates PCC was also experienced by participants in our study.[24] Therefore, supporting teamwork might be a general measure to facilitate PCC regardless of the particular care setting.

In addition to previous models of PCC our interviews revealed that interviewees considered themselves and other patients as determining PCC. This included eg, active participation in care plans, and seeking care from the adequate provider at the right moment. In addition to the “activated patient” as described in the Chronic Care Model [3] an intrinsically “active patient” was perceived as being a facilitator for PCC. Nevertheless to fulfil this role, easily accessible understandable information materials and training offers need to be available. Additionally, treatments which match the personal health, but also social situation should be chosen to facilitate active participation of the patient.

Another finding adding to previous models is the importance of all contact persons in health and social care not only as often termed “clinicians” or “physicians”. Sometimes non-clinical staff members eg, receptionist, insurance staff, cleaning or service staff contribute to or hinder

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PCC provision as much as health professionals. Therefore, trainings in eg, patient communication should be offered for all staff members who potentially get into contact with patients, not only medical staff. This is also related to the interviewees’ perception of PCC being facilitated not only by individuals but also by functioning teams. Providers who consider themselves as part of a whole care team within and across organizations without shifting responsibilities from one person or from one institution to another were experienced an enabler of PCC. Such care models should be facilitated, encouraged and supported by further incentivising integrated care contracts. Especially in ambulatory care, health care centers could be an option to also physically support team based care provision, since different providers are at one place. Patients with chronic illnesses usually need care from various providers from different sectors, which can be overwhelming.[25] Providing structured support in navigating through the care system and contacting the right providers may facilitate PCC.[26] Approaches such as the *Guided Care Model* might help to finding the appropriate health care providers and developing a long-term treatment plan, increasing the patient perception of care quality and physicians’ satisfaction with care processes.[27-29] While this approach of managing care by a trained guided-care nurse was tested in the ambulatory sector, it might also be used in the hospital sector when it comes to transitions from hospital to other providers or to home. However, when implementing structured care models, a balanced level between standardizing and individualizing must be given. [30] Patients generally value the advantages of eg, DMPs, but some patients reported pressure to subscribe or felt being controlled by physicians and the SHI. Therefore interventions intended to improve PCC need to be voluntary and despite being structured leave room for individual adaptations such as extending monitoring intervals in case of stable conditions and high adherence to care plans.[30]

Some of the determinants of PCC expressed by the interviewees are ambivalent or even conflicting. While on the one hand patients expect a smooth and uncomplicated exchange of

data between care providers, they also prefer to share only specific health care information with specific providers, which impedes communication among providers and interdisciplinary care. Reasons for this behaviour are diverse, (eg, embarrassment, lack of trust in provider) and solutions are not yet systematically established.[31] Another ambivalence relates to, study participants' and German patients' request for the most effective care, but at the same time demanding the reimbursement and more frequent use of eg, homeopathy and other therapies, which still lack high quality evidence for its effectiveness in comparison to conventional medicine but are nevertheless considered helpful.[32 33] Such findings raise the question of how to integrate patient preferences and expectations and the best external clinical evidence into evidence based PCC, which is currently discussed.[34] Another ambiguous finding was that GPs are considered important actors in coordinating care and visiting a GP first was considered as a facilitator of PCC with regard to preventing unnecessary resource use. Nevertheless, interviewees objected to a gatekeeper system, since they prioritized their freedom of seeking care from any provider, but receive recommendations for specific specialist from GPs. However, rules of professional conduct of physicians in Germany allow specific referrals only in case of sufficient reasoning, since local physicians are obliged to maintain neutrality towards other providers.[35] Finally this study identified facilitators and barriers on the macro level, which previously received less attention.[8] Due to the complexity of the German and other countries' health and social care system, it is difficult for patients to know all regulations regarding eg, financing, reimbursement and care structures. The imbalance in information can induce distrust in the health care system and providers, non-acceptance and misconceptions about choices made health care. Next to medical patient information, easily accessible and understandable information on the health care system in general should be made available.

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Limitations

Our study has several limitations. Firstly, the experiences expressed by the interviewees are subjective and might be subject to recall bias, since not all experiences were reported right after the event took place. However, looking back for a longer time frame also allowed the patients to reflect on their past experiences. Also, all patients had at least one care experience in the last three months. We also considered all experiences as relevant, since we were mainly interested in the interviewees’ subjective expectations rather than absolute truth of reported experiences. Secondly, we only interviewed patients living in Cologne or surrounding communities. This implies an overrepresentation of people living in urban areas. However, interviewees also reported experiences from former places of living including rural areas. Additionally, we expect determinants to be universal since none of them particularly relates to urban care provision.

Conclusion

Many determinants of PCC addressed by patients can be supported by changes in individual behaviors, restructuring of care processes within organizations and supporting team based care provision. Future research should investigate in more detail which particular interventions are suggested by patients to improve PCC in various settings and on various decision levels.

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Ethics approval The Ethics Committee of the Medical Faculty of the University of Cologne approved the study (reference number: 17–210). All participants provided written informed consent. All participants who travelled to the University Hospital Cologne were covered by travel insurance.

Patient consent for publication Not required.

Data statement Since complete transcripts of interviews potentially allow for identification of individuals, complete transcripts cannot be provided.

Author contributions

SSt (female, f), LK (male, m), LA (f) conceived the study. VV (f), KH (f), HH (m) and SSt specified the methods. VV conducted the interviews. VV, KH and HH analysed the interviews. VV drafted and revised the manuscript in cooperation with KH and HH. All authors critically read, revised and approved the final manuscript. VV is guarantor. KH, HH, and VV were PhD candidates at the time of conducting the study. SSt (MD) is professor for Patient Centered-Care and Applied Health Economics, LA is professor for Organisation-related Health Services Research, and LK is professor of Business Administration and Health Care Management.

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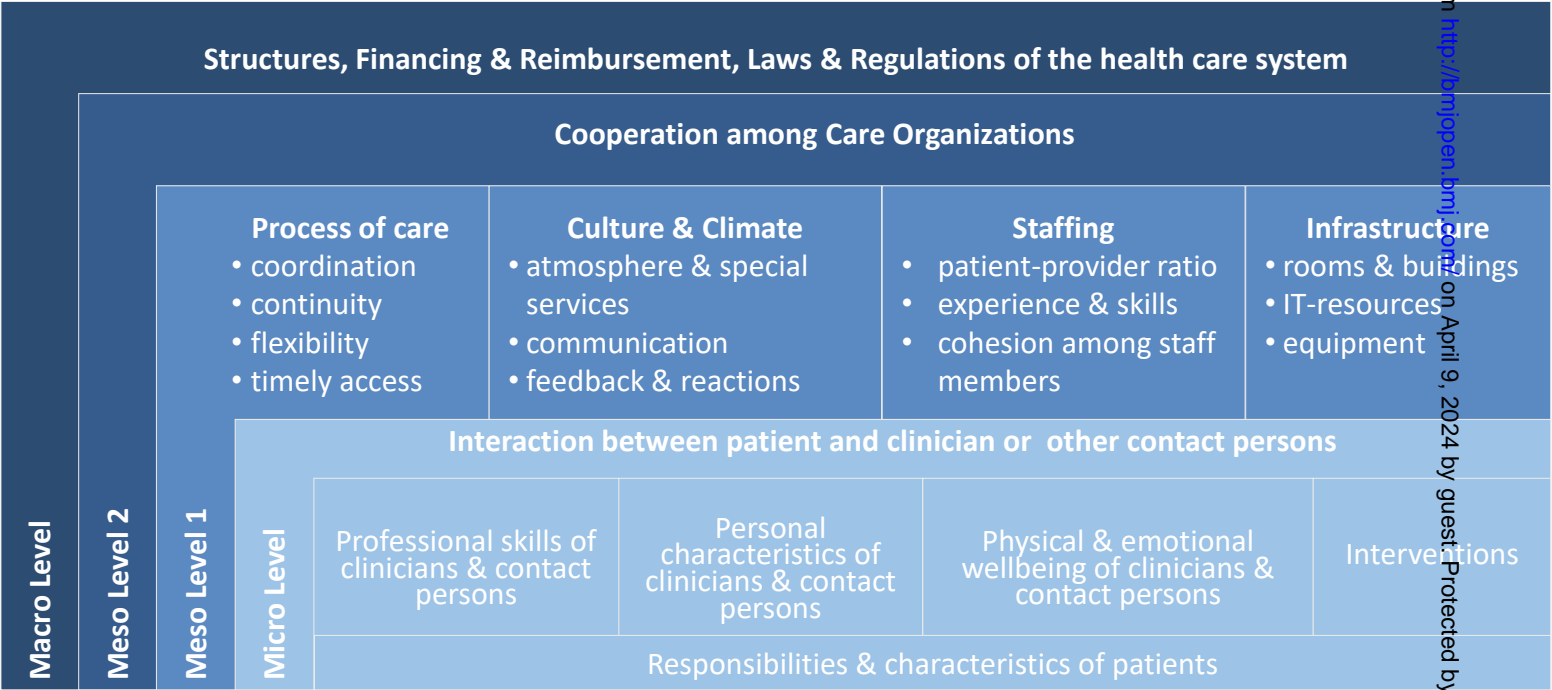
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For peer review only



OrgValue

Interview guide for patient interviews

General information

Aim	The aim of the interview is to get a patients' assessment of what is critical for a patient centered care.
Duration of the interview	ca. 30-60 minutes
Place of interview	At the meeting room of the Institute for Health Economics and Clinical Epidemiology, at the patient's home, by telephone
Preparation	(As the circumstances require) Providing: <ul style="list-style-type: none">- Recording device- Office supplies (pens, paper)- Patient questionnaire- Flipchart
Arrival of the participants	Seating, Offering beverages, collecting patient questionnaire & informed consent forms if not submitted in advance

Part 1: Introduction, Presentation of the project, Preparation

Introduction	Welcome and thank you for taking the time to participate in our study. My name is Vera Vennedey. I'm a research associate at the Institute for Health Economics and Clinical Epidemiology at the University Hospital of Cologne.
Presentation of the project	The project, of which this survey is part of, is financed by the ministry of education and research. We would like to establish a network for research and development dedicated to improve the regional health care provision for different patient groups and to develop ideas, how to make provision more patient centred. That means to acknowledge the patients' needs and wishes. Today's survey is about what you expect of health care, what you would assess as positive and what is needed of improvement.
Recording device & Data privacy	With your consent I would like to record our discussion. Later on it will be transcribed and evaluated, that means we will summarize your statements. Your statements will only be published anonymously, that means your name will under no circumstances appear in reports or publications. The recordings will be kept securely and will be deleted after the transcription. After this, only the written text will be available but not the original recordings. Your participation in the interview is voluntary and you are free to stop at any time. You are allowed to refuse to answer questions. In general, there is no right or wrong answers to the questions I ask, it is just about your personal opinion. You are allowed to ask questions at any time during the interview. When you answer the questions, there is no need to name specific persons or institutions, since I am mainly interested in what you experienced and not who exactly did the things you tell. So it is enough if you tell eg, "My GP always does..." and do not mention his name.



Part 2: Describing the patients’ point of view on patient centered care

Topic	Key question	Follow-up questions
What is patient centered care from the patient’s perspective (facilitators)?	<p>Can you describe a situation in which you, as a patient or person were treated, consulted or taken care of in a particularly positive way?</p> <p>Further stimulus, in case the participant doesn’t know any:</p> <p>This, for example, could be a situation with</p> <ul style="list-style-type: none">- a doctor,- a hospital,- a nurse- a pharmacist- a therapist- insurance- another person in context of health care	<p>What was particularly good? Why?</p> <p>Who or what contributed to it?</p> <p>What was the main aspect, which made the situation a positive experience?</p> <p>Do you remember another situation?</p> <p>Can you tell how this started and was addressed by ...?</p> <p>Possible additional topics depending on the referred issues in the participant’s answer</p> <ul style="list-style-type: none">- Integration of medical and non-medical provision- Coordination and continuity of care- Accessibility of care- Important traits of doctors/ providers- Connection with provider- Communication- Involvement in care (patients)- Involvement of family and friends- Patient (Empowerment)- Physical support (pain reduction, functionality, etc.)- Emotional support- Acknowledgement as an independent and individual person with biopsychosocial needs- Information for patients- surroundings
What is patient centered care from the patient’s perspective (barriers) ?	<p>Can you describe a situation in which you, as a patient or person were treated, consulted or taken care of in a not so pleasant way?</p> <p>Specification of the Situation, in case the participant doesn’t know any:</p>	<p>What was particularly negative? Why?</p> <p>What or who contributed to this?</p> <p>What was the main aspect, which made the situation a negative experience?</p> <p>What would you have liked to happen?</p> <p>Do you remember another situation?</p>

	<p>This, for example, could be a situation with</p> <ul style="list-style-type: none"> - a doctor, - a hospital, - a care attendant - a pharmacist - a therapist - insurance - another person in context of health care 	<p>Can you tell how this started and was addressed by ...?</p> <p>Possible additional topics depending on the referred issues in the participant's answer</p> <ul style="list-style-type: none"> - Integration of medical and non-medical provision - Coordination and continuity of care - Accessibility of care - Important traits of doctors/ providers - Connection with provider - Communication - Involvement in care (patients) - Involvement of family and friends - Patient (Empowerment) - Physical support (pain reduction, functionality, etc.) - Emotional support - Acknowledgement as an independent and individual person with biopsychosocial needs - Information for patients - surroundings
<p>What could be improved? Additional suggestions</p>	<p>How would you like your health care to be improved?</p> <p>Was there anything you had in mind and wanted to tell me today, but I did not ask a question where it would fit?</p> <p>Free association and the possibility to address wishes and suggestions.</p>	



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Responsibilities and characteristics of patients

- So I said to him, “I’m very scared, could you be a bit careful – or talk to me?” Then he knew what was going on and could act accordingly, and that made it much easier in the end.
- I don’t need to do any injections, take any tablets, or anything. But only as long as I take care of it myself, you know? (10)
- I move home a lot, so especially when a new GP in a new town asks “So, have you got your records?” Well, eventually I started collecting everything from my past, more or less. (25)
- I think it was kind of a three-part solution: the operation went well, then I stuck to the rules, and then I did the physiotherapy. (18)
- I believe you have the best experiences when you take an active interest yourself – so you don’t call the doctor every time you feel a little poorly and you take responsibility for your own health instead. But on the other hand, you need to speak openly about what you want, or what’s wrong with you. And don’t be vague – saying “I don’t feel well,” or whatever. Try to be specific about what the problem is.” (18)
- Yeah, I mean, any fool knows to take their car for a regular MOT, get their tyres changed for the winter and have everything checked over. So above all else, I should do the same for my body. So I think you have to take a lot of responsibility for your own health. (18)
- As a patient in that kind of situation, you have to remain vigilant, play an active role in the process – think for yourself, be assertive, you know? And you can’t expect that from a patient – you can’t expect them to be able to think about things first and be assertive. That’s not how things work, is it? (23)
- Or you need to pay quite a lot of money – depending on when you want the space. [Space in a dementia care facility] (21)
- Because I always have to pay extra for compression socks – but you do notice that actually, when you still constantly pay have to extra. (25)
- And I mean it’s common that you essentially have to take a lot of responsibility for things yourself. When it comes down to it, it can feel a bit isolating sometimes. Especially with things like when one doctor refers you to another – then you’re expected to more or less trust them immediately, automatically. (6)
- Because if I don’t like something, I say it. But I don’t mean just whining for the sake of it. I try to express my concerns reasonably and make it clear to him that I don’t agree with it – either because he’s not explained it to me well enough or because I know for myself that you don’t need it. (18)

Professional skills of clinicians and contact persons

- Most of all, what I never really experienced for some reason, and still don’t sometimes – I mean, it could be different with this doctor, I don’t know – I’d like them to put a bit more emphasis on natural healing stuff, you know? Instead of always taking the nuclear option, using a sledgehammer to crack a nut, you know? (16)
- Yes, I mean “experienced” in the sense or “professional,” that was the impression I got. That the people knew what they were doing. I didn’t see anyone who was panicking or looked like they needed help. (17)
- I mean, I’m getting on, and so my doctors are, too. I don’t get on well with younger ones, because they seem to me like they lean too heavily on medical equipment and appliances. And that wasn’t the case with the older ones – you’d known them for over ten, twenty years, so they know what your issues were and what to do about them, you know? (18)

- There are also a lot of doctors who don't have much experience with dementia – I didn't either until my husband got the condition. I mean, you have to speak really slowly, even if he doesn't understand everything, so it's a completely different way of talking. And if you don't have that experience as a doctor then – well, it's not great for the patient. (21)
- She would have treated me like any other patient who doesn't take blood thinners, which would be – I mean, even my tooth – if she slips, I could start bleeding, and then I'd really start bleeding. (25)
- And the GP – well, firstly, I'd say he knows me pretty well. And secondly he seems in good shape. Even if he's just my GP, of course, whose practice is just around the corner. But that's the most important thing for me, actually. (6)
- Maybe that's one of his characteristics: he's not just a medical expert – whatever he studied, I've no idea what he specialised in – he's got an additional qualification too, it says it on his sign. A diploma in Psychology. And he doesn't offer psychological consulting as far as I know; he's just a general doctor. But I think that's why he's maybe better than your average GP – because he's got that extra qualification in psychology. That means he's qualified to engage with his patients a bit more on a personal level. Not just, "Hello – here's your medicine – bye!" He treats his patients like people. (6)
- Sometimes the best doctors are the ones who know so much that they don't just give you an injection – they tell you, "In my experience, you don't actually need this injection."
- And she just took one look and said, "Here's your diagnosis". And she said she didn't understand how all the other doctors I'd been to hadn't recognised it. (9)
- I just had pains that no one had ever taken seriously. It wasn't until I was in my early twenties, when I met a consultant at (hospital name) – he saw me come in and said "I know what's wrong with you." He prescribed me corrective shoes, took me off all the pills, and then I could walk. (9)
- As a patient, I can't keep track of where everything comes from anymore. And no-one seems to care. I've always dreamed of finding a doctor who specialised in holistic medicine – someone who would look at my body as a whole and see how the different issues affect one another. (9)
- That kind of active listening plays an important role, especially in discussions between a patient and their doctor. He didn't do it. (23)
- I changed GP recently. I just felt that with this genetic defect and the embolism, my previous doctor – while she was great for me on a personal level – sometimes wasn't so good on the technical side. (24)
- Because he was technically good, you know? But most of all, I was able to say to him, "Mind your tone – if you want to tell me something, you shouldn't say it like that." And then he said he was really glad I wrote him that letter. And that was such a positive experience: to be able to go in to see a doctor and make yourself understood, and let them know if you're not happy with something. (21)
- So I'd like my doctor to actually say to me, "I don't know," if it's not his field or whatever. I mean, it's only human really, if you can't do everything. And then he should have sent me straight to the vascular surgeons, but – well, at first he didn't really want to sign the referral. (25)
- Then I'd say, for me, good treatment is a combination of mutual respect – a good relationship – and then really high quality on the medical side. Those two components, basically. (21)
- Well, for me it's definitely important. If I notice someone has the medical expertise but I don't really get on with them or whatever – then it's definitely important for me to be able to express that. (21)

- Well, firstly the staff here were very competent: starting with the lady at reception, where you sign in when you arrive, and then the kitchen staff, the doctors, psychologists, psychiatrists, sports therapists, occupational therapists, art therapists – there was no-one who really made you think... You could tell they really liked their jobs. (11)

Personal characteristics of clinicians and contact persons

- He was rushing so much and he wasn't really listening anymore. And he was already heading for the door, like he was going to leave – and I wasn't finished talking. I was still sat there, and he was already at the door. (12)
- They were nice and friendly. They said hello, asked, "How are you doing today?" and so on. They didn't just bluntly wander in, do something and then rush out again. (17)
- And next time I was there, I could tell he'd been thinking about it. He said as well, "For some reason I couldn't stop thinking about it." And then he explained that he wanted to give me this – what was it now? A probiotic. But because my immune system was already weaker than usual, he couldn't. It could lead to an exacerbation in my intestines and so on. But at least he'd explained it to me very well again, and I could see that he cared – that my concerns mattered to him, you know? (16)
- Well, he said that it ran in his family, too. And when I was there for the second time, I think, the results from my lungs were much better, and he was practically jumping for joy because he was so happy about it. And it was infectious – I actually felt really good when I left. (24)
- I worry, but they don't leave me alone with my worries. They speak to me. I ask very specific questions and they notice I'm scared, and then we talk about it, too. They don't try and dismiss it, tell me it's not that bad or that it depends on the weather. They say, "These are the risks, these are the dangers. Don't go on holiday on your own, don't go hiking in the Norwegian wilderness" – all that kind of thing. (20)
- He just knew, "Okay, (patient name) is done. Done with the world." And somehow he managed to connect with me, you know? Or I connected with him, in the end. (16)
- It was the human side, too: you're not just sitting in front of someone who's only communicating in writing, who doesn't even look at you or acknowledge you. And you'll notice with me – well, let's just say that if there's something troubling me, I need to get it off my chest. (5)
- "And if you're going to do that, then please tell me, otherwise I won't be ready. I get scared very easily." And then she was very dismissive; she said, "Well, I didn't know you were going to be so sensitive." (17)
- Well, I think I would have liked a little empathy. For instance, he could have said, "[...]. And I understand it's not an easy decision for you to make, but I would advise you do it." So he could have started off a little differently, and then said, "But based on your symptoms, I really think this is the right thing to do." (21)
- And most importantly, he tells me when one type of therapy or other doesn't make sense for me anymore. "The cartilage is gone, why would I give you a hyaluronic acid injection? That would just be fleecing you. Nothing else is going to build back up there; it won't work. It's too late for that, you know?" He could just as easily say, "Okay, I'm going to give you this and this, and it costs this much" – because it's not covered by the insurance, you know? And I wouldn't be able to pay for it anyway. But that honesty, I like it, you know? After all, I'm honest with him. (13)
- And to start with he was just sat in his armchair like a friendly old uncle, just listening to me. And it was really nice, you know? He didn't just get straight down to business. He didn't just say, "Okay, let's have a look," then start shoving medical instruments in me or

whatever. He actually listened to me, then really calmly, he said, "I'll need to take a quick look." And he explained everything to me, and that was great. (17)

- She's very laid back. She doesn't speak in medical jargon all the time – she's very easy to understand. And I really like that; it shows that she cares. (25)
- Yes, she [the Nursing Director] made time for us. She kept coming back now and then, and she spoke to my husband, too. There were so many things that had gone wrong, and she always showed an interest. (22)
- The doctor's attitude towards me, the way he was lounging on his chair...(10)
- Yes, absolutely. I usually reply, "I may be old, but I'm not stupid!" And that works. It shocks them when you just come out and say it, you know? And sometimes they start apologising: "Oh God, I'm sorry, did I say something wrong?" And I say, "Yes, you did." (20)
- Well, firstly the staff here were very competent: starting with the lady at reception, where you sign in when you arrive, and then the kitchen staff, the doctors, psychologists, psychiatrists, sports therapists, occupational therapists, art therapists – there was no-one who really made you think... You could tell they really liked their jobs. (11)

Physical and emotional well-being of clinicians and contact persons

- It is what it is. Looking back, I think, "That poor young woman, I overwhelmed her." I think that sometimes. (5)
- Well, I don't know if it's the shortage of staff everyone's always talking about – I read about it in the paper, you know? The nursing crisis. I couldn't say. But if there is one, they didn't let on, you know? And that's something, at least. (17)
- So you have to wait for a long time. The practice was very full, very busy – overrun, it seemed to me. (17)
- You need to be patient, I think. You can't just expect it of others – you need to show a little understanding yourself, you know? The doctors have a lot on their plates, right? And you need to remember that as a patient, I think. (8)
- Of course, I understand that they're often overrun, the GPs and their practices. But why should I be the one who suffers for that, you know? I mean, that isn't right. You know? (12)

Intervention

- Interviewer: How did you know that you were getting good medical care?
Participant: Well, I felt better afterwards, didn't I? (3)
- I have to say, I felt well looked after, well cared for, in a purely medical sense. Maybe that's not the right word, but I kept getting stronger physically, you know? (10)
- I complained once that the tablets were too big – that they were hard for me to swallow. Once, I almost choked! And since then, I've always said, "No, they need to be powdered." (1)
- And with me it took less than a week – my situation improved thanks to the therapy with [medication]. And I was really pleased with that – that it went a bit faster, then. (15)

Meso Level 1&2

Process of care

Coordination of care

- On Monday morning they said “Hmm, sorry, but we’ve had to call off [the operation]. There’s been an emergency.” Okay, that kind of thing can happen. I’ll wait another day, it’ll be fine. Then in the morning, I think, they got me ready and made sure everything was in place, then they took me to be prepped – not straight to the operation prep room though. They put me in some kind of waiting room where there were several beds, but I was on my own. They left me lying there for four hours, while [my family] were sat there worrying. My operation was scheduled for twelve or whenever, but nothing happened – no one came to tell me I’d have to wait a bit longer. Then quite a bit later, a cleaning lady turned up with her mop and bucket, and she said, “Oh, you’re still here!” It took quite a long time, I have to say. Of course, they told me there had been another emergency and so on. And then he said, “They might schedule another operation for you, at eight o’clock this evening.”
I: Okay
B: I was lying there for quite some time again. And then someone else came in and said, “No, sorry, we won’t be doing it today after all.” Hmm, I mean, it makes you think, of course. It’s all about this, you know? [Points to heart] (4)
- There’s so much needless repetition. You give them the results from your GP, and they say, “Those are from another lab, we’re not interested. We’ll do them all again.” (23)
- If a doctor or whoever says, “We’re going to do this and this and this,” so the next doctor and the nursing staff are all kept in the picture – then I know that everything works hand in hand, and that the communication is good.” (21)
- I came in and they examined me, then I was just sitting there and sitting there, and they ended up forgetting me.” (22)
- Now and then I feel a bit like it’s a bit of a hassle – when there’s nothing wrong with me at that moment, then I think “Hm, I need to go to the doctor’s again.” It’s not a big thing, it’s no real effort, but it always happens at the wrong time – when you’re just about to leave the house.
- Okay, so we sent them our documents and records, right? Mine and my daughter’s. Recommendations from therapists on both sides – my daughter had a psychiatrist, of course. So we’d sent them a lot of information, and recommendations for this one facility. We sent them to our health insurance company first, but they said, “That’s not our area – you need to speak to your pension insurance company. We’ll pass your documents on to them.” So we waited, and waited, and waited. And after three months, I thought, “I’ll just ask politely and see how things are going, what the status is.” Then they said, “We haven’t received any documents.” I said, “You can’t be serious. That’s confidential information – doctor’s letters for me and my daughter! The health insurance people assured me you’d received them – I have the date they sent them off right here.” “Nope, we don’t have anything.” Okay, so I called the health insurance company again and spoke to them. And at some point they said there was an association I could speak to that helped in situations like this. So I went there...” (11)
- But they [the nursing staff] were always paying attention, so if you had any kind of issues, they would pass it on and a doctor would turn up. (12)
- I think that [medical care units] would be good. I wouldn’t need to keep going back and forth, driving up there and so on. I’ve got a friend whose husband is really ill with cancer, and she said all the driving is a nightmare, you know? Therapy here, another thing there, then back to the urologist. If it was all in one practice it would save so much time, you know? Not to mention stress. (13)

- Nope, no-one told me anything. I had to find the doctor's office myself. And sometimes I had to ask, "Er, hold on, what's going on here? Just one nurse comes in here and tells me I need to go to another hospital – what's going on?" (14)

Continuity of care

- Well, personally I find it a bit difficult to get used to someone new – or if I'm expecting someone else it confuses me for a second, and I need to readjust. And then I might have to start from the beginning and explain everything yet again; it's a bit difficult. (17)
- I'm meant to be receiving continuous treatment at the Breast Centre, but every time I'm there it's a different doctor. You don't get chance to establish a rapport with anyone. They can't go, "Oh, she was dealing with that last year, let's see how it's developed." And I miss that. (9)
- Well, I'm getting continuous check-ups [in the Disease Management programme] again, too. I feel well looked after. (8)
- "Patient-centred", they call it. Everything's provided for the patient – if they can't look after themselves, you know? If there are no family or friends looking after them. People should be paying a lot more attention to the patient's interests and personal situation – making sure they understand what's going to happen with them, you know? If they ask whether they can go back home and don't know what's going on. I'm not going to go home and lie around unable to do anything, you know? (23)
- Basically, it comes down to the doctor [GP]. I've been to other doctors occasionally, but you hardly know them, so you don't have that same relationship and trust. And the GP – first and foremost, I think he knows me quite well. (6)
- But then you get a phone call at home: "What's wrong with you?" I've noticed that before. "Are you going to keep coming in or not? How are you doing?" That's great. (22)

Flexibility of care

- And he's also flexible with his time. I mean, he has his fixed hours, you know? And his consulting hours are fixed too, but he sticks to his schedule really well, and it's really easy to alter your appointment with him if you need to. So he's flexible, and I can decide when my appointment will be. (15)
- But then they also gave me the option straight away: "If we can't get the child to calm down here, then you can stay here." Then I'd get a bed in the room, too. That was great. (8)
- And I thought it was really good that they decided on a case-by-case basis to keep me there. (15)

Timeliness of care

- You need to make an appointment to speak to the specialist. And I can't say I've really had a positive experience outside of this rehab facility, you know? You're a patient – they do the bare minimum for you, and if that's not enough you need to come back, or you're sent away. You often feel like you're just in the way. (11)
- But in a lot of cases where you're really in pain, you just have to wait, and you're sent away. (11)
- So I went to two dermatologists, and the first one said, "We don't have any appointments free, you'll have to come back in six months." So I say, "But I don't know if I'll even still have the rash in six months. Don't you have special consulting hours for acute cases?" Apparently they didn't. So I went to the next dermatologist: "Five months." So I said, "I don't know if I'll still have it in five months." (13)

- If I've got an acute illness, I want to be given an appointment or taken on straight away, you know? (13)
- I came to the outpatient's department there, and they decided straight away that it was an emergency, and that they wanted to operate on the same day. The whole procedure was organised perfectly; the anaesthetist came straight away and they slotted the operation in in the evening, so to speak. They let me stay overnight and looked after me really well. You could tell that it was actually an outpatient case, but I didn't have anyone to look after me, because I'm on my own. (15)
- And then the fact that everything had to be sorted out so quickly with a place in a hospice, which we hadn't been able to get... That's the problem. And then in the end they put you back in the ward, you know? Like they're saying, "If we can't find a space then the ward will just have to keep the patient. We can't exactly shoot him in the head," you know? Pretty crazy, right? We couldn't take him home with us either, and you can't put a 52-year-old in a home for the elderly – and they're all full to the brim, anyway, the hospices too. You know? He needed his medication, he needed round-the-clock care – we wouldn't have been able to afford that at all. (16)
- I find it incredibly difficult to get an appointment with a specialist in the city. (24)

Culture and Climate

Atmosphere, special services and communication

- In outpatient oncology too, it's more like a conveyor belt – not really somewhere you can feel comfortable, you know? They don't offer you anything, like a cup of tea or coffee, or biscuits, or a newspaper. (22)
- I was just an inconvenience for him, it felt like – I really wasn't welcome as a patient at that moment in time. That's how it seemed to me, I've got to say. (10)
- He was the heart and soul of that department. And the doctors were very friendly with one another, I always thought – you notice that as a patient, too. (10)
- There was all this fuss, you know? You could see from how they acted that the nurses weren't happy. And that really affects the atmosphere and sense of comfort. (16)
- And then they [the staff] were more or less screaming at each other on the ward. Well, it was just awful. (11)
- And it was so great there, I found out – in East Germany. At the polyclinic, they had everyone: internists, dentists, surgeons, dermatologists. They had the minor skin operations, then the place where they put a plaster cast on you, and do minor surgery. So if they couldn't get to the bottom of some kind of specialist issue, the GP could send the patient next door to see the internist. And if the internist couldn't solve it... So all the preliminary examinations were done at the polyclinic. (12)
- But the thing is, it's not that easy to say to a doctor, "What you're doing here is nonsense – you need to do something different." You don't really feel you can do that as a patient. So it's not great with these gastroenterologists. And I've wondered about going to a different one, but I don't know – that's a hassle as well. (6)
- So if my GP has less and less time for me, and I feel like they're not looking after me properly anymore, then I find a new GP. That's always an option. I want to be looked after properly – as a patient, I want someone who listens to me and takes me seriously, you know? Instead of just sending you to the next room. (12)
- Then I thought, "No, it's not worth the stress." I'll tell anyone who'll listen about it [inappropriate behaviour on the part of a doctor]. (13)
- Well, I imagine that's something doctors don't hear often enough. Of course, all the pressure falls on them if something doesn't go right – if they screw up (pardon my French).

On all the ratings websites, too. So if things go well, that needs to be said as well – preferably to their face. (17)

Feedback and reactions

- Well, for me it's definitely important. If I notice someone has the medical expertise but I don't really get on with them or whatever – then it's definitely important for me to be able to express that. (21)
- And since I don't know the first thing about care homes, I asked a lot of questions about why things were done a certain way – lots of things. And at first they took that as criticism. (21)
- But I'd say by now that if something's bothering me, I go straight to the manager at the home and tell her. We have a really good relationship now, where we can speak to one another openly. (21)

Staffing and Workload

Patient provider ratio, experience and skill mix, cohesion among staff members

- I know a lot of them have a lot of patients, and not much time either. Less and less time, in fact, because a lot of carers and nurses are under pressure from so many different facilities, insurance companies and doctors, of course. I know that. But it's still important to keep good medical records. (7)
- The nurses really did everything, in spite of how busy the hospital was. (11)
- And there was no one left to help, you know? I mean, I could walk a bit, but there was an elderly woman next to me who was getting no care. She was lying there, wet, with no-one...So I always fed her, this lady. She needed some fluids, something to eat. And everyone there was ill, and there was one nurse on the ward, and of course she couldn't keep up. It was a really unpleasant experience. (12)
- I mean, I never once had the feeling she had no time for me. Even if she didn't, you know? That's always the trick of course: not to let it show when you're under stress. That's part of providing a good service, really, and I think it's really good. (17)
- I was really shocked that you didn't have to go right to the end of the hall, or past all the guests and the care staff – that they actually do consolidate things a little, and then maybe there's an annex or something.

Infrastructure

Rooms and buildings, IT resources, equipment

- It [the examination and treatment equipment] is a bit more rounded, a bit softer, a bit quieter. And of course it's nice to meet doctors who are open to that, you know? Instead of saying, "The equipment in my practice has lasted a hundred years – it'll last another hundred too." (17)
- So there was one bath for a whole maternity ward. That's really not enough. You wouldn't believe it if you saw that today. (8)
- I think it's really nice. Really, they tell you everything you need: if you're a young family they say they have rooms for families, tell you where they are, and where you can rest from your journey. I think it's really, really nice. (8)

Macro Level

Structures of the health care system

- I'd like it if private patients could get more information on how your whole system works. Because they need to pay a lot up front, but they can also use the benefits and so on. Maybe there could be a platform so they could find out more about how the system looks after them. (15)
- Well, in my opinion it should all be more under state control, instead of the doctors trying to compete with one another. (19)
- Really, they send you from A to B, then from B to A, and then it's: "Oh, I think you need to go back there..." (11)
- Almost every district has an emergency doctor who's open outside normal GP operating hours, right? There needs to be more information about that in the papers, or the citizens need to be told about it some other way – so they know about it, you know?"

Financing and Reimbursement

- Because it really is a lot of money, what I pay for my health insurance very month. And I understand that it's a good system, but it's not always fair in terms of your income. And if you're self-employed and not earning much but you still have to pay that much health insurance, it really puts a strain on you. (6)
- Well, it seems to me that it's harder to get an appointment with a specialist if you're publicly insured. How often do you get asked, "What insurance do you have, what company are you with?" That's not a good feeling. And on top of that, while I'm still on a public insurance scheme, I actually pay the maximum rate there – and if you're paying over 700 euros a month in a country like Germany, you should be able to expect a decent level of care. (15)
- The health insurance companies just send you where you're meant to go. They don't care what happens after that. Even the advice centres don't ask anymore. They used to ask you to fill in a survey at least, then they'd ask how it went, but now they don't care about any of that. (7)
- And I'd love to see homeopathy or natural medicine given more of a chance when it comes to patient care. A natural medicine practitioner needs two or three hours to draw up a medical history – no health insurer's going to pay for that. (9)
- Well, I had a breakdown, basically. I couldn't keep going to work. And I submitted an application for a rehab facility or health resort. Then I got a rejection from Medical Services at the health insurance company – they said I was just a little overworked, and I should have a weekend away with my husband. (11)
- Let me tell you, everything was easier a few years ago. But now there's so much streamlining, you know? The doctors can't get the funds for these things; they have a limited allocation for each patient. And that's not the doctors' fault – that comes from somewhere else, you know? So I'd like to see things made easier for patients again. (11)
- We pay our health insurance, right? Then you have to pay all the prescription fees on top of that. For example, I've got these special insoles; apparently they cost around 150 euros. And I have to pay 38 euros on top of that, and that really hurts. (11)
- You fall out of the system, of course. I'm just costing money, not bringing any more in. I'm just costing them money. And that really brought me down, that legal dispute with my pension insurance company, you know? To be just dismissed like that: "She's just causing a fuss." (11)
- My physiotherapist is great – I've got a really good one, I get on with him really well. But the downside is that I only get a prescription for physiotherapy every three months – six

1
2
3 sessions. It's not enough at all. But you know, no-one can do anything about it; that's the
4 way the system works. The insurance companies are overrun. (13)
5
6

7 **Laws and regulations**

- 8 • I'd like it if the doctors had more time. That would mean they'd need to employ more
9 doctors – the Associations of Statutory Health Insurance Physicians would need to issue
10 more approvals for the individual specialist fields. Especially in the country – they need
11 more doctors there, especially specialists. (15)
12
13 • Because there's doctors who have a calling – that's how they see it. And maybe it's not
14 that great if they're struggling to make a living off it because they have a budget and they
15 have to pay out of their own pockets if they go over it. (13)
16
17 • So I look to see who can offer me an MRT, you know? Where can I go? Then I need to call
18 them all up and see who can give me an appointment the soonest. And that can sometimes
19 take two, three, even four weeks. (11)
20
21 • But now there's so much streamlining, you know? The doctors can't get the funds for these
22 things; they have a limited allocation for each patient. Sometimes I wonder why
23 everything's always getting more complicated. (11)
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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

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		Page
Reporting Item		Number
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Title		
#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

1	Abstract		
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4		#2	2
5		Summary of the key elements of the study using the	
6		abstract format of the intended publication; typically	
7		includes background, purpose, methods, results and	
8		conclusions	
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14	Introduction		
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17	Problem formulation	#3	4-5
18		Description and significance of the problem /	
19		phenomenon studied: review of relevant theory and	
20		empirical work; problem statement	
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25	Purpose or research	#4	5
26	question	Purpose of the study and specific objectives or	
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30	Methods		
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33	Qualitative approach	#5	6-8
34		Qualitative approach (e.g. ethnography, grounded	
35		theory, case study, phenomenology, narrative	
36	and research paradigm	research) and guiding theory if appropriate;	
37		identifying the research paradigm (e.g.	
38		postpositivist, constructivist / interpretivist) is also	
39		recommended; rationale. The rationale should	
40		briefly discuss the justification for choosing that	
41		theory, approach, method or technique rather than	
42		other options available; the assumptions and	
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transferability. As appropriate the rationale for several items might be discussed together.

Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	27
Context	#7	Setting / site and salient contextual factors; rationale	5-6
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	27
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	6-7

1	Data collection	#11	Description of instruments (e.g. interview guides,	6-7,
2			questionnaires) and devices (e.g. audio recorders)	supplement
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4			used for data collection; if / how the instruments(s)	1
5	technologies		changed over the course of the study	
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11	Units of study	#12	Number and relevant characteristics of participants,	8
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13			participation (could be reported in results)	
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19	Data processing	#13	Methods for processing data prior to and during	7-8
20			analysis, including transcription, data entry, data	
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22			integrity, data coding, and anonymisation /	
23			deidentification of excerpts	
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31	Data analysis	#14	Process by which inferences, themes, etc. were	7-8
32			identified and developed, including the researchers	
33			involved in data analysis; usually references a	
34			specific paradigm or approach; rationale	
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41	Techniques to enhance	#15	Techniques to enhance trustworthiness and	8
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43	trustworthiness		audit trail, triangulation); rationale	
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48	Results/findings			
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51	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and	11-22
52			themes); might include development of a theory or	
53	interpretation		model, or integration with prior research or theory	
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Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	supplement 2
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	22-25
Limitations	#19	Trustworthiness and limitations of findings	26
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	27
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	27

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BMJ Open

Patients' perspectives of facilitators and barriers to patient-centered care: insights from qualitative patient interviews

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Title Patients' perspectives of facilitators and barriers to patient-centered care: insights from qualitative patient interviews

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Word count: 6,309

Abstract

Objectives Previous studies on patient centered care (PCC) and its facilitators and barriers usually considered specific patient groups, health care settings, and aspects of PCC or focused on expert perspectives. The objective of this study was to analyse patients’ perspectives of facilitators and barriers towards implementing PCC.

Design We conducted semi-structured individual interviews with chronically ill patients. The interviewees were encouraged to share positive and negative experiences of care and the related facilitators and barriers in all settings including preventive, acute, and chronic health issues. Interview data were analysed based on the concept of content analysis.

Setting Interviews took place at the University Hospital Cologne, nursing homes, at participants’ homes or by telephone.

Participants Any person with at least one chronic illness living in the region of Cologne was eligible for participation. 25 persons with an average age of 60 years participated in the interviews. The participants suffered from various chronic conditions including mental health problems, oncological, metabolic, neurologic diseases, but also shared experiences related to acute health issues.

Results Participants described facilitators and barriers of PCC on the micro- (eg, patient-provider-interaction), meso- (eg, health and social care organization, HSCO) and macro-level (eg, laws, financing). In addition to previous concepts, interviewees illustrated the importance of being an active patient by taking individual responsibility for health. Interviewees considered functioning teams and healthy staff members a facilitator of PCC as this can compensate stressful situations or lack of staff to some degree. A lack of transparency in financing and reimbursement was identified as barrier to PCC.

Conclusion Individual providers and HSCOs can address many facilitators and barriers of PCC as perceived by patients. Large-scale changes such as reduction of administrative barriers, the expansion of care networks or higher mandatory nurse to patient ratios require political action and incentives.

Study registration German Clinical Trials Register DRKS00011925

Strength and Limitations

- Interviewees had a diverse background in disease and treatment experiences, including acute and chronic illness care.
- The open nature of the interviews encouraged interviewees to express various positive and negative experiences resulting in a rich collection of facilitators and barriers of patient-centred care from the patient perspective.
- Due to self-selection our sample might be biased since probably more involved and active patients participated.

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INTRODUCTION

The number of studies including the term “patient centered care” (PCC) continuously increased during the last 3 decades.[1] PCC also gained recognition and acceptance in policy and practice.[1-4] Moreover, the importance of the patients’ perspective in care is reflected e.g. by introducing and implementing patients’ rights acts.[5 6] Usually themes such as the biopsychosocial perspective, coordinated care, proactive care, integrated & continuous care, proactive and prepared care teams, shared decision making, individual needs, are associated with PCC.[7-14] These themes are relevant for all patients, but received growing attention with the ageing of the population, the worldwide increase of chronic disease incidence and multi-morbidity of patients.[15] While acute health problems can often be treated by one professional, with one intervention in one setting, care for chronically ill patients requires integrated, coordinated, continuous care usually from various health and social care organizations (HSCO).[16] The effects of the demographic and epidemiologic developments on the delivery system require change in structures, processes and goals of care (i.e. cure vs effective long-term management). To addresses the shift in health care needs of chronically ill patients, while still meeting needs of patients with acute health problems, PCC is considered an adequate concept.[17 18] Up until now, no universal definition of PCC or its facilitators and barriers exists despite extensive work on the topic. In 1969 Balint described the core aspect of PCC as considering a patient as a “unique human-being” [19](p. 269) instead of purely looking at an illness to treat. Later, the IOM established the widely accepted definition of PCC as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”.[20](p. 5) A similar definition is used by Reynolds who defined PCC as care which “focuses on the patient and the individual's particular health care”.[21] Despite the variety of definitions of PCC, these definitions usually include the concepts of considering the patient’s individuality beyond clinical diagnoses, reacting to the individual’s needs, preferences and values. In its report

“Crossing the Quality Chasm” the Institute of Medicine (IOM now National Academy of Medicine, NAM) named six core principles of high quality care, with PCC being one of them.[20] To implement PCC the IOM defined eight guiding principles: respect for patients’ preferences, coordination and integration of care, information and education, physical comfort, emotional support, involvement of family and friends, continuity and transition, as well as access to care.[22] These guiding principles have been taken up by subsequent conceptual papers and reviews even though some principles were termed differently or two or more principles are reflected in one additional term such as “shared decision making” reflecting “respect for patients’ preferences” & “information and education”.[7-14 23 24] Previous models of PCC and studies identifying barriers and facilitators for its implementation focused on expert opinions [7 17 23 25-29], conducted patient interviews with a very specific patient group [14 30-32], or addressed only specific care settings.[24 29 33 34] “A comprehensive investigation of barriers and facilitators of the identified dimensions of patient-centeredness is necessary”[7](p.8) especially from the patient perspective. Additionally, previous comprehensive reviews or individual studies on barriers and facilitators of PCC lacked information on the macro level i.e. laws, regulation, policies, payment, and reimbursement.[7] Therefore, the aim of this study was to identify barriers and facilitators of PCC related to the micro-, meso-, and macro-level of care, as perceived from patients’ perspectives including a broad range of disease and treatment experiences.

METHODS

The study conduct and reporting is based on the “Consolidated criteria for reporting qualitative research” (COREQ).[35]

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Setting: German Health and Social Care System

In the German health care system ambulatory care, hospital care, ambulatory and stationary rehabilitation and nursing care is provided. Ambulatory health care is mainly provided at local physician offices, with general practitioners (GP) usually being the first contact persons. However, patients can opt for an ambulatory specialist visit directly and without additional out-of-pocket costs. Hospital care ranges from regular basic hospitals to centres of medical excellence usually being an academic hospital, which provide care for all indications and levels of disease severity. Ambulatory care, inpatient hospital care, rehabilitation, local therapist, and long-term nursing care each have their own mode of financing and reimbursement and are often separated from a delivery, but also a financial perspective.[36] As an example to overcome this separation, improve chronic illness care and incentivise care integration, disease management programs (DMP) are implemented in Germany.[37]As health and social care often provided simultaneously and some aspects of care provision are addressed in health insurance acts, and others in additional acts on social insurances (nursing insurance, , accident insurance, pension insurance), the term ‘health and social care’ is used in this study. The term “patient-centered care” is associated more with functional recovery and “person centered care” considers the overall wellbeing of a person.[38 39] Based on this differentiation, “patient-centered care” will be used throughout this article since it better reflects the German statutory health insurances’ tasks of “maintaining, recovering, or improving an insurees health state“(SGB V).[40]

Patient and public involvement

This project was conducted within the Cologne Research and Development Network (CoRe-Net), which consists of scientists, patient organizations, HSCOs, municipality representatives and other stakeholders.[41] The data collection for this study took place within the research

project OrgValue (Characteristics of Value-Based Health and Social Care from Organizations' Perspectives), which is one of currently four projects affiliated with CoRe-Net.[42] CoRe-Net members participated in developing ideas on the study conduct. The study results were partly presented at public CoRe-Net events and will be disseminated to all participants.

Participant recruitment & sample

To be eligible for this study, participants had to be 18 years or older and feel cognitively and emotionally able to participate in an interview. They also had to be diagnosed with at least one chronic condition to be able to share experiences from acute and chronic illness care. Participants were recruited via newspaper advertisement, flyers and posters distributed at public places, primary care physician offices, and nursing homes. The diversity of sampling strategies was used to reach maximum variation [43] regarding age, gender, or disease specific characteristics (physical and mental health indications, fluctuating and stable symptoms, life-threatening diseases).

Data collection methods & setting

Data was collected through individual interviews from January until May 2018. Depending on the participants' mobility or preference, the interviews took place at a meeting room in the University Hospital, in their long-term care institution, at home or by telephone. Prior to the interviews, each interviewee was called to provide explanations of the study. After this phone call, participants received informed consent forms describing aims and procedures of the study and a questionnaire on socio-demographic and disease specific data. This data was used to prepare the interviewer for the personal situation of the interviewee and get acquainted with disease characteristics.

The first author (VV) conducted all interviews, and the process of interviewing was regularly discussed in the interdisciplinary research team. The interviews were guided by a semi-

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structured interview guide including open-ended questions posed in flexible order (supplementary file 1). The interview guide was developed by extracting aspects of PCC from previously published models and reviews.[7 9 17]

Each interview started with a personal introduction of the interviewer including position and research interests. In the interview, participants were asked to describe situations, in which they experienced as optimal and suboptimal health care subjectively judged provision. For both situations, participants were encouraged to explain the facilitators and barriers that made them judge their experiences as optimal or suboptimal. The interviewer followed up on topics, which participants initially mentioned as minor comments. The interviews were finalized by collecting ideas and suggestions, for changes in health care provision, which they perceive of added value. Throughout and after the interviews participants were allowed to ask questions. All interviews were audiotaped and transcribed verbatim according to scientific guidelines.[44]

An iterative process of data collection and analysis was applied. This included listening to audiotapes after each interview, discussing preliminary results in the research team and identifying topics needing more detailed discussions in subsequent interviews. Each participant was offered to contact the researchers after the interview by phone or e-mail to share additional ideas or memories. Field notes were taken after the interview in case any particular observations or a specific atmosphere was noticed. Participants were allowed to access, correct or withdraw their audiotapes or transcripts.

Data Analysis

Data were analysed based on concepts of qualitative content analysis based on Miles et al.[43] The coding scheme was developed in a combination of an inductive and deductive approach. Themes from previous concepts of PCC were complemented by themes emerging from the data. Existing codes related to the categorization of facilitators and barriers into the micro,

meso,- and macro level as described by Scholl et al.[7] Aspects of care provision which relate to individual interactions between a patient and a care provider or other contact persons were coded under micro level. The meso level included aspects related to one care providing organization (meso level 1) or the cooperation of several care providing organizations (meso level 2). Laws, regulations, policies, and guidelines shaping health care provision were considered facilitators and barriers on the macro level. The sub-codings were developed, revised and finalized by the team of researchers (KH, HH, and VV) alongside conducting the interviews. Using this scheme, at least two researchers (KH, HH, and VV in varying teams) coded each interview. Data coding was performed using MAXQDA 12. Prior to data collection and analysis, all researchers received training in qualitative research methods.

RESULTS

Participants & atmosphere

32 persons reported interest to participate in the study of which interviews took place with 25 persons. The remaining could not be followed up, were unable to read and sign informed consent materials or could not be interviewed for other reasons. Participants suffered from diseases such as breast and gastric tumours, diabetes mellitus type 2, asthma, chronic obstructive pulmonary disease, depression & anxiety disorder, hypertension, hypercoagulability with thrombosis and embolism or multiple sclerosis. Supplementary file 2 contains additional information on participants' health care experiences. Socio-demographic characteristics of the 25 analysed participants are summarized in table 1. While one interview was terminated after 6 minutes due to cognitive limitations of the participant, the interviews lasted 30-80 minutes with an average of 44 minutes. The variation of interview length resulted from varying amounts of experiences with or ideas for implementing PCC. Participants were open, dared to be critical, and perceived the interview as a good opportunity to share experiences. For some participants, the interview was very emotional. Participants also

described situations of close relatives or friends to illustrate their understanding of PCC. One participant contacted the researchers after the interview to share additional experiences, which were considered in the analysis. After around 20 interviews no new themes emerged.

Table 1 Participants’ characteristics

Characteristic	Number of participants (%)
Gender	
Male	8 (32)
Female	17 (68)
Age	
18-29	2 (8)
30-39	1(4)
40-49	3 (12)
50-59	5 (20)
60-69	5 (20)
≥70	9 (36)
Marital status	
Living with partner (married)	8 (32)
Living with partner (unmarried)	1 (4)
no partner, divorced or widowed	15 (60)
Persons within household	
1	12 (48)
2-3	11 (44)
≥4	1 (4)
Education	
No degree	0
Secondary school	5 (20)
High school	6 (24)
College	13 (52)

Other degree	1 (4)
Professional qualification	
Vocational training	11 (44)
University degree	10 (40)
Retired	15 (60)
Net household income	
500-999€	3 (12)
1000-1499€	5 (20)
1500-1999€	1 (4)
2000-2499€	8 (32)
2500-2999€	2 (8)
≥3000€	2 (8)
Degree of disability^a	
0	13 (52)
1-19	0 (0)
20-39	1 (4)
40-59	6 (24)
60-79	1 (4)
80-100	3 (12)
Nursing scheme^b	
None	22 (88)
1	1 (4)
2-4	0
5	1 (4)

^a Higher value corresponds to greater extent of impairments; ^b Higher nursing scheme represents a greater need for nursing care; if number of patients ≠ 25, data are missing

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Facilitators & barriers of PCC

Figure 1 summarizes the facilitators and barriers as identified from the patient perspective. The identified facilitators and barriers on the micro level relate to patient and contact person characteristics (personal & professional), the physical and emotional well-being of the contact person, and the available interventions, which all together shape the interaction between patient and contact persons. On the meso level, facilitators and barriers related to processes of care, the culture and climate in a health care organization, staffing, and the health care organization’s infrastructure. The structures, financing, reimbursement, laws and regulations shaping the health care system were identified as barriers and facilitators on the macro level. Citations for the corresponding barriers and facilitators are displayed in supplementary file 3. Please include Figure 1 somewhere here (Legend: Figure 1 Facilitators and barriers of patient-centred care)

Micro level- Facilitators and barriers of the interaction between patient and clinicians or other contact persons

Responsibilities and characteristics of patients

Interviewees reported their role in establishing a good provider-patient relationship as a facilitator. It was considered especially helpful if patients share all health problems with the health care provider and treat the provider with respect. Moreover, communicating personal wishes or fears (eg, anxiety disorder) upfront was seen as a precondition for consideration by the provider. Interviewees acknowledged the necessity of being open to take up suggestions of the care provider, also if they require active participation in care (eg, psychotherapy, physical activity, healthy diet). Patients described the responsibility to show a high level of self-initiative and commitment within the current health care system to receive safe and effective care. This included *medical* (eg, regular administration of tablets) as well as *organizational* (make appointments in time), and *informational* (collect and organize medical

and non-medical information) duties. Moreover, some patients perceived a *financial* responsibility to save some money for non-reimbursed therapies or co-payments. Patients highlighted, however, that such a high level of self-responsibility cannot be expected from all patients in every situation (eg, in case of mental health problems, bedfastness, lower education, unemployment). Especially patients with mental illnesses felt burdened by coordinating care from different and often unknown providers, and to inform themselves adequately.

Patients differentiated their role as customers in the health care system in comparison to their role as customers in other situations, which implied eg, that waiting times even for scheduled appointments sometimes just need to be accepted since health care cannot be timed exactly. Patients described their and other patients' duty to request existing health care services in an efficient manner, eg, by contacting emergency primary care services instead of the hospital emergency departments whenever possible. Also they consider themselves and other people responsible for treating short-term minor complaints individually without seeking professional care immediately and thereby using physician time, which might be needed by more seriously ill patients. Few interviewees exclusively considered health professionals responsible for their patients' health status.

Professional skills of clinicians and contact person

Participants expected providers to possess comprehensive medical knowledge to make a fast and accurate diagnosis based on state-of-the-art knowledge; and can offer treatments which are effective, safe, easy to administer and integrate into daily routine, while fitting the individual patient's needs. Taking a holistic view on the patient, considering family history (eg, genetic predispositions), the current personal situation and the patient's social environment were mentioned as prerequisites for PCC. Some patients appreciated knowledge and official qualifications on complementary medical therapies, since it broadens the therapeutic scope of a provider.

Finally, continuous trainings and specializations were considered to improve provider skills. Especially, communication skills for interacting with eg, demented or anxious patients were regarded as facilitators of PCC. Complementary, expertise and professionalism were considered relevant to assess own professional limits in treating specific patients and, depending on these limits, referring the patient to a specialized colleague. Next to clinicians, participants referred to other professions who facilitate PCC provision, eg by managing transitions between HSCOs (case managers), maintaining proper hygiene (cleaning staff) or providing information and guidance (receptionists).

Personal characteristics of clinicians and contact persons

Individual participants reported a variety of care providers’ personal characteristics facilitating PCC. All were considered necessary to maintain humanity in care, but their degree of importance and expected intensity differed depending on patients and situations of seeking care. Firstly providers must *be present & pleasant*, meaning that they should focus on the patient and should not be distracted or pressured (eg, by time constraints) during patient appointments. Specifically, providers ought to create a friendly and pleasant atmosphere and dedicate a sufficient amount of time to answer questions and explain treatment plans. In addition to being present, providers should also *show interest & understanding* for the patient’s complaints, needs, and fears and take them seriously, even though they seem to be less relevant from a medical perspective. Being understanding towards the patient’s needs and use of services, conveyed towards the patient through a positive attitude (eg, reporting personal experiences, emotional involvement) without comparing one patient’s health problems to the severity of another patient were considered important facilitators. Interviewees expected providers to *show commitment* to the patients’ interests and responsibility for pursuing patients’ interests within the process of care, irrespective of opposing financial incentives and constraints. Moreover, providers should *be flexible* in making treatment plans since patients seek individualized care based on personal needs and

circumstances. This includes actively considering patient preferences (eg, regarding treatment alternatives). Interviewees explained that providers should also be flexible in their behavior and communication depending on the particular patient (eg, child vs. adult, demented vs. non-demented). This was also one reason why some participants considered it particularly important that providers are *able to take negative feedback* without feeling personally blamed or challenged by the patient. Participants stated that asking for more information or additional explanation was sometimes misconstrued as affronting professionals. They also reported feeling uncomfortable providing feedback within short consultations. Hence, taking criticism seriously was considered a valuable trait eg, to adapt the treatment plan or developing a trustful relationship. A common reported option of expressing negative feedback was to seek health care from another provider. Finally, providers were expected to *be honest & open*. On the one hand, this facilitates understanding of clinicians and other person's recommendations and instructions. On the other hand, it allows patients to critically think through recommendations and have realistic expectations about their situation. While interviewees considered all these characteristics important, none of them could compensate for low professional skills.

Physical and emotional well-being of clinicians and contact person

Participants generally acknowledged that health care professionals across organizations are facing a high responsibility and workload. Some participants reported situations in which work overload and exhaustion decreased the provider's ability to provide PCC and increased the risk of errors. Patients also reported that they feel uncomfortable when requesting services from an overburdened staff member and sometimes preferred not to ask for help or information to prevent further burdening.

Interventions

Interviewees expressed several general characteristics of interventions selected during the care process. The major goal of seeking care as stated by participants was improving health or preventing deterioration of their health status by receiving interventions or recommendations, which *effectively* address the individual’s physical or mental health problem. Moreover, interventions facilitate PCC if they have none or individually acceptable *side effects*, are *easily administrable* and *can be integrated into the individual patient’s daily living*. What to consider effective, acceptable side effects or easily administrable differed between patients eg, due to differing perceptions of sensitiveness to side effects and different individual treatment expectations.

Meso level (1) – Facilitators and barriers related to health and social care organizations

Process of care within an organization

Coordination of care

Participants report various deficits, but also positive experiences of related coordination of care. Waiting times were perceived as acceptable if the provider later on also takes sufficient time for patients or if more severely ill patients were prioritized. Nevertheless, patients often assumed deficits in the coordination of care processes instead of emergencies to be the cause of waiting times.

Interviewees reported that the delivery of documents and information often happens due to the patient's initiative rather than as an institutional process. A joint coordination of the following procedures in care was requested by interviewees. This implied eg, communicating the next diagnostic or therapeutic steps as well as discharges or referrals to another care provider. Related to inpatient hospital care interviewees reported their appointments sometimes to be canceled at short notice or that patients have been forgotten for therapy. This seemed to be a

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3 minor problem in nursing homes, where interviewees perceived a regular and predictable
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5 schedule. Regarding structured care programs (eg, DMP) interviewees valued the well-
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7 coordinated care process, but sometimes also felt controlled if follow-up intervals were not
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9 adapted to individual needs, but strictly followed a guideline.
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12 13 Continuity of care 14 15

16 For participants, PCC is facilitated through *continuity of the process and continuity in contact*
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18 *persons*. Interviewees requested eg, aligned and gapless care, meaning, that someone oversees
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20 and coordinates all steps of care and can guide the patient through the process. Especially at
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22 points of transitions or significant interventions, interviewees requested a structured check eg,
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24 regarding the question whether the patient is able to fulfil activities of daily living or needs
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26 help. Interviewees also mentioned that sometimes a longer time frame lies in between
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28 diagnostics and start of treatment, implying a disrupted care process during which the patient
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30 is left on its own. Continuity of care was perceived as being established satisfactorily within
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32 DMPs since regular appointments are required.
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37 Continuous contact persons were highlighted as an important facilitator of PCC, since
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39 establishing relationships of trust and in-depth knowledge of individual medical history takes
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41 time. Interviewees explained this theme in particular in relation to GPs. Especially elderly
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43 participants, participants with life-threatening disease or with mental health problems reported
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45 difficulties in getting acquainted with new people over and over again. Frequent changes in
46
47 contact person were reported to occur often during hospital care.
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51 52 Flexibility of care 53 54

55 Next to the individual care provider's flexibility, participants appreciated flexibility of care
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57 processes in organizations in terms of individualized planning of care adapted to the needs of
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59 patients and relatives. This included eg, consultation hours, which are feasible for fulltime
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employees especially those with chronic diseases, who often have medical appointments. Moreover, individually planned transitions, or a flexible change of appointments and a self-initiated appointment allocation (eg, via online systems) were requested. Positively evaluated examples were especially rehabilitation units with individualized therapies and schedules, which is adapted flexibly to the patient's needs. In line with this, individual decisions on hospital discharge in cooperation with the patient were positively evaluated, eg, if patients need to organize home modification or nursing services.

Timeliness of access to care

Participants requested waiting times for appointments to be reasonable. This was considered an important criterion of well-organized care. Participants regarded it difficult to get specialist appointments promptly, especially when being insured with the SHI and that despite appointments they often have to wait a long time in the waiting room. Particularly waiting times for diagnostics or treatments in the course of serious diseases such as cancer was perceived as very stressful. The acceptability of waiting time length for and at appointments varied between participants eg, in relation to disease severity or depending on whether participants were retired or working fulltime. Interviewees explained that transparency about processes and reasons for delays would contribute to higher acceptance of waiting time. Interviewees consider GPs' support in finding specialists a facilitator for receiving care more quickly. To do so, participants considered GPs who operate in networks or medical service centers valuable.

Culture and Climate

Atmosphere & special services

A welcoming *atmosphere* and a feeling of being respected within a HSCO or its units were perceived as facilitators of PCC. Interviewees considered an accepted leader and content staff

members necessary for a good atmosphere. A “conveyor-belt”-like climate at HSCO was experienced to be barrier for PCC. The provision of *non-medical special services* such as magazines, water, coffee or tea made interviewees feel welcome at a HSCO; and depending on waiting times these were even considered necessary (eg, water).

Communication & cohesion among staff

For participants’ perspective staff members *communicating* harshly with each other or negatively about other patients induced daunting feelings, which was perceived as a barrier to PCC. Communicating calm and friendly despite stressful situations was reported to calm down patients and facilitates the feeling of being cared for by a competent and functioning team. The style of communication was also perceived to be linked to the level of *cohesion among staff members*. Interviewees explained that even the most experienced and skilled care providers can only provide PCC if they work closely together, support each other and apply the variety of staff skills as needed disregarding hierarchies. Sometimes interviewees even had the feeling that a well-functioning team can compensate a lack of staff members.. Participants perceived a higher level of task separation being a barrier to PCC, since care providers would feel responsible for only a minor part in the process of health care provision.

Feedback & Reactions

Interviewees would value *structured feedback options* such as patient surveys on the level of HSCOs, first to improve their own care, but also to improve care for future patients in a particular HSCO. Since structured feedback methods are not common -especially in the ambulatory care sector- the only way to express negative feedback is seeking care from another HSCO. This was often considered necessary since other options were unavailable. Participants who expressed feedback (verbally or in writing) felt disregarded and very disappointed if such feedback was not replied to either through a dialogue or by implementing suggested improvements in the HSCO.

Staffing & Workload

Patient- provider-ratio

Interview participants described that teams of care providers can only provide good care if the *number of staff* is sufficient in relation to the number of patients. An adequate staff to patient or staff to task ratio, respectively, was regarded important to maintain safety, hygiene, and effectiveness in care.

Mix of experience and skills

Next to a sufficient number of staff, interviewees considered the *mix of experience and skills* within the team as facilitating or impeding PCC. This mix facilitates eg, inexperienced staff members being supported by experienced colleagues in practical and communicative skills. Interviewees considered different professions within a HSCO as a facilitating factor since eg various examinations and treatments could be performed at one place.

Infrastructure

Rooms and buildings

Interviewees described the relevance of the *built environment* on their care. First, HSCO need to be accessible for all patients, which includes being geographically close to patients' homes, having wheel-chair ramps and informative signs. Interviewees' expectations related to inpatient care included clean and modern facilities with small units. Patient rooms, which allow for privacy and recovery, were considered valuable. Shared rooms with only two to three patients or separate rooms for examinations and consultations with care providers facilitate PCC. Also sharing bathrooms with less people was considered more comfortable and hygienic. Interviewees perceived private conversations with relatives and friends to be facilitated by safe havens such as seating areas away from hallways or waiting areas While interviewees appreciated that hospitals are not hotels, negative experiences such as dirty

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3 facilities or confined spaces considerably influenced participants overall perception of patient-
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5 centeredness in a HSCO.
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8 Information technology (IT) 9

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11 Interviewees explained that the availability and use of *IT* was important to reduce loss of
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13 information between different departments especially in the case of large
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17 Meso level (2) Facilitators and barriers related to the cooperation among health and social
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19 care organizations
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22 At this meso level 2 patients considered all factors summarized under *processes of care*
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24 described on the level of one organization relevant for the collaboration between
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26 organizations as well. Barriers experienced by participants mostly related to coordination and
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28 continuity of care eg when information was not provided to subsequent care providers.
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30 Moreover, coordination barriers were experiences when transitions between HSCOs were not
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32 planned well or none of the involved HSCO felt responsible, but always another provider is
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34 assumed to take responsibility. Hence, a specific person who is responsible for the overall
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36 care process was suggested as a facilitator for PCC. Participants reported experiencing
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38 repetitive diagnostics, as a barrier for PCC, since all care providers should perform
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40 diagnostics at the same level of quality and share their results. Moreover, interviewees
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42 considered such diagnostics inappropriate cost drivers and felt that time consumed for
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44 repetitive diagnostics could be used more effectively (eg, explaining procedures).
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46 Interviewees reported a lack of information when being referred to other providers, and
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48 receiving specific recommendations for a provider was considered helpful in finding qualified
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50 providers, but also providers who smoothly cooperate with the patient's GP.
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Macro level – Facilitators and barriers related to structural, financial and legal conditions of care provision

Structures of the health care system

Participants described the structures of the German health care as very complex and sometimes confusing with its high degree of separation. Interviewees often mentioned that they were sent to other providers since the provider they contacted was not the primarily responsible provider for the particular health problem at stake. This was especially the case for ambulatory out-of-office hour GP-practices, which were meant to be visited instead of hospital emergency departments in case of non-life-threatening conditions. In line with this, interviewees described examples of the fragmentation of care provision eg, by having to contact different providers at different locations of whom none feels responsible for the overall care process. Interviewees felt not educated well about the structures of the health care system to prevent unnecessary or wrong utilization of health care services.

Financing & Reimbursement

Interviewees considered fairness elements in modes of insurance payment and service provision a facilitator of PCC. This includes eg, that contributions to the SHI are levied as percentage of actual income or receiving care based exclusively on medical need. Sometimes patients perceive the insurance status (statutory or private) leads to differences in treatment not justified based on medical need. This was illustrated eg, by being asked first about the health insurance when requesting an appointment rather than being asked about the medical condition.

Regarding reimbursement, interviewees often expressed that they do not understand why particular therapies are reimbursed and others are not. Ambulatory physicians in Germany have a so-called care-budget, which they have available for distribution among patients and interventions. Participants often did not know whether physicians do not prescribe eg,

medication or therapy because the physician considers it too expensive to prescribe this from the care budget, whether it is not covered by the insurance in general or whether care providers actually base their recommendation on the effectiveness, given the clinical situation. The same doubts were reported for recommendations regarding out-of-pocket paid interventions. Only few participants were aware of specific reimbursement processes and most perceived reimbursement decisions to be intransparent. Such complexity of payment schemes and non-transparency was reported to induce distrust towards providers and insurances, and a feeling of insecurity regarding trustworthiness of recommendations. Several interviewees also called for the extension of the SHI's benefits catalogue particularly for naturopathy, homeopathy, eurhythmics or other alternative forms of therapies, since they experienced them as helpful in their personal care process and facilitating PCC.

Laws & regulations

Interviewees described that they perceive supervising mechanisms of clinical care practice such as regular audits of physicians to be unavailable or implemented insufficiently. These were considered necessary since interviewees themselves felt insecure about judging the quality of medical care by themselves. In the case of perceived medical errors, over- and undertreatment interviewees were unsure how to react. Regular checks of local physician offices by an independent institution were considered to facilitate PCC.

Interviewees also perceived the integration of health care with other social services related to health care as suboptimal. The health insurance is responsible for covering the treatment of patients, while the pension insurance is responsible for the payment of rehabilitation of working patients. Interviewees perceived that the boundaries between treating patients and re-integrating them into the labour market are not that clear cut in practice, which sometimes lead to health insurance and pension insurance discussing about the financial responsibilities and thereby delaying care initiation. Also, rehabilitation was sometimes perceived to be

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approved by insurances primarily to evaluate whether patients are able to return to work fulltime instead of focussing on recovery, which patients sometimes experienced as degrading. Interviewees urged for a more timely reaction to challenges requiring political action. Since challenges such as lack of professional staff or financing and reimbursement mechanisms require political action, challenges often cannot be addressed flexible, but require long periods. During these periods, the level of PCC was perceived to decrease. Interviewees perceived the political initiatives to address problems in health care supply as insufficient.

DISCUSSION

This study identified facilitators and barriers of PCC from the perspective of patients. They described facilitators and on the micro-, meso- and macro level of health and social care.

The two facilitators of PCC on the *mirco level* expressed by all participants and also observed in previous studies, were receiving effective interventions [7 11] and the successful interaction with contact persons.[8 9 17 24] The variety of personal & professional skills facilitating PCC and their different importance in different situations illustrate that behaviours of professionals constantly need to be adapted for the particular situation and patient. Participants also perceived physically and mentally healthy staff members as being better able to provide PCC- an impression supported by other studies.[26 27 45 46]

In addition to previous studies, our interviews revealed that interviewees considered their personal behaviour as facilitating or impeding PCC. This included eg, active participation in health care. In addition to the patient being “activated” by health care providers as described in models of PCC [7 8 11 17] an intrinsically “active patient” was perceived as a facilitator for PCC. This implies that patients themselves need to be active, interested and willing to facilitate PCC. Nevertheless, to fulfil this role, patients need guidance and access to easily

understandable information, and therapies, which match their health and personal needs. Another finding was the importance of contact persons in health and social care beyond the usually mentioned “clinicians” or “physicians” in previous studies.[7-9] Sometimes non-clinical staff members facilitate or impede PCC provision as much as health care providers. Therefore, trainings in eg, patient communication should address all staff members who get into contact with patients.

On the *meso level* participants described a smooth flow of information within and between organizations as well as functioning care teams with clear responsibilities as important facilitators PCC. As observed in previous studies, interviewees preferred to have continuous contact persons, which enables building trustful relationships, having a complete overview of the medical history, and feeling responsible for the whole care process.[7 8 11 14] Therefore, supporting teamwork and cohesion among staff members facilitate PCC in any setting.

In addition to previous studies, participants expressed the importance of a person, who is responsible for the overall care process within, but especially across HSCOs. Such care models could be encouraged and supported by further incentivising eg integrated care contracts. Approaches such as the *Guided Care Model*, where a trained guided-care nurse facilitates guidance through the health care system, developing a long-term treatment plan, and managing patients’ transitions between HSCOs, might increase the patient perception of patient centeredness.[47 48]

Facilitators and barriers of PCC on the *macro level* received little attention in previous studies including patients.[7] Participants considered the structure of the health care system, financing and reimbursement mechanisms, and laws and regulations facilitating and impeding PCC. Due to the complexity of the German health and social care systems, interviewees described that a lack of transparency and comprehensibility of regulations were perceived as barriers to

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PCC. This complexity can induce distrust of the patient towards the health care system and care providers, including non-acceptance about choices made health care.

Legally established structured care models, such as DMPs were considered a facilitator for PCC, but some patients reported pressure to subscribe or felt being controlled by physicians and the SHI. Interventions intended to improve PCC need to be voluntary and despite being structured leave room for individual adaptations such as extending monitoring intervals in case of stable conditions or high adherence to care plans.[49]

Next to medical patient information, PCC could be strengthened by structured support in navigating through the care system.[50] This navigation can be implemented eg, by GPs providing recommendations for specific specialist. However, to maintain neutrality, rules of professional conduct of physicians, referrals to specific colleagues are only allowed in case of sufficient reasoning.[51]

A theme regardless of the micro-, meso-, and macro level and not previously discussed in relation to PCC is the participants' *ambivalence* regarding several facilitators and barriers. While participants consider the exchange of information between care providers a facilitator of PCC, they also prefer to share only specific information with specific providers, which impedes communication and interdisciplinary care. Reasons for this behaviour are diverse, (eg, embarrassment, lack of trust in provider).[52] Additionally, GPs as first contact persons in health care were considered as facilitating PCC with regard to preventing unnecessary resource use and coordinating care. Nevertheless, interviewees perceived a formal gatekeeper system as a potential barrier to PCC, since they value the free choice of providers. Another ambivalence relates to study participants' and German patients' request for the most effective care, but at the same time demanding the reimbursement and more frequent use of, for example, homeopathy and other therapies, which still lack high quality evidence for its effectiveness.[53 54]

Strength & limitations

Our study has several limitations. Firstly, the experiences, facilitators and barriers expressed by the interviewees are subjective and might be influenced by recall bias. However, looking back for a longer period also allowed the patients to reflect on their experiences. Moreover, all patients had at least one recent care experience. Secondly, we only interviewed patients living in Cologne or surrounding communities. This implies an overrepresentation of the urban population. However, interviewees also reported experiences from former places of living including rural areas. As a strength, we consider the results generalizable to other regions, since none of them particularly relates to urban care provision. Moreover, the diversity of our sample regarding socio-demographic and disease related characteristics also supports generalizability of results to other patients.

Conclusion

Many facilitators and barriers of PCC addressed by patients can be supported by changes in individual behaviors, restructuring of care processes within organizations and supporting team based care provision. Future research should investigate the importance of individual facilitators and barriers in more detail and elicit patients' suggestions on interventions to improve PCC in various settings and on various decision levels.

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Patient consent for publication Not required.

Data statement Since complete transcripts of interviews potentially allow for identification of individuals, complete transcripts cannot be provided.

Author contributions

SSt (female, f), LK (male, m), LA (f) conceived the study. VV (f), KH (f), HH (m) and SSt specified the methods. VV conducted the interviews. VV, KH and HH analysed the interviews. VV drafted and revised the manuscript in cooperation with KH and HH. All authors critically read, revised and approved the final manuscript. VV is guarantor. KH, HH, and VV were PhD candidates at the time of conducting the study. SSt (MD) is professor for Patient Centered-Care and Applied Health Economics, LA is professor for Organisation-related Health Services Research, and LK is professor of Business Administration and Health Care Management.

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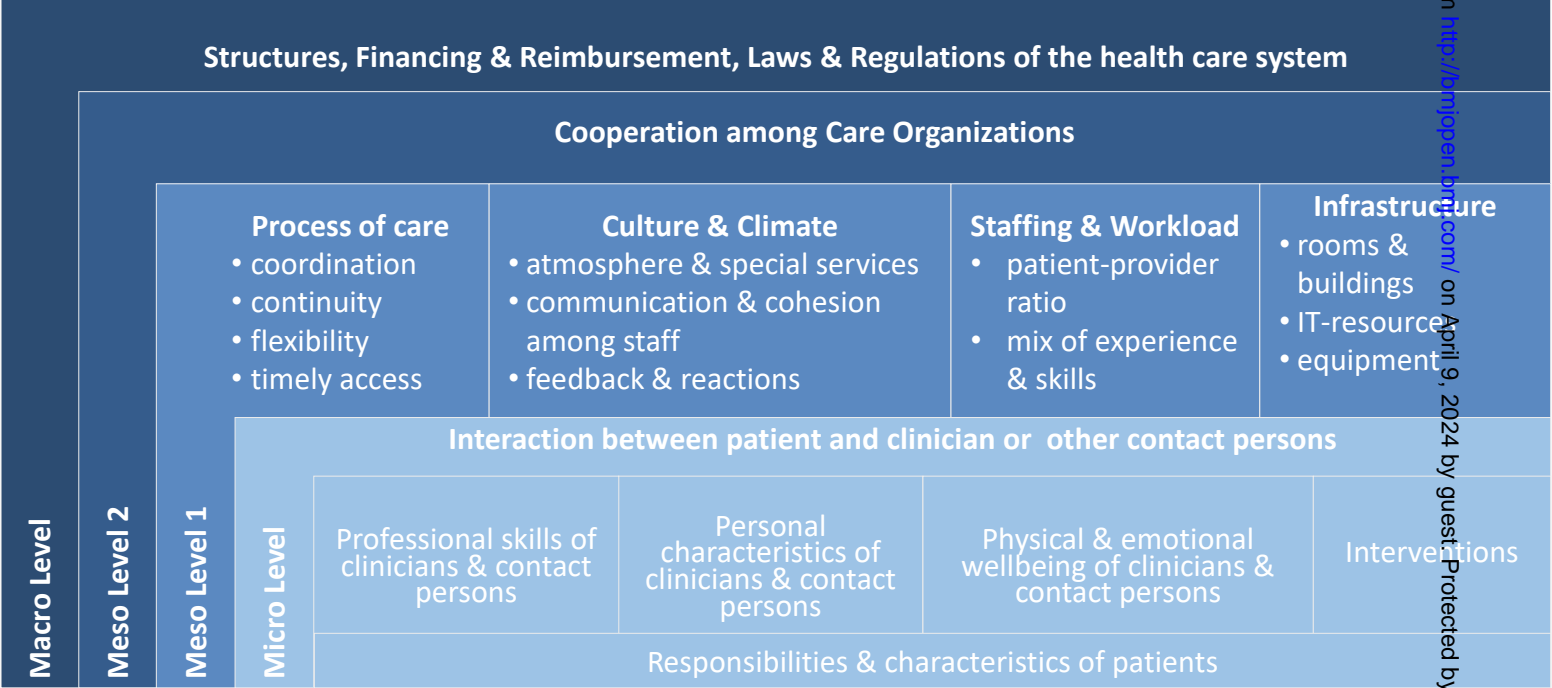
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For peer review only





OrgValue

Interview guide for patient interviews

General information

Aim	The aim of the interview is to get a patients' assessment of what is critical for a patient centered care.
Duration of the interview	ca. 30-60 minutes
Place of interview	At the meeting room of the Institute for Health Economics and Clinical Epidemiology, at the patient's home, by telephone
Preparation	(As the circumstances require) Providing: <ul style="list-style-type: none">- Recording device- Office supplies (pens, paper)- Patient questionnaire- Flipchart
Arrival of the participants	Seating, Offering beverages, collecting patient questionnaire & informed consent forms if not submitted in advance

Part 1: Introduction, Presentation of the project, Preparation

Introduction	Welcome and thank you for taking the time to participate in our study. My name is Vera Vennedey. I'm a research associate at the Institute for Health Economics and Clinical Epidemiology at the University Hospital of Cologne.
Presentation of the project	The project, of which this survey is part of, is financed by the ministry of education and research. We would like to establish a network for research and development dedicated to improve the regional health care provision for different patient groups and to develop ideas, how to make provision more patient centred. That means to acknowledge the patients' needs and wishes. Today's survey is about what you expect of health care, what you would assess as positive and what is needed of improvement.
Recording device & Data privacy	With your consent I would like to record our discussion. Later on it will be transcribed and evaluated, that means we will summarize your statements. Your statements will only be published anonymously, that means your name will under no circumstances appear in reports or publications. The recordings will be kept securely and will be deleted after the transcription. After this, only the written text will be available but not the original recordings. Your participation in the interview is voluntary and you are free to stop at any time. You are allowed to refuse to answer questions. In general, there is no right or wrong answers to the questions I ask, it is just about your personal opinion. You are allowed to ask questions at any time during the interview. When you answer the questions, there is no need to name specific persons or institutions, since I am mainly interested in what you experienced and not who exactly did the things you tell. So it is enough if you tell eg, "My GP always does..." and do not mention his name.



Part 2: Describing the patients' point of view on patient centered care

Topic	Key question	Follow-up questions
What is patient centered care from the patient's perspective (facilitators)?	<p>Can you describe a situation in which you, as a patient or person were treated, consulted or taken care of in a particularly positive way?</p> <p>Further stimulus, in case the participant doesn't know any:</p> <p>This, for example, could be a situation with</p> <ul style="list-style-type: none">- a doctor,- a hospital,- a nurse- a pharmacist- a therapist- insurance- another person in context of health care	<p>What was particularly good? Why?</p> <p>Who or what contributed to it?</p> <p>What was the main aspect, which made the situation a positive experience?</p> <p>Do you remember another situation?</p> <p>Can you tell how this started and was addressed by ...?</p> <p>Possible additional topics depending on the referred issues in the participant's answer</p> <ul style="list-style-type: none">- Integration of medical and non-medical provision- Coordination and continuity of care- Accessibility of care- Important traits of doctors/ providers- Connection with provider- Communication- Involvement in care (patients)- Involvement of family and friends- Patient (Empowerment)- Physical support (pain reduction, functionality, etc.)- Emotional support- Acknowledgement as an independent and individual person with biopsychosocial needs- Information for patients- surroundings
What is patient centered care from the patient's perspective (barriers) ?	<p>Can you describe a situation in which you, as a patient or person were treated, consulted or taken care of in a not so pleasant way?</p> <p>Specification of the Situation, in case the participant doesn't know any:</p>	<p>What was particularly negative? Why?</p> <p>What or who contributed to this?</p> <p>What was the main aspect, which made the situation a negative experience?</p> <p>What would you have liked to happen?</p> <p>Do you remember another situation?</p>

	<p>This, for example, could be a situation with</p> <ul style="list-style-type: none"> - a doctor, - a hospital, - a care attendant - a pharmacist - a therapist - insurance - another person in context of health care 	<p>Can you tell how this started and was addressed by ...?</p> <p>Possible additional topics depending on the referred issues in the participant's answer</p> <ul style="list-style-type: none"> - Integration of medical and non-medical provision - Coordination and continuity of care - Accessibility of care - Important traits of doctors/ providers - Connection with provider - Communication - Involvement in care (patient) - Involvement of family and friends - Patient (Empowerment) - Physical support (pain reduction, functionality, etc.) - Emotional support - Acknowledgement as an independent and individual person with biopsychosocial needs - Information for patients - surroundings
<p>What could be improved? Additional suggestions</p>	<p>How would you like your health care to be improved?</p> <p>Was there anything you had in mind and wanted to tell me today, but I did not ask a question where it would fit?</p> <p>Free association and the possibility to address wishes and suggestions.</p>	



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Additional information on participants' health care experiences

	Number of participants sharing experience with the respective health care provider
General practitioner	25
Specialist physician	24
Hospital	24
Ambulatory nursing	2
Rehabilitation	12
Nursing home	4
Psychotherapy	6
Other therapists (speech therapy, occupational therapy, physiotherapy etc.)	11

Acute health issues participants reported

- Severe cuts
- Falls & accidents
- Common cold
- (inflamed) Cysts
- Vaccinations
- Tuberculosis
- Pregnancy
- Endometriosis
- Hysterectomy and / or Oophorectomy
- Tinnitus
- Vertigo
- Food intolerance
- Respiratory obstruction
- Tonsillitis
- Appendectomy
- Cholecystectomy
- Back pain
- Eczema & rash
- Pain
- Allergies / acute allergic reactions
- Burns
- Disc prolapse
- Haematochezia
- Ruptured appendix
- Fractures (arm, jaw)
- Pneumonia
- ruptured appendix
- shoulder & gall bladder surgery

Participants’ citations related to the identified facilitators and barriers of PCC

Micro Level	
Codings for facilitators and barriers code description	Participants’ citations
Responsibilities and characteristics of patients - activities & responsibilities, patients have to take over independently to facilitate and improve their care - patients’ behaviours, which facilitate or impede PCC provision)	<ul style="list-style-type: none">• “So I said to him, “I’m very scared, could you be a bit careful – or talk to me?” Then he knew what was going on and could act accordingly, and that made it much easier in the end”. (17)• “I don’t need to do any injections, take any tablets, or anything. But only as long as I take care of it myself, you know?” (10)• “I move home a lot, so especially when a new GP in a new town asks “So, have you got your records?” Well, eventually I started collecting everything from my past, more or less.” (25)• “I think it was kind of a three-part solution: the operation went well, then I stuck to the rules, and then I did the physiotherapy.” (18)• “I believe you have the best experiences when you take an active interest yourself – so you don’t call the doctor every time you feel a little poorly and you take responsibility for your own health instead. But on the other hand, you need to speak openly about what you want, or what’s wrong with you. And don’t be vague – saying “I don’t feel well,” or whatever. Try to be specific about what the problem is.” (18)• “Yeah, I mean, any fool knows to take their car for a regular MOT, get their tyres changed for the winter and have everything checked over. So above all else, I should do the same for my body. So I think you have to take a lot of responsibility for your own health.” (18)• “As a patient in that kind of situation, you have to remain vigilant, play an active role in the process – think for yourself, be assertive, you know? And you can’t expect that from a patient – you can’t expect them to be able to think about things first and be assertive. That’s not how things work, is it?” (23)• “Or you need to pay quite a lot of money – depending on when you want the space. [Space in a dementia care facility]” (21)• “Because I always have to pay extra for compression socks – but you do notice that actually, when you still constantly pay have to extra.” (25)• “And I mean it’s common that you essentially have to take a lot of responsibility for things yourself. When it comes down to it, it can feel a bit isolating sometimes. Especially with things like when one doctor refers you to another – then you’re expected to more or less trust them immediately, automatically.” (6)• “Because if I don’t like something, I say it. But I don’t mean just whining for the sake of it. I try to express my concerns reasonably and make it clear to him that I don’t agree with it – either because he’s not explained it to me well enough or because I know for myself that you don’t need it.” (18)

Professional skills of clinicians and contact persons

- skills relating to the professional qualification of staff
 - skill portfolio & diversity
 - continuous training & breadth of knowledge
 - professional soft skills (e.g. active listening, explaining, understanding of professional role)
 - ways in which professional skills facilitate or impede PCC provision

- “Most of all, what I never really experienced for some reason, and still don’t sometimes – I mean, it could be different with this doctor, I don’t know – I’d like them to put a bit more emphasis on natural healing stuff, you know? Instead of always taking the nuclear option, using a sledgehammer to crack a nut, you know?” (16)
- “Yes, I mean “experienced” in the sense or “professional,” that was the impression I got. That the people knew what they were doing. I didn’t see anyone who was panicking or looked like they needed help.” (17)
- “I mean, I’m getting on, and so my doctors are, too. I don’t get on well with younger ones, because they seem to me like they lean too heavily on medical equipment and appliances. And that wasn’t the case with the older ones – you’d known them for over ten, twenty years, so they know what your issues were and what to do about them, you know?” (18)
- “There are also a lot of doctors who don’t have much experience with dementia – I didn’t either until my husband got the condition. I mean, you have to speak really slowly, even if he doesn’t understand everything, so it’s a completely different way of talking. And if you don’t have that experience as a doctor then – well, it’s not great for the patient.” (21)
- “She would have treated me like any other patient who doesn’t take blood thinners, which would be – I mean, even my tooth – if she slips, I could start bleeding, and then I’d really start bleeding.” (25)
- “And the GP – well, firstly, I’d say he knows me pretty well. And secondly he seems in good shape. Even if he’s just my GP, of course, whose practice is just around the corner. But that’s the most important thing for me, actually.” (6)
- “Maybe that’s one of his characteristics: he’s not just a medical expert – whatever he studied, I’ve no idea what he specialised in – he’s got an additional qualification too, it says it on his sign. A diploma in Psychology. And he doesn’t offer psychological consulting as far as I know; he’s just a general doctor. But I think that’s why he’s maybe better than your average GP – because he’s got that extra qualification in psychology. That means he’s qualified to engage with his patients a bit more on a personal level. Not just, “Hello – here’s your medicine – bye!” He treats his patients like people.” (6)
- “Sometimes the best doctors are the ones who know so much that they don’t just give you an injection – they tell you, “In my experience, you don’t actually need this injection.”” (6)
- “And she just took one look and said, “Here’s your diagnosis”. And she said she didn’t understand how all the other doctors I’d been to hadn’t recognised it.” (9)
- “I just had pains that no one had ever taken seriously. It wasn’t until I was in my early twenties, when I met a consultant at (hospital name) – he saw me come in and said “I know what’s wrong with you.” He prescribed me corrective shoes, took me off all the pills, and then I could walk.” (9)
- “As a patient, I can’t keep track of where everything comes from anymore. And no-one seems to care. I’ve always dreamed of finding a doctor who specialised in holistic medicine – someone who would look

	<p>at my body as a whole and see how the different issues affect one another.” (9)</p> <ul style="list-style-type: none">• “That kind of active listening plays an important role, especially in discussions between a patient and their doctor. He didn’t do it.” (23)• “I changed GP recently. I just felt that with this genetic defect and the embolism, my previous doctor – while she was great for me on a personal level – sometimes wasn’t so good on the technical side.” (24)• “Because he was technically good, you know? But most of all, I was able to say to him, “Mind your tone – if you want to tell me something, you shouldn’t say it like that.” And then he said he was really glad I wrote him that letter. And that was such a positive experience: to be able to go in to see a doctor and make yourself understood, and let them know if you’re not happy with something.” (21)• “So I’d like my doctor to actually say to me, “I don’t know,” if it’s not his field or whatever. I mean, it’s only human really, if you can’t do everything. And then he should have sent me straight to the vascular surgeons, but – well, at first he didn’t really want to sign the referral.” (25)• “Then I’d say, for me, good treatment is a combination of mutual respect – a good relationship – and then really high quality on the medical side. Those two components, basically.” (21)• “Well, for me it’s definitely important. If I notice someone has the medical expertise but I don’t really get on with them or whatever – then it’s definitely important for me to be able to express that.” (21)• “Well, firstly the staff here were very competent: starting with the lady at reception, where you sign in when you arrive, and then the kitchen staff, the doctors, psychologists, psychiatrists, sports therapists, occupational therapists, art therapists – there was no-one who really made you think... You could tell they really liked their jobs.” (11)
<p>Personal characteristics of clinicians and contact persons</p> <p>- any personal characteristics, which shape the contact persons’ style of interaction and relationship with the patient</p> <p>- ways in which personal characteristics facilitate or impede PCC provision</p>	<ul style="list-style-type: none">• “He was rushing so much and he wasn’t really listening anymore. And he was already heading for the door, like he was going to leave – and I wasn’t finished talking. I was still sat there, and he was already at the door.” (12)• “They were nice and friendly. They said hello, asked, “How are you doing today?” and so on. They didn’t just bluntly wander in, do something and then rush out again.” (17)• “And next time I was there, I could tell he’d been thinking about it. He said as well, “For some reason I couldn’t stop thinking about it.” And then he explained that he wanted to give me this – what was it now? A probiotic. But because my immune system was already weaker than usual, he couldn’t. It could lead to an exacerbation in my intestines and so on. But at least he’d explained it to me very well again, and I could see that he cared – that my concerns mattered to him, you know?” (16)• “Well, he said that it ran in his family, too. And when I was there for the second time, I think, the results from my lungs were much better, and he was practically jumping for joy because he was so happy about it. And it was infectious – I actually felt really good when I left.” (24)• “I worry, but they don’t leave me alone with my worries. They speak to me. I ask very specific questions and they notice I’m scared, and then we talk about it, too. They don’t try and dismiss it, tell me it’s not that bad or

that it depends on the weather. They say, “These are the risks, these are the dangers. Don’t go on holiday on your own, don’t go hiking in the Norwegian wilderness” – all that kind of thing.” (20)

- “He just knew, “Okay, (patient name) is done. Done with the world.” And somehow he managed to connect with me, you know? Or I connected with him, in the end.” (16)
- “It was the human side, too: you’re not just sitting in front of someone who’s only communicating in writing, who doesn’t even look at you or acknowledge you. And you’ll notice with me – well, let’s just say that if there’s something troubling me, I need to get it off my chest.” (5)
- ““And if you’re going to do that, then please tell me, otherwise I won’t be ready. I get scared very easily.” And then she was very dismissive; she said, “Well, I didn’t know you were going to be so sensitive.”” (17)
- “Well, I think I would have liked a little empathy. For instance, he could have said, “[...]. And I understand it’s not an easy decision for you to make, but I would advise you do it.” So he could have started off a little differently, and then said, “But based on your symptoms, I really think this is the right thing to do.”” (21)
- “And most importantly, he tells me when one type of therapy or other doesn’t make sense for me anymore. “The cartilage is gone, why would I give you a hyaluronic acid injection? That would just be fleecing you. Nothing else is going to build back up there; it won’t work. It’s too late for that, you know?” He could just as easily say, “Okay, I’m going to give you this and this, and it costs this much” – because it’s not covered by the insurance, you know? And I wouldn’t be able to pay for it anyway. But that honesty, I like it, you know? After all, I’m honest with him.” (13)
- “And to start with he was just sat in his armchair like a friendly old uncle, just listening to me. And it was really nice, you know? He didn’t just get straight down to business. He didn’t just say, “Okay, let’s have a look,” then start shoving medical instruments in me or whatever. He actually listened to me, then really calmly, he said, “I’ll need to take a quick look.” And he explained everything to me, and that was great.” (17)
- “She’s very laid back. She doesn’t speak in medical jargon all the time – she’s very easy to understand. And I really like that; it shows that she cares.” (25)
- “Yes, she [the Nursing Director] made time for us. She kept coming back now and then, and she spoke to my husband, too. There were so many things that had gone wrong, and she always showed an interest.” (22)
- “The doctor’s attitude towards me, the way he was lounging on his chair...” (10)
- “Yes, absolutely. I usually reply, “I may be old, but I’m not stupid!” And that works. It shocks them when you just come out and say it, you know? And sometimes they start apologising: “Oh God, I’m sorry, did I say something wrong?” And I say, “Yes, you did.”” (20)
- “Well, firstly the staff here were very competent: starting with the lady at reception, where you sign in when you arrive, and then the kitchen staff, the doctors, psychologists, psychiatrists, sports therapists, occupational

	therapists, art therapists – there was no-one who really made you think... You could tell they really liked their jobs.” (11)
Physical and emotional well-being of clinicians and contact persons - situations in which the well-being of staff members facilitated or impeded PCC provision - reasons, why well-being of staff members facilitated or hindered PCC provision	<ul style="list-style-type: none">• “So you have to wait for a long time. The practice was very full, very busy – overrun, it seemed to me.” (17)• “You need to be patient, I think. You can’t just expect it of others – you need to show a little understanding yourself, you know? The doctors have a lot on their plates, right? And you need to remember that as a patient, I think.” (8)• “Of course, I understand that they’re often overrun, the GPs and their practices. But why should I be the one who suffers for that, you know? I mean, that isn’t right. You know?” (12)• “It is what it is. Looking back, I think, “That poor young woman, I overwhelmed her.” I think that sometimes.” (5)• “And they [staff members] are all stressed out, you notice this.” (21)
Intervention - characteristics of intervention, patients regard as facilitating PCC - valuation of characteristics - expectations towards patient centered interventions	<ul style="list-style-type: none">• Interviewer: “How did you know that you were getting good medical care?” Participant: “Well, I felt better afterwards, didn’t I?” (3)• “I have to say, I felt well looked after, well cared for, in a purely medical sense. Maybe that’s not the right word, but I kept getting stronger physically, you know?” (10)• “I complained once that the tablets were too big – that they were hard for me to swallow. Once, I almost choked! And since then, I’ve always said, “No, they need to be powdered.”” (1)• “And with me it took less than a week – my situation improved thanks to the therapy with [medication]. And I was really pleased with that – that it went a bit faster, then.” (15)

Meso Level 1&2

Codings for facilitators and barriers code description

Participants' citations

Process of care within an organization (and across organizations)

Coordination of care

- experience of coordination of care and explanations whether and how this facilitated or impeded care being experienced as patient centered
- aspects of coordination which are perceived as important to receive PCC

- “On Monday morning they said “Hmm, sorry, but we’ve had to call off [the operation]. There’s been an emergency.” Okay, that kind of thing can happen. I’ll wait another day, it’ll be fine. Then in the morning, I think, they got me ready and made sure everything was in place, then they took me to be prepped – not straight to the operation prep room though. They put me in some kind of waiting room where there were several beds, but I was on my own. They left me lying there for four hours, while [my family] were sat there worrying. My operation was scheduled for twelve or whenever, but nothing happened – no one came to tell me I’d have to wait a bit longer. Then quite a bit later, a cleaning lady turned up with her mop and bucket, and she said, “Oh, you’re still here!” It took quite a long time, I have to say. Of course, they told me there had been another emergency and so on. And then he said, “They might schedule another operation for you, at eight o’clock this evening.””
I: “Okay.”
B: “I was lying there for quite some time again. And then someone else came in and said, “No, sorry, we won’t be doing it today after all.” Hmm, I mean, it makes you think, of course. It’s all about this, you know?” [Points to heart] (4)
- “There’s so much needless repetition. You give them the results from your GP, and they say, “Those are from another lab, we’re not interested. We’ll do them all again.”” (23)
- “If a doctor or whoever says, “We’re going to do this and this and this,” so the next doctor and the nursing staff are all kept in the picture – then I know that everything works hand in hand, and that the communication is good.” (21)
- “I came in and they examined me, then I was just sitting there and sitting there, and they ended up forgetting me.” (22)
- “Now and then I feel a bit like it’s a bit of a hassle – when there’s nothing wrong with me at that moment, then I think “Hm, I need to go to the doctor’s again.” It’s not a big thing, it’s no real effort, but it always happens at the wrong time – when you’re just about to leave the house.” (10)
- “Okay, so we sent them our documents and records, right? Mine and my daughter’s. Recommendations from therapists on both sides – my daughter had a psychiatrist, of course. So we’d sent them a lot of information, and recommendations for this one facility. We sent them to our health insurance company first, but they said, “That’s not our area – you need to speak to your pension insurance company. We’ll pass your documents on to them.” So we waited, and waited, and waited. And after three months, I thought,

	<p>“I’ll just ask politely and see how things are going, what the status is.” Then they said, “We haven’t received any documents.” I said, “You can’t be serious. That’s confidential information – doctor’s letters for me and my daughter! The health insurance people assured me you’d received them – I have the date they sent them off right here.” “Nope, we don’t have anything.” Okay, so I called the health insurance company again and spoke to them. And at some point they said there was an association I could speak to that helped in situations like this. So I went there...” (11)</p> <ul style="list-style-type: none">• “But they [the nursing staff] were always paying attention, so if you had any kind of issues, they would pass it on and a doctor would turn up.” (12)• “I think that [medical care units] would be good. I wouldn’t need to keep going back and forth, driving up there and so on. I’ve got a friend whose husband is really ill with cancer, and she said all the driving is a nightmare, you know? Therapy here, another thing there, then back to the urologist. If it was all in one practice it would save so much time, you know? Not to mention stress.” (13)• “Nope, no-one told me anything. I had to find the doctor’s office myself. And sometimes I had to ask, “Er, hold on, what’s going on here? Just one nurse comes in here and tells me I need to go to another hospital – what’s going on?”” (14)
<p>Continuity of care - experience of continuity of care and explanations whether and how this facilitated or impeded to care being experienced as patient centered - aspects of continuity which are perceived as important to receive PCC</p>	<ul style="list-style-type: none">• “Well, personally I find it a bit difficult to get used to someone new – or if I’m expecting someone else it confuses me for a second, and I need to readjust. And then I might have to start from the beginning and explain everything yet again; it’s a bit difficult.” (17)• “I’m meant to be receiving continuous treatment at the Breast Centre, but every time I’m there it’s a different doctor. You don’t get chance to establish a rapport with anyone. They can’t go, “Oh, she was dealing with that last year, let’s see how it’s developed.” And I miss that.” (9)• “Well, I’m getting continuous check-ups [in the Disease Management programme] again, too. I feel well looked after.” (8)• “Patient-centred”, they call it. Everything’s provided for the patient – if they can’t look after themselves, you know? If there are no family or friends looking after them. People should be paying a lot more attention to the patient’s interests and personal situation – making sure they understand what’s going to happen with them, you know? If they ask whether they can go back home and don’t know what’s going on. I’m not going to go home and lie around unable to do anything, you know?” (23)• “Basically, it comes down to the doctor [GP]. I’ve been to other doctors occasionally, but you hardly know them, so you don’t have that same relationship and trust. And the GP – first and foremost, I think he knows me quite well.” (6)• “But then you get a phone call at home: “What’s wrong with you?” I’ve noticed that before. “Are you going to keep coming in or not? How are you doing?” That’s great.” (22)• “But when I really need to see a doctor, so for example when there I have a really urgent problem and need to see the doctor that day, I just go to see any doctor for treatment, but if it not really urgent, I make sure to see the doctor I trust in, the one who knows me.” (12)
<p>Flexibility of care</p>	<ul style="list-style-type: none">• “And he’s also flexible with his time. I mean, he has his fixed hours, you know? And his consulting hours are fixed too, but he sticks to his schedule

<p>- experience of flexibility in care and explanations whether and how this facilitated or impeded to care being experienced as patient centered</p> <p>- aspects of flexibility which are perceived as important to receive PCC</p>	<p>really well, and it's really easy to alter your appointment with him if you need to. So he's flexible, and I can decide when my appointment will be." (15)</p> <ul style="list-style-type: none"> • "But then they also gave me the option straight away: "If we can't get the child to calm down here, then you can stay here." Then I'd get a bed in the room, too. That was great." (8) • "And I thought it was really good that they decided on a case-by-case basis to keep me there." (15)
<p>Timeliness of care</p> <p>- situations in which timeliness of care influenced PCC provision</p> <p>- when is timely care necessary to meet the patient's needs and preferences</p> <p>- situations in which timely care is more/less relevant for experiencing care as patient centered</p>	<ul style="list-style-type: none"> • "You need to make an appointment to speak to the specialist. And I can't say I've really had a positive experience outside of this rehab facility, you know? You're a patient – they do the bare minimum for you, and if that's not enough you need to come back, or you're sent away. You often feel like you're just in the way." (11) • "But in a lot of cases where you're really in pain, you just have to wait, and you're sent away." (11) • "So I went to two dermatologists, and the first one said, "We don't have any appointments free, you'll have to come back in six months." So I say, "But I don't know if I'll even still have the rash in six months. Don't you have special consulting hours for acute cases?" Apparently they didn't. So I went to the next dermatologist: "Five months." So I said, "I don't know if I'll still have it in five months." (13) • "If I've got an acute illness, I want to be given an appointment or taken on straight away, you know?" (13) • "I came to the outpatient's department there, and they decided straight away that it was an emergency, and that they wanted to operate on the same day. The whole procedure was organised perfectly; the anaesthetist came straight away and they slotted the operation in in the evening, so to speak. They let me stay overnight and looked after me really well. You could tell that it was actually an outpatient case, but I didn't have anyone to look after me, because I'm on my own." (15) • "And then the fact that everything had to be sorted out so quickly with a place in a hospice, which we hadn't been able to get... That's the problem. And then in the end they put you back in the ward, you know? Like they're saying, "If we can't find a space then the ward will just have to keep the patient. We can't exactly shoot him in the head," you know? Pretty crazy, right? We couldn't take him home with us either, and you can't put a 52-year-old in a home for the elderly – and they're all full to the brim, anyway, the hospices too. You know? He needed his medication, he needed round-the-clock care – we wouldn't have been able to afford that at all." (16) • "I find it incredibly difficult to get an appointment with a specialist in the city." (24)
<p>Culture and Climate</p>	
<p>Atmosphere, special services</p> <p>- situations in which the atmosphere/special</p>	<ul style="list-style-type: none"> • "In outpatient oncology too, it's more like a conveyor belt – not really somewhere you can feel comfortable, you know? They don't offer you anything, like a cup of tea or coffee, or biscuits, or a newspaper." (22)

<p>services facilitate or impede PCC provision - which behaviours/ atmosphere/extra services create a patient centered environment</p>	<ul style="list-style-type: none"> • “I was just an inconvenience for him, it felt like – I really wasn’t welcome as a patient at that moment in time. That’s how it seemed to me, I’ve got to say.” (10) • “He was the heart and soul of that department. And the doctors were very friendly with one another, I always thought – you notice that as a patient, too.” (10) • “There was all this fuss, you know? You could see from how they acted that the nurses weren’t happy. And that really affects the atmosphere and sense of comfort.” (16) • “And then they [the staff] were more or less screaming at each other on the ward. Well, it was just awful.” (11) • “And it was so great there, I found out – in East Germany. At the polyclinic, they had everyone: internists, dentists, surgeons, dermatologists. They had the minor skin operations, then the place where they put a plaster cast on you, and do minor surgery. So if they couldn’t get to the bottom of some kind of specialist issue, the GP could send the patient next door to see the internist. And if the internist couldn’t solve it... So all the preliminary examinations were done at the polyclinic.” (12) • “So if my GP has less and less time for me, and I feel like they’re not looking after me properly anymore, then I find a new GP. That’s always an option. I want to be looked after properly – as a patient, I want someone who listens to me and takes me seriously, you know? Instead of just sending you to the next room.” (12) • “Well, I imagine that’s something doctors don’t hear often enough. Of course, all the pressure falls on them if something doesn’t go right – if they screw up (pardon my French). On all the ratings websites, too. So if things go well, that needs to be said as well – preferably to their face.” (17)
<p>Communication and Cohesion among staff members - situations in which patients experienced the communication and level cohesion as facilitating or hindering PCC - situations in which cohesion can be observed</p>	<ul style="list-style-type: none"> • “He was the heart and soul of that department. And the doctors were very friendly with one another, I always thought – you notice that as a patient, too.” (10) • “And then they [the staff] were more or less screaming at each other on the ward. Well, it was just awful.” (11)
<p>Feedback and reactions - situations & ways in which patients can express feedback and how it facilitates PCC provision</p>	<ul style="list-style-type: none"> • “Well, for me it’s definitely important. If I notice someone has the medical expertise but I don’t really get on with them or whatever – then it’s definitely important for me to be able to express that.” (21) • “And since I don’t know the first thing about care homes, I asked a lot of questions about why things were done a certain way – lots of things. And at first they took that as criticism.” (21) • “But I’d say by now that if something’s bothering me, I go straight to the manager at the home and tell her. We have a really good relationship now, where we can speak to one another openly.” (21)

<p>- relevance of expressing feedback to facilitate PCC</p>	<ul style="list-style-type: none"> • “Then I thought, “No, it’s not worth the stress.” I’ll tell anyone who’ll listen about it [inappropriate behaviour on the part of a doctor].” (13) • “But the thing is, it’s not that easy to say to a doctor, “What you’re doing here is nonsense – you need to do something different.” You don’t really feel you can do that as a patient. So it’s not great with these gastroenterologists. And I’ve wondered about going to a different one, but I don’t know – that’s a hassle as well.” (6)
Staffing and Workload	
<p>Patient provider ratio - situations in which the number of staff facilitated or hindered PCC provision</p>	<ul style="list-style-type: none"> • “I know a lot of them have a lot of patients, and not much time either. Less and less time, in fact, because a lot of carers and nurses are under pressure from so many different facilities, insurance companies and doctors, of course. I know that. But it’s still important to keep good medical records.” (7) • “The nurses really did everything, in spite of how busy the hospital was.” (11) • “And there was no one left to help, you know? I mean, I could walk a bit, but there was an elderly woman next to me who was getting no care. She was lying there, wet, with no-one. So I always fed her, this lady. She needed some fluids, something to eat. And everyone there was ill, and there was one nurse on the ward, and of course she couldn’t keep up. It was a really unpleasant experience.” (12) • “I mean, I never once had the feeling she had no time for me. Even if she didn’t, you know? That’s always the trick of course: not to let it show when you’re under stress. That’s part of providing a good service, really, and I think it’s really good.” (17) • “Well, I don’t know if it’s the shortage of staff everyone’s always talking about – I read about it in the paper, you know? The nursing crisis. I couldn’t say. But if there is one, they didn’t let on, you know? And that’s something, at least.” (17)
<p>Mix of experience and skills - situations in which patients perceive the experience and skill mix of providers as facilitating or hindering PCC provision</p>	<ul style="list-style-type: none"> • “It is what it is. Looking back, I think, “That poor young woman, I overwhelmed her.” I think that sometimes.” (5) • “And it was so great there, I found out – in East Germany. At the polyclinic, they had everyone: internists, dentists, surgeons, dermatologists. They had the minor skin operations, then the place where they put a plaster cast on you, and do minor surgery. So if they couldn’t get to the bottom of some kind of specialist issue, the GP could send the patient next door to see the internist. And if the internist couldn’t solve it... So all the preliminary examinations were done at the polyclinic.” (12) • “And then the more experienced nurse in the team explained to her (nursing student), you cannot talk to someone in this way.” (21)
Infrastructure	
<p>Rooms and buildings - characteristics of rooms and building, which facilitate or impede PCC provision - suggestions for improved rooms and buildings</p>	<ul style="list-style-type: none"> • “So there was one bath for a whole maternity ward. That’s really not enough. You wouldn’t believe it if you saw that today.” (8) • “I think it’s really nice. Really, they tell you everything you need: if you’re a young family they say they have rooms for families, tell you where they are, and where you can rest from your journey. I think it’s really, really nice.” (8) • “I was really shocked that you didn’t have to go right to the end of the hall [to come to isolation rooms], or past all the guests and the care staff – that they actually do consolidate things a little, and then maybe there’s an annex or something.” (8)

IT resources - examples of IT resources or lack thereof which patients perceive as facilitating or impeding PCC provision	<ul style="list-style-type: none">• “Yes, yes, this [electronic health record], sounds very reasonable to me. The main point is that I do not have to check which physician is informed about particular data, whether something is missing.” (24)• “But they [social health insurance company] have this nice app for example. [...]. This is brilliant. You have to agree to data protection regulations. [...] it contains such basic things, but as I said before, I cannot remember the names of all diseases and anyway, this App, [...] has an overview of my medications.” (6)
Equipment - situations in which equipment facilitated or impeded PCC provision - type of equipment that is addressed	<ul style="list-style-type: none">• “It [the examination and treatment equipment] is a bit more rounded, a bit softer, a bit quieter. And of course it’s nice to meet doctors who are open to that, you know? Instead of saying, “The equipment in my practice has lasted a hundred years – it’ll last another hundred too.”” (17)• “The device was broken. And now, once you experienced this, at doctors’ offices, you check whether the device is TÜV-certified (TÜV, German Association for Technical Inspection).” (9)

Macro Level	
Codings for facilitators and barriers code description	Participants' citations
Structures of the health care system - structures within the health care system which facilitate or impede the patients' experience of PCC - examples of situations where patients experienced structures facilitating or impeding PCC provision	<ul style="list-style-type: none"> • "I'd like it if private patients could get more information on how your whole system works. Because they need to pay a lot up front, but they can also use the benefits and so on. Maybe there could be a platform so they could find out more about how the system looks after them." (15) • "Well, in my opinion it should all be more under state control, instead of the doctors trying to compete with one another." (19) • "Really, they send you from A to B, then from B to A, and then it's: "Oh, I think you need to go back there..." (11) • "Almost every district has an emergency doctor who's open outside normal GP operating hours, right? There needs to be more information about that in the papers, or the citizens need to be told about it some other way – so they know about it, you know?" (12) • "The health insurance companies just send you where you're meant to go. They don't care what happens after that. Even the advice centres don't ask anymore. They used to ask you to fill in a survey at least, then they'd ask how it went, but now they don't care about any of that." (7)
Financing and Reimbursement -financial structures and conditions within the health care system which facilitate or impede the patients' experience of PCC - examples of situations where patients experienced financing and reimbursement mechanisms facilitating or impeding PCC provision	<ul style="list-style-type: none"> • "Because it really is a lot of money, what I pay for my health insurance very month. And I understand that it's a good system, but it's not always fair in terms of your income. And if you're self-employed and not earning much but you still have to pay that much health insurance, it really puts a strain on you." (6) • "Well, it seems to me that it's harder to get an appointment with a specialist if you're publicly insured. How often do you get asked, "What insurance do you have, what company are you with?" That's not a good feeling. And on top of that, while I'm still on a public insurance scheme, I actually pay the maximum rate there – and if you're paying over 700 euros a month in a country like Germany, you should be able to expect a decent level of care." (15) • "And I'd love to see homeopathy or natural medicine given more of a chance when it comes to patient care. A natural medicine practitioner needs two or three hours to draw up a medical history – no health insurer's going to pay for that." (9) • "Well, I had a breakdown, basically. I couldn't keep going to work. And I submitted an application for a rehab facility or health resort. Then I got a rejection from Medical Services at the health insurance company – they said I was just a little overworked, and I should have a weekend away with my husband." (11) • "Let me tell you, everything was easier a few years ago. But now there's so much streamlining, you know? The doctors can't get the funds for these things; they have a limited allocation for each patient. And that's not

	<p>the doctors’ fault – that comes from somewhere else, you know? So I’d like to see things made easier for patients again.” (11)</p> <ul style="list-style-type: none">• “We pay our health insurance, right? Then you have to pay all the prescription fees on top of that. For example, I’ve got these special insoles; apparently they cost around 150 euros. And I have to pay 38 euros on top of that, and that really hurts.” (11)• “You fall out of the system, of course. I’m just costing money, not bringing any more in. I’m just costing them money. And that really brought me down, that legal dispute with my pension insurance company, you know? To be just dismissed like that: “She’s just causing a fuss.”” (11)• “My physiotherapist is great – I’ve got a really good one, I get on with him really well. But the downside is that I only get a prescription for physiotherapy every three months – six sessions. It’s not enough at all. But you know, no-one can do anything about it; that’s the way the system works. The insurance companies are overrun.” (13)
<p>Laws and regulations - laws and regulations which patients perceive to facilitate or hinder PCC provision - examples of situations where patients experienced laws and regulations facilitating or impeding PCC provision</p>	<ul style="list-style-type: none">• “I’d like it if the doctors had more time. That would mean they’d need to employ more doctors – the Associations of Statutory Health Insurance Physicians would need to issue more approvals for the individual specialist fields. Especially in the country – they need more doctors there, especially specialists.” (15)• “Because there’s doctors who have a calling – that’s how they see it. And maybe it’s not that great if they’re struggling to make a living off it because they have a budget and they have to pay out of their own pockets if they go over it.” (13)• “So I look to see who can offer me an MRT, you know? Where can I go? Then I need to call them all up and see who can give me an appointment the soonest. And that can sometimes take two, three, even four weeks.” (11)• “But now there’s so much streamlining, you know? The doctors can’t get the funds for these things; they have a limited allocation for each patient. Sometimes I wonder why everything’s always getting more complicated.” (11)

Manuscript: Clinicians' perspectives of parental decision-making following diagnosis of a severe congenital anomaly: qualitative study.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 28
3. Occupation	What was their occupation at the time of the study?	Page 28
4. Gender	Was the researcher male or female?	Page 28
5. Experience and training	What experience or training did the researcher have?	Page 9,28
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Page 7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page (see supplementary file 1 Interviewguide)
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 28

Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 8-9
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 7-8
12. Sample size	How many participants were in the study?	Page 9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 9
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Page 7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 10-11, supplementary file 2
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 7, supplementary file 1
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No, inferred on Page 8
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 8
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Page 8

21. Duration	What was the duration of the inter views or focus group?	Page 9
22. Data saturation	Was data saturation discussed?	Page 10
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 8
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Page 9
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 12-22, supplementary file 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 8-9
27. Software	What software, if applicable, was used to manage the data?	Page 9
28. Participant checking	Did participants provide feedback on the findings?	Page 8
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Supplementary file 3
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Compare results section to supplementary file 3
31. Clarity of major themes	Were major themes clearly presented in the findings?	Page 12-24, Figure 1
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 26 Discussion of ambivalence

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
Title	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2 & 3
Introduction	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5

Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	6-8
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	28
Context	#7	Setting / site and salient contextual factors; rationale	6-7
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	7
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	28

1	Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7-8
2				
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12	Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7-8, supplementary file 1
13				
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20	Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	10 supplementary file 2
21				
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27	Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	7-8
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36	Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	8-9
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44	Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8-9
45				
46				
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49	Results/findings			
50				
51				
52	Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	12-23
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Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	supplementary file 3
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	24-27
Limitations	#19	Trustworthiness and limitations of findings	27
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	28
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	28

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