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InCept – Patients' perceptions of primary health care provision with respect to access, continuity and coordination: international qualitative perspectives.

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Due to the dynamic study situation, it is possible that sources with more recent findings have not yet been considered.

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APN	Advanced practice nurse	
BMC	Federal association managed care	Bundesverband Managed Care
CHD	Coronary Heart Disease	
DEGAM	German Society for General Practice and Family Medicine	Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin
DGK	German Society of Cardiology	Deutsche Gesellschaft für Kardiologie
DGPR	German Society for Prevention and Rehabilitation of Cardiovascular Diseases	Deutsche Gesellschaft für Prävention und Rehabilitation von Herz-Kreislauferkrankungen
EHR	Electronic Health Record	
ePA	German EHR	elektronische Patientenakte
EPD	Swiss EHR	Elektronisches Patientendossier
GP	General practitioner	
MI	Myocardial infarction	
MVZ	Medical care center	Medizinisches Versorgungszentrum
NEHR	Nationwide Electronic Health Record	
NP	Nurse practitioner	
NPÖ	Swedish EHR	Nationell Patientöversikt
OECD	Organisation for Economic Co-operation and Development	
PC	Primary care	
PVZ	Primary health care center	Primärversorgungszentrum
WHO	World Health Organization	

1 Introduction

Health care systems differ worldwide. Even in Western Europe, where in total a similar standard of living prevails, health systems differ in terms of financing, quality of care, type of health insurance and access to health care.

By comparing different health systems and different outcomes related to the systems, researchers hope to be able to derive insights about health care. Yet it is not so easy to assess the quality of care or health care systems. Researchers try to compare the quality of health care systems by different indicators. One of them is the *"amendable mortality".*[1] Another key indicator is the life expectancy, which was, for example, especially high in Switzerland.[2] In order to compare health care systems and draw evaluative conclusions, the main characteristics and peculiarities of the country-specific health systems and their current challenges are described below.

1.1 Different health care systems – different strengths and weaknesses

All participating countries are members of the OECD (Organisation for Economic Co-operation and Development). For this study, this means that all systems investigated, already have a certain standard, as the OECD operates as a kind of advisor and conducts research regarding health care outcomes, such as quality of health care.[2] The following aims to provide a brief overview of the important characteristics of the health systems of the participating countries, whereas there is no claim to completeness.

1.1.1 Germany

Since the governance of the health system in Germany is split up between federal, state, and municipal level and corporatist bodies, health care provision is quite shattered and its steering including reforms and amendments are protracted and the latter difficult to implement. In addition, the strict separation of the individual sectors of the health care system such as ambulant primary care, ambulant specialized care, inpatient care, and public health has a fragmenting effect on care delivery. As a result, policy makers have to deal with a deficient

coordination through health care levels and poor information transfer between sectors.[3]

Another important topic when it comes to the German health system is the non-committal gatekeeping system. Although GPs (general practitioners) act theoretically in the gatekeeper role, there is no obligation for patients to contact their GP before the specialist and therefor can consult the latter directly. Nevertheless, this does not apply to patients who are voluntarily participating in the GP-centred model of care, in which they must first contact their GP, as a gatekeeper in the classic role.[3]

In Germany, every inhabitant is obliged to have health insurance. The largest part (88 percent) of the German society is insured under the statutory insurance (SHI) scheme, while only 10 percent are covered by the private health insurance (PHI), for which the insured person must provide proof of a certain income. This separation makes it even more complicated to navigate through the system due to restrictions on service provider choice and lack of transparency regarding benefit entitlements.[3]

1.1.2 Sweden

In Sweden there is no gatekeeper system, patients can choose both their GP and their specialist freely and contact them directly.[4, 5]

Inhabitants are automatically protected by the national insurance in Sweden. However, citizens can purchase additional private insurance.[5]

Worth mentioning is the allocation of significant financial resources towards the strengthening of the outpatient care sector, which transcended the average spendings of other European countries.[4] One part of empowering the outpatient sector is to enhance nurses in primary care and establish specialist nurses and so-called advanced practice nurses (APNs), especially for the care of patients with chronic diseases. The effectiveness of these strengthening ambitions of the outpatient sector showed itself in reduced rates of hospital admissions.[4]

Improving access to health care was aimed through a waiting time limit, which was established in 2019. The objective was to reduce waiting times for medical evaluation in a primary care setting to three days and to receive specialist care, when referred by a GP and medical indicated surgeries or treatment within 90

days. Nevertheless, access to health care was described as poor in a review of the OECD from 2019 which found that access to physicians is particularly poor, with only 65% of people reporting seeing a doctor when needed.[2] Another point that needs improvement is a deficient care coordination. In an international comparison, Swedish patients reported the worst care coordination.[4] In 2009 the "Nationell patientöversikt" (NPÖ), the Swedish EHR was introduced[4], which has a beneficial effect on interprofessional communication and the degree of comprehensiveness of care.[6] Health care providers can use the NPÖ to access patient data with the patients' consent.[7] Moreover, Sweden is one of four countries, playing a pioneering role in the development of national electronic health records (NEHR) in Europe.[8]

1.1.3 Switzerland

Because of the very decentralized political system in Switzerland, the Swiss health system is equally fragmented with an important status of cantons and municipalities, which results in care coordination, that needs to be improved. However, the political system allows the residents to actively participate in health care reforms.[9]

In Switzerland, every inhabitant is obliged to have a mandatory health insurance (MHI). The respective premium is independent of the income of the insured person, but dependent of the region the patient lives in and the age of the patient.[2, 9, 10] In general, there is no strict gatekeeping in Switzerland. Nevertheless, people can commit to seeing a GP for a specialist referral by joining a managed-care plan.[5]

Moreover, Switzerland aims to improve informational continuity by being one of four countries, who play a pioneering role in the development of national electronic health records (NEHR) in Europe[8], even if it is still in its infancy.[5]

The Swiss health care system is known to be an efficient health care system with a healthy population, measurable among others by life expectancy, which at 83,6 years was the second highest in Europe compared to other OECD countries.[2] Conversely, the health care system can be seen as a financial burden for Swiss inhabitants, as both the share of the gross domestic product spent on the health system and the amount of out-of-pocket payments range far above the European

average. As a result, a small part of three percent of the population with low-income stated that they refrained from medical measures because of financial obstacles. This was more often the case than in other European countries such as Austria or Germany.[9]

1.1.4 Jersey

As the interviewed patients in this study are not from the United Kingdom but from Jersey, a selection of relevant differences between the Jersey Healthcare System and the NHS (National Health Service) of the United Kingdom is explained in the following: patients in Jersey may pay fees and co-payments[11], while in the UK the utilization of GPs, specialists and hospitals is covered by the NHS.[5] For example, GPs in Jersey charge a fee for their services, even if one has the local Social Security health card for Jersey.[11] Citizens who lived at least six months on the island of Jersey and paid contributions to the Social Security may receive a Social Security health card.[11, 12] Citizens have to commit to a main GP practice.[13] The Jersey Care Model (JCM) Review from 2020 aimed to highlight relevant weaknesses in the system: it stated that citizens of Jersey perceived the health care system of Jersey to be fragmented leading to an uneconomical repeated involvement of different providers.[13] Moreover, the 30.000 registered emergency department visits in 2018, which were actually no emergencies are an expression of the poorly developed primary care on the island of Jersey.[13] Poor coordination in the sense of guidance and advice is reflected in peoples limited knowledge of available health care offers, which was also described in the JCM Review.[13]

1.1.5 Summary

It can be summarised, that some weaknesses overlap between countries while others are country specific. For example, Sweden enjoys a strong outpatient sector, while Germany has room for improvement in this respect, which can partly be observed by the avoidable admissions to hospital. These tend to be lower in countries with strong outpatient care (Sweden) while they are high in countries with an expandable outpatient sector, like Germany or Jersey.[4, 13] The maldistribution between urban and rural areas and therefore longer waiting times exists in Sweden.[4] Because of the small size of the country and a well-developed

public transportation network, the maldistribution doesn't play such a big role in Switzerland.[9]

1.2 Addressing key challenges to health systems by reducing the patient experience gap

1.2.1 Current challenges to healthcare systems

Health care systems all over the world are facing among others three challenges, that are predominantly independent of the type and organization of the underlying health care system: an increasing burden of multimorbidity combined with an aging society and an unmet need of general practitioners.[14-16]

There is no uniformly valid definition of multimorbidity. Depending on the source, it is determined as the existence of more than one health condition or more than two respectively three chronic conditions. Because of the ambiguous definition, also prevalence is inconclusive, ranging between 55% and 98% in an elderly population.[17, 18] In 2016, Tetzlaff et. al. examined, to what extent multimorbidity is increasing in Germany. They concluded that, measured by the morbidity ratio (proportion of life years with multimorbidity to total life expectancy), the mean lifetime spent with multimorbidity rose significantly within ten years (2005 – 2014), while the years spent in multimorbidity increased not only in relative, but also in absolute numbers.[14] These findings were confirmed by another international study, which showed that the prevalence of multimorbidity increased from 2006 to 2015 in ten European countries, including Germany, where the prevalence increased from 34,2% to 44,6%.[19] Besides the prevalence of multimorbidity, also the prevalence of chronic diseases increased worldwide over the last decades.[20] This can be illustrated using the relevant example of diabetes mellitus. In Germany, the occurrence of diabetes mellitus in the adult population increased from 6,5% to 9,7% between 2000 and 2009.[21] A similar development took place between 1990 and 2017 in Switzerland, where the prevalence of diabetes mellitus rose by approximately 1% to 7,3% for men and 5,6% for women.[22] Increases of the prevalence of diabetes mellitus were moreover recorded in Sweden between 2007 and 2013[23] and the UK[24, 25]. A recent analysis from 2023 estimated the further increase in the global prevalence of diabetes mellitus based

on an analysis of the "Global Burden of Diseases, Injuries, and Risk Factors Study" and predicted a further rise in the burden of disease by 2050.[26]

In addition, the demographic change with an ageing society moves forward. Combined with falling birth rates, elderly form an increasingly large part of the society and thus can strain the health care system. The percentage of people over the age of 65 years almost doubled from 1960 to 2017 and is predicted to increase even faster. The demographic change in turn entails an increase in multimorbidity and chronic disease, as these have a higher prevalence among the elderly.[2] In summary, globally, health care systems face challenges that include an ageing society and an increasing prevalence of multimorbidity which has influences on an individual as well as a societal level: Multimorbidity has been proven to increase mortality[27] as well as reduce the patients' quality of life, if not only the count but also the severity of the existing diseases is considered.[28] As for the consequences for the society, multimorbid patients tend to have a higher take-up rate of health care services which results in higher costs.[29] The higher utilization rate is seen in higher hospital admission and referral rates among multimorbid patients.[30, 31] One explanation for higher hospital admission rates could be the insufficiency of the outpatient sector for multimorbid patients, as the health care system is still too much designed to treat acute and single diseases.[32]

As the prevalence of multimorbidity rises, decision-makers must find answers to the challenges described. Here, primary care could be a central part of the answer.

The situation is further exacerbated as for example Germany will face a lack of general practitioners. In Germany, 45 percent of physicians are aged 55 and older, which is not only above the OECD average but a strikingly high proportion in international comparison and especially in comparison to the other countries, participating in this study. In addition, in Germany the proportion of doctors working as general practitioners is particularly low with 17 percent. In comparison, countries such as Finland or Belgium achieved GP shares close to 40 percent. In Sweden, the proportion of doctors practising as GPs is also relatively high at 27 percent.[2] In the last 20 years, the balance between physicians working in family care to specialised doctors shifted in favour of the

specialists.[3] The replacement, additional and expansion demand of general practitioners, that are required to face the increasing multimorbidity, cannot be met, as only nine to eleven percent of medical students consider working as general practitioners. This contrasts with the fact, that 30 to 40 percent would be needed to meet the overall need for GPs.[3, 16] Combined with an overall increase in the use of doctors, including GPs in Germany, which has been forecast for the coming decades until 2035, the situation poses a serious problem.[33] As other OECD countries, like Belgium, France and the Netherlands don't have this issue, by having a politically determined GP education quota of 40 to 45 percent, German political decision makers must consider restructuring of the primary and secondary health care system.[16]

1.2.2 Primary care as a central linchpin

As defined in the Declaration of Alma-Ata of 1978, primary care should provide a suitable setting to be first point of contact for each new requirement, should provide a broad and comprehensive range of health care services and should have a routing, coordinating function, if specialist consultation is required.[34] Starfield et. al. summarized these features of primary care in the four C's, which are "*first-contact access for each new need, long-term person- (not disease) focused care, comprehensive care for most health needs; and coordinated care when it must be sought elsewhere*".[35] Considering the tasks and goals of primary care and the emerging challenges health systems face, which are described in chapter 1.4.1, primary care can function as a central linchpin in a health care system and be part of the answer to the nascent challenges, especially because of the following central dimensions and characteristics. The four core dimensions (access, continuity, coordination, comprehensiveness), that define the process level of primary care, were elaborated by Kringos et. al.[36], by finding the following essential features of these in their systematic literature review.[36]

The four core elements of the process level defined by Kringos et. al.[36] are well suited for capturing patient experiences, as these are the criteria that patients directly experience when receiving care. In the following, the core dimensions will be explained in more detail.

The dimension **access** includes everything, that happens before the actual contact to the primary care setting, means facilitations or obstacles that influence if or how the patient reaches the care he or she needs. This covers for example appointment booking systems, geographical or financial hurdles but also the physician density or inequality due to social characteristics.[36] As GP care is the only institution that can guarantee easy threshold access in Germany, it has to be part of the answer to the increasing numbers of chronically ill and multimorbid patients.[37]

An international approach, that provides the opportunity to investigate different structural conditions, attempts to distinguish between structural elements with negative or positive influence on patients' experiences. This way, the possibly best structural elements for patients' access to health care can be specified and implemented in a health care system.

The collective term of **continuity** includes three different aspects. It contains longitudinal continuity, which means as much as medical contact between patient and provider over a longer time and is based on a patient-centred and not disease-centred approach. Also, this contact should not only be long-lasting but also match the patients' requirements. Furthermore, every provider involved in the patients' care should always have access to the patients' history and medical findings, especially if the provider did not collect the information himself. This ensures informational continuity.[36] As the GP practice is the only institution that can meet these requirements in terms of continuous contacts at different stages of the illnesses and concerning different diseases, primary care and in particular GPs can be part of the response to the emerging challenges that include an aging society and the increase in multimorbidity.[38] Particularly chronically ill and multimorbid patients find themselves in a circle of repetitive referrals between specialised practitioners, which leads to their need for a constant. This can be provided particularly comprehensive by GP care.[37] In line with this, the DEGAM (German Society for General and Family Medicine) described their ideal of care of chronically ill patients: the family practice should function as the point of contact for the patient and his or her family in every moment of life.[39] Continuity of care

appears to be associated with various outcomes, that have an impact at both the individual and societal level. US-American studies revealed that a lack of continuity is associated with poorer health, especially of chronically ill patients, in the case of this study inflammatory bowel diseases.[40] Moreover, poor continuity has been shown to be correlated with a higher rate of hospitalizations and increased expenses in the US.[41] The evidence from a systematic literature review from 2006 supports this finding: apparently, patients with continuous care are hospitalized less frequently, for shorter periods of time and less acutely.[42] Staying with the positive influences of continuous care, a Finnish cross-sectional study could show that constant contact with the same GP in terms of good longitudinal and interpersonal continuity results in higher contentment among patients.[43] However, monitoring of patients' living conditions, risk factors and lifestyle is also more likely to be ensured if continuity is given.[42]

The importance of continuity is contrasted by a structural change and thus a possible, threatening damage, especially to the longitudinal continuity. While forecasts predict that there will be more outpatient physicians in Germany in total, the number of hours practiced will decline until 2030.[44] This is due to the facts, that especially female but also male physicians prefer to work part-time, and general medicine is more beloved among female physicians while their education.[16] This feminization and the rising popularity of part-time work especially among women results in a theoretically increasing lack of especially longitudinal continuity. Given this evidence for a threatening lack of continuity due to an increasing fragmentation of supply, surveys of multimorbid and chronically ill patients, as the most affected group, seem warranted. In this manner, ways could be found to ensure continuity despite structural change among physicians and first of all general practitioners in Germany.

As it is known that continuity affects both individual and societal levels, it is important to examine, if patients' preferences and experiences can provide information and possible solutions to emerging challenges. Our objective was not only to examine primary care continuity but also continuity across settings, which is why we aimed to interview patients with myocardial infarction or stroke, who are more likely to make use of different sectors of the health care system.

The dimension of **coordination** is influenced by several components. For example, the term refers to the composition within a family practice. A brief example might clarify this: for the overall and comprehensive organisation and coordination of a patients' health care process, it is relevant, how a primary care team is structured, whether there are any other non-physician staff and how the distribution of tasks in the team is organised.
Not only the coordination within a primary care practice, but also communication and cooperation between the PC (primary care) practice and other health care providers such as specialist physicians, rehabilitation clinics or psychotherapists affect the coordination of a patients' health care process and thus fall under the dimension of coordination. This also includes the gatekeeping function as well as the competence to outsource care to specialists if necessary.[36] At this point, one should distinguish between coordination and guidance, which in turn nevertheless falls under coordination. While guidance is more of an informative, advisory role[45], coordination is more about organising and managing care processes and thus ensuring a frictionless delivery of care.[36] This in turn is an interface with the category of continuity. As a care process can be more easily comprehensive under the condition that the coordinative processes are in a good state, at this point there is also the first junction between the dimensions of coordination and comprehensiveness.[36] As the dimensions comprehensiveness and continuity will be covered elsewhere, it will not be discussed further at this point. Especially because of the rise of multimorbidity and thus the more frequent demand for different medical services, such as hospital stays, specialist appointments and GP visits, effective coordination between practitioners and institutions becomes even more important than it already is. Broken down, this means that once several persons are involved in a multimorbid patients' healthcare, coordination and communication processes have to be improved in order to achieve the best possible outcome for the patient.[29,46]

Furthermore, free access to specialist practitioners and the associated over- and misuse exacerbate the increasing specialisation of medicine and the numeric disparity between GPs and specialists of 10% to 90% in Germany.[16] Consequently, gatekeeping in form of a GP-centred approach

("Hausarztzentrierte Versorgung" respectively "Hausarztvertrag") could counteract this trend.[16] Beyond that, GP-centred health care systems have been shown to be associated with better communication between GPs and specialists in 2020, and thus less fragmented care and better developed quality of care. Consequently, the degree of coordination also influences the dimension continuity, more precisely informational continuity. Eventually, higher rates of feedback letters from specialists to GPs could be detected in countries with gatekeeper systems. As this was only examined by questioning physicians, it is now relevant to examine these effects from the patient's point of view.[47]

Furthermore, according to Starfield et. al. and the Declaration of Alma Ata, primary care should be comprehensive.[34, 35] As already emphasized above, comprehensiveness and coordination have intersection points. Nevertheless, **comprehensiveness** is an own dimension and one of the four C's, described by Barbara Starfield et. al..[35] It is about the breadth of health and prevention services that are offered, which in turn depends on the technical equipment, professional competence and staffing.[36] Barbara Starfield's et. al. research from 2005, which looked, inter alia, at different characteristics of strong primary care, showed that the degree of comprehensiveness of care offered by general practitioners, influences the strength of primary care in a positive way.[35] Especially for chronically ill and multimorbid patients, comprehensive care is relevant, as the sole focus on an acute health problem can lead to deficits in preventive actions.[37, 39]

To improve systems, they must be constantly appraised. An established assessment tool is the SELFIE framework, which was developed to evaluate **integrated and patient-centered care** systematically and comparably for the unique needs of multimorbid patients. The different components such as *"service delivery, leadership and governance, workforce, financing, technologies and medical products and information and research"* all aim to treat the patient as a holistic individuum, in view of the patients' environmental characteristics, e.g. wishes, competences, social network or financial situation.[48] Due to the importance of PC in addressing the nascent challenges, the further assessment

and improvement of primary care will not become less important but will gain. On this occasion, PC can be assessed from different perspectives and with the help of various dependent variables.

In order to meet the challenges described in chapter 1.4.1, positive characteristics of health care systems need to be identified to be able to strengthen or even establish them in other settings. An international comparison of different care settings seems to be suitable to figure out how different structural features influence the strength of health care systems and thus patients' experiences. For example, it could be conceivable, that innovative structures that have been entrenched in other countries make an impact on experiences of patients or the strength of a health care system. To create a basis for comparing different health care settings, the characteristics of the various international health systems of the participating partners have been described in the previous chapters, whereas it is not intended to be complete but to present important, individual innovations or special features of the different health care systems.

1.2.3 Lack of patient experiences

The four dimensions described above define the process level of primary care and are based on the four C's by Barbara Starfield et. al. The 4 C's (1st contact, comprehensive, continuous, coordinated) in turn describe the main mission of primary care and the quality of PC can be rated by these features.[35] As primary care may be part of the answer to the difficulties described above and needs to be evaluated with an eye toward future improvement, Jimenez et. al.[49] summarized studies that aimed to investigate the impact of different interventions on the quality of primary care in terms of the 4 C's. They found that different dependent variables were used to infer the quality of primary care. Most frequently the examined dependent variables were healthcare costs, utilisation, and population-health outcomes, while provider and especially patient satisfaction were studied least often.[49] This shows that the health care system is too often viewed from the system level and patients' perceptions and experiences are underrepresented in decision making.[2, 49] Similarly, the still influential results of Kringos et. al.[36], which describe the core dimensions of PC and are presented

above, show that more attention is paid to the system level than to patient experiences. This is probably due to the fact, that measuring quality of care based on experiences is way more individual than measuring other final variables. Nevertheless, there are attempts to understand patients' requirements for health care. In an international qualitative study based on the SELFIE framework described earlier, focus group interviews were conducted with patients, in pursuance of finding out what constitutes good quality of care for multimorbid patients. Features on a human level, like trust, emotional support, good communication and respect were described as good care by patients. Also, patient centred factors like individualised care planning or shared decision making as well as longitudinal and informational continuity resulted in care, which was described as positive by patients.[50] Although there are some studies, that have examined patient experiences, there is still a lack of open-ended, qualitative methods that examine them and answer the question of whether patients can describe their requirements and whether there is a link to structural conditions.[49]

1.3 Formulation of the research questions

The foregoing chapters discussed the rationale behind InCept, that aims to compare the effectiveness of different healthcare systems from the perspective of patients. It explains the challenges faced by healthcare systems and how these challenges are approached differently due to differences in systems and structures. As patient satisfaction is rarely used to examine quality of health care, one of the projects' aims is to gather data about patients' perceptions of their health care. More specifically we want to understand, how chronic, multimorbid patients perceive the aspects of access, coordination, and continuity, or rather to what extent these pleasing or deficient experiences can be linked to structural elements of different international care settings. A second aim is to test, whether information about quality of care can be gained through qualitative patients' experiences. These considerations lead to the following methodological and content-related research goals and hypotheses to be answered:

1) We want to find out, if and to what extent patients' perceptions of their care provision can provide information about the quality of their care considered against the background of different health care settings.

2) Furthermore, we aim to identify which specific structural components of the care pathway (particularly those related to access, coordination and continuity) affect patients' experiences in a positive or negative direction. To answer this, it must be examined, whether similar structures, independent of the national healthcare system produce similar experiences among patients and how these compare between international settings. Moreover, it will be interesting to see whether the structural characteristics are the only modifying factors or whether there are other additional parameters that affect patients' perceptions.

In summary we are interested in the contribution that information about patient experiences in relation to the setting can make to improving primary care and thus the entire health care system.

2 Material and methods

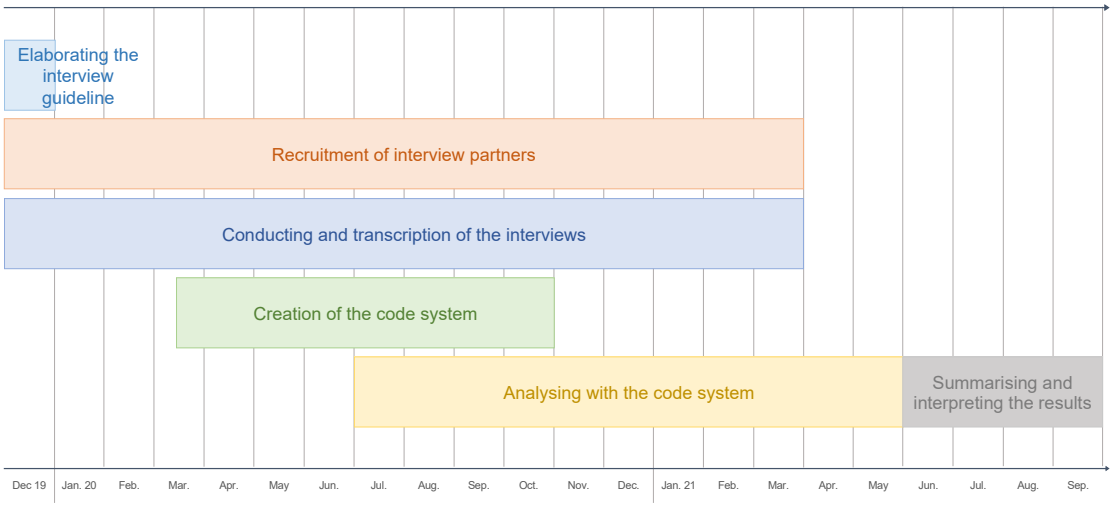

Figure 1 Project schedule

2.1 Description of the overall project

As this dissertation is part of InCept, as an overarching international study, the overall project is described in the following. International partners from Germany, Sweden, Switzerland, and Jersey participated in the joint project and interviewed patients from all participating four countries. The more detailed description of the method is presented in the following chapters.

The internal reference number of the ethics vote is **F-2019-087.**

2.1.1 Allocations of contributions

The German, Swiss, Swedish, and Jersey interviews were recruited and conducted by the staff of the respective team, using the jointly prepared interview guideline. While the team from Sweden also accomplished their own transcription and analysis, using the German and Jersey code system, the German, Jersey, and Swiss interviews were all transcribed and analysed by the German team. For the analysis, a code system was needed, which was jointly created by the German and Jersey team.

The present thesis made a significant contribution to the German team by actively participating in the collaborative development of the interview protocol, the recruitment of both general practitioners and patients, the execution of the interviews in Germany, and the partial transcription of both the German interviews and those conducted in Switzerland. Furthermore, as part of a mixed team

comprising Jersey and German researchers, this doctoral thesis contributed to the development of a comprehensive code system that was employed by all countries to conduct a rigorous analysis of the collected data. Ultimately, a comprehensive analysis of the collected data from the Jersey, Swiss and German interviews was conducted in collaboration with a fellow German researcher, utilizing the previously designed code system. Additionally, this work was enriched by the inclusion of additional interview material from Sweden, broadening the scope of the comparative analysis. To achieve a comprehensive comparative analysis, a collection of interview statements sourced from Germany, Sweden, Switzerland, and Jersey were systematically assigned to the self-established code system, facilitating a comprehensive comparative analysis.

2.2 Underlying method

Our primary objective was to comprehensively capture the opinion of patients, that is underrepresented by now[49], giving them the opportunity to add unique insights that may have been overlooked during the initial set up of the interview guideline. Additionally, this approach enables to gather further information through follow-up questions. In this way a more comprehensive data collection can be promoted. Therefore, the choice was qualitative content analysis, the aim of which is to capture not only the statements, but also the subtle and sometimes hidden meaning of the material, in our case the interviews, while methodical control and systematically rules are nevertheless very important.[51] There are three different approaches to qualitative content analysis. One can proceed by structurally analysing the data in terms of content. Furthermore, there are the evaluative procedure and the type-forming approach. The aim was neither to sort the patients by type (type-forming approach), nor did we pursue the goal of sorting the content on a scale (evaluative approach). As a result, category-based methods for a **content structuring qualitative content analysis** were chosen and used.[51]

2.1.1 Hermeneutics as a basis of qualitative content analysis (QCA)

While analysing content, hermeneutical principles should be paid attention to. Understanding and analysing the data requires prior knowledge and interpretation of the data, known as the “hermeneutic circle”. In accordance with

this, understanding of data is a helical process, which contains multiple passes through the material. With each pass through the interviews, our researchers could gain more understanding, which in turn could be applied to the coding, analysis and interpretation in the next pass.[51]

2.1.2 Quality criteria of QCA

Our main target was to describe systematically, what the patients said in the interviews, in order to answer the previously described research question. Thereby, the description sort of depends on the analysts' perception and requires a certain degree of interpretation. However, the systematic and regulated procedure of QCA is important.[52]

Reliability and objectivity

If coding and interpretation is the same, independent on which researcher carried it out, objectivity is achieved.[52, 53] As the re-execution of the interviews would be not suitable, retest-reliability is not reasonable in QCA. In QCA, reliability and objectivity can be verified by coding consistency at different points in time (intracoder reliability), which is achieved through code definitions, that function as a guidance for coders. On the other hand, the reliability of the work could be checked through a transparent process, that included description of each measure taken during the research process.[51-53]

Validity

Furthermore, the coding frame must be valid. Validity is reached, when the coding frame matches the material and captures what is asked in the research question. In qualitative content analysis, there is a higher risk, that a method is not valid. By creating the coding frame to some extent in an inductive, data-driven way, we were able to reduce this risk of not being valid.[51-53]

Plausibility verification

Plausibility verification within the scope of qualitative content analysis aims to ensure that the results are reasonable and accurate, although the analysts' perceptions and interpretations assume an important role. This can be achieved by establishing validity, reliability, and objectivity. As we worked with code

definitions, a coding frame and both intra- and intercoder reliability we aimed to prevent biases and therefore achieve plausibility verification.[51-53]

2.3 Project procedure

In her book “Qualitative content analysis in practice”[53], Margit Schreier explains that the first step should be the derive of a relevant research question from the current state of research. In order to structure the data, the development of a coding frame followed after and while data collection and selection. Next, a phase of trial and alteration of the coding frame proceeded, which required several passes through the material. In the last step, the main analysis with evaluation, description and interpretation of the results took place.[53]

2.3.1 Interview guideline

Before the recruitment of interview partners, it was necessary to set up an interview guideline. The guideline is supposed to be a framework, which supports the interviewer and helps him or her not to forget important questions. Also, results from different interviews from different countries are more comparable if there is a frame. On the other hand, it shouldn’t be too rigid so that the interviewee can add his or her own points and use his or her own language to explain reasons for the answers.[51]

We structured our interview guideline in three parts. In the beginning, the interviewees were asked an incident-related open question, concerning the pathway after the event (stroke/myocardial infarction) happened. The purpose of this was, to get the patient talking and thinking through the whole process.[54, 55] After becoming an overview and going through the pathway together, the second part was composed of the critical incident technique by Flanagan.[56] In this one, the interviewee is asked to remember an especially positive and a particularly negative situation in the whole pathway of care. Once the patient remembered one, the interviewer could ask deeper and more detailed questions about what led to the incident, how the involved persons behave and reacted to each other, why the actions were that effective or negative and what was the outcome of the situation.[56, 57]

This method combines several advantages. It's an effective method, means one can capture a lot of information in a short time, while it's still very flexible. Thus, the interviewer guides the interviewee through the conversation, which leads to important questions not being forgotten, helps the interviewee to be precise and accurate, while finding out rich information and still leaving the patient the possibility to add aspects.[57] For this part of our interview guideline, we followed the guide of Ewertowski et. al.[55] who examined the quality of palliative care, using the critical incident technique to interview patients.

As our aim was to find out whether and which special structural components of care pathways affect the patients' experience, the last part of the interview consisted of detailed questions about the dimensions described before, that are commonly used to assess the quality of primary care.[35, 36] Therefore, we extracted the topics of the QUALICOPC (Quality and costs of Primary Care in Europa)[58] questionnaire, which in turn was emerged from several existing validated questionnaire tools and claimed to cover all dimensions, assessing primary care. Asking about continuity, coordination, and access, we rounded off our interview guideline.[58]

This resulted in the following approach: Concerning the dimension **continuity**, we wanted to know, whether the patient always sees the same doctor, how often he or she sees the GP or the specialist but also questions referring to informational continuity. We asked if the patient has the feeling that his or her practitioners know about their health condition, how they behave, when they want to see a specialist and if the collaboration between different health profession works, in order to gather information about the dimension **coordination**. To find out about the dimension **access**, we asked about the patients' perception of the opening hours of the practice, his or her access routes and waiting times, but also about issues related to other health care structures, like specialists, rehabilitation and support structures.[58]

2.3.2 Recruitment of interview partners

Before recruiting interview partners, ethical approval by ethical review was obtained. All interview partners signed the patient information form and agreed to the interviews being conducted, recorded, and transcribed.

Because the aim of qualitative analysis is to analyse a case as a whole and thorough, it's common practice to recruit less patients than in quantitative analysis. Therefore, we planned to interview twelve patients in Germany and at least three in each of the other participating countries.[53]

From December 2019 to April 2021, we as the German research team contacted general practitioners in different regions. To provide a wide range in terms of the type and population density of the regions, we chose one major city (7 GPs), one (university) town (5 GPs*)*, two small cities in the "Schwäbische alb region" (1 and 1 GP) and two rural regions near Nuremberg (1GP) resp. Stuttgart (1GP).[59-61] In total we contacted 16 GPs in Germany, of which twelve didn't participate,: The main reason for non-participation was the lack of feedback from six GPs even though they were planning to take part. Two other GPs couldn't find suitable patients and thus couldn't participate, whereas another GP provided one patient with depression, which was a drop-out reason. The lack of capacity for the project was the reason for non-participation for two GPs. In addition, four Swedish, two Swiss and one Jersey GP practice took part in the recruiting.

	Population	Characteristics test	Participating GPs	Number of patients
City 1	1502969 [59]	state capital, among the largest cities in Germany	3	6
City 3	6508 [60]	city which is located relatively isolated in the Swabian Alb region	1	2
City 5	4424 [61]	is located in the middle of a densely populated area (including large cities and university towns)	1	1
Total			**5**	**9**

Table 1 Recruitment cities in Germany

We asked them if they could provide patients with the following inclusion criteria: Participating patients should have suffered a **stroke and/or a heart attack** during the **past year** or should have an underlying chronic disease from the spectrum of the metabolic syndrome (**diabetes mellitus** and/or **arterial hypertension** and/or **obesity** and/or **lipometabolic disorder**) or **heart failure**. We excluded

patients with a psychiatric disease. We especially chose these inclusion criteria, because of the following reasons. Firstly, patients with an acute incident, like stroke or heart attack usually go through various institutions of the health care system, like hospital, primary care provider and possibly rehabilitation. In addition, these diseases have a functional impact, meaning patients feel they need care. Patients with an underlying chronic disease as well as multimorbid patients have frequent contact with the health care system, which shows in higher hospital admission and referral rates among multimorbid patients.[30, 31] In addition, they have repeatedly contact with their general practitioner and other specialists because of their multimorbidity.[62] To ensure a comprehensive understanding of the interface between general practitioner and hospital, interview partners with these tracer conditions were selected as they possess the necessary knowledge and experiences to provide valuable insights.

It was possible to conduct ten interviews in Germany, including one drop out. In the end, nine German, three Swiss, three Jersey and seven Swedish interviews could be analysed. In summary, the dataset for this study consisted of interview data obtained from a total of 22 patients. In Germany the male to female ratio was balanced with five men and five women with an overall average age of 74,2 years. This was also the case in Sweden (three males, four females) with an average age of 81,2 years. All seven patients from Sweden suffered from heart failure. The Jersey team was able to conduct interviews with three male patients suffering from a stroke. The overall average age was 76,6 years. In Switzerland, two men and one woman were interviewed. Two suffered from myocardial infarction and one from stroke. The average age in Switzerland was 76 years.

Country	Participants	Sex	test	Diagnosis			average age
		female	male	stroke	myocardial infarction	heart failure	
Germany	9	4	5	2	7	0	74,2
Sweden	7	4	3	0	0	7	81,2
Switzerland	3	1	2	1	2	0	64
Jersey	3	0	3	3	0	0	76,6
Total	**22**	**9**	**13**	**6**	**9**	**7**	**74**

Table 2 List of recruited participants

Data saturation

Data saturation was achieved through structured interviews.[63]

2.3.3 Conducting the interviews

In the beginning of the project, our intention was to conduct the interviews in person, as it allows for greater intuitive and empathic response to the patients' emotions and reactions. In December 2019 we were able to do this with two patients. The same applied to the participating international partners, who all conducted their interviews in person. From March 2020, the corona pandemic occurred, which made interviews in person not acceptable. To avoid an unwanted interruption, and since video interviews appeared to be unfeasible, we decided to carry out the following German interviews by telephone. The GPs provided the telephone numbers of the patients after they had signed a release from confidentiality. In Germany, we were able to conduct ten interviews, lasting between 22 and 73 minutes, with an average of 44 minutes. One German interview could not be used due to the diagnosis of depression, which was an exclusion criterion. The three Jersey interviews lasted between 22 and 33 minutes, with an average of 29 minutes. In Switzerland the duration of the three interviews varied between 16 and 51 minutes (average 33 minutes). As the Swedish team transcribed their interviews by themselves the durations of the Swedish interviews remain unclear.

2.3.4 Transcription of the interviews

All interviews were recorded digitally. The transcription process of the Jersey, Swiss and German interviews was carried out partially within the scope of this doctoral thesis and partially by a professional transcription company, called Amanu. The Swedish team transcribed their interviews by themselves.

2.3.5 International cooperation

Throughout the project, the German research team provided guidance on how to conduct the interviews, and a code system was developed to analyse the material in MaxQDA. Within the work of this doctoral thesis, the Swiss, Jersey and German interviews were analysed directly using the code system ending in a condensation of information. However, due to the language barrier, our Swedish colleagues collected and condensed their information extracted from their interviews in the form of quotes themselves and passed it on to us. We then collected all the information in form of categorized and itemized statements and

quotes transnational, which allowed us to arrive our substantiated results. Afterwards, only necessary cites of the Swedish interviews were translated. The interview guideline, as well as the code system, can be found in the appendix. Additionally, the German team regularly held telephone conferences to establish reliability and objectivity. In summary, this thesis also integrates information obtained from interviews conducted by our foreign colleagues. The analysis of all interviews, in turn, was part of this work.

2.4 Analysis

2.4.1 Creation of a code system

An essential part to analyse the material is the coding frame. Coding frames consist of major categories, which in turn comprise a couple of subcategories.[51] Category or code systems are relevant for all kinds of content analysis.[51] There are three different types of the organisation of a coding frame: a linear form, a frame in form of a hierarchy and a network form.[51] As we wanted to use different levels with possible subcategories to structure the content properly, we built our coding frame as a hierarchy. A linear system would not have been sufficient for the complexity and comprehensive amount of the generated data.

Coding systems have two essential aims. Firstly, the coding frame strives to reduce material to material that is relevant to answer the research questions. Secondly it aims to structure, cluster and summarize data.[51, 53]

Our concept of building a code system was deductive as well as inductive. Based on the interview guideline, some categories were pre-defined, viz. deductive, or also called a-priori category creation independent of the interview material.[51] While working with the material, more categories and subcategories arose from the text material. This represents the inductive part of the creation of the code system.[51, 53]

As described in chapter 1.4.2 Primary care as a central linchpin, access, coordination, and continuity are important dimensions for assessing the quality of health care structures and are therefore represented as deductive categories in our coding frame. An additional deductive category was the category “pathway”, which describes the different stations, through which the patient has passed and

the first point of access. Other main categories “case description”, “interview setting”, “patient centeredness” and “perceived quality of care” as well as the subcategories arose inductively during the work with the material. Subcategories pursue the target to further organize and specify the content that is coded by the main categories.[53]

Since the Jersey and German teams participated in the creation of the coding framework by first creating their own systems, it was a parallel process. This ended in a comparison of the coding systems and an elaboration of the differences and similarities with a subsequent summary of the systems. After that, a circle of testing and improving of the code system followed by analysing the Swiss and German interviews as well as the interviews from Jersey. As already described in chapter 2.3.5 International cooperation, the Swedish colleagues extracted their data from the interviews themselves due to the language barrier but were also guided by the common code system.

When developing a code system, each category must be defined, to reach reliability, security and guidance for encoders.[51] Paraphrasing the content of a category or using triggers as well as quotes as examples can help distinguish between categories.[51] The final version of our code system consisted of eight main categories and 85 subcategories of different levels.[53]

Code definitions

The following definitions were developed to specify the category system. The comprehensive, complete code book including definitions and examples can be found in the appendix.

Category	Definition
1 Case description	general information about each instance
2 Interview setting	Circumstances under which the interview took place
3 Patient centeredness	Patient centeredness is one of the six characteristics defined by the Institute of medicine (IOM), that qualitative health care should be able to provide; accordingly, patient centered care should be driven by the individual decisions and needs of the

	patient or the patient relatives; clinical decisions have to be guided by individual needs and aims[64]
4 Pathway	purpose is to show where and when the patient entered the health care system, got the first care of the stroke/heart attack and how the care continued
5 Access	includes everything, that happens before the actual contact to the primary care setting, means facilitations or obstacles that influence if or how the patient reaches the care he or she needs; this covers for example appointment booking systems, geographical or financial hurdles but also the physician density or inequalities due to social characteristics.[36]
6 Continuity	includes three different aspects; contains longitudinal continuity, which means as much as medical contact between patient and provider over a longer time, which is based on a patient-centred and not disease-centred approach; should not only be long-lasting but also match the patients' requirements; every provider involved in the patients' care should always have admission to the patients' history and medical findings, especially if the provider did not collect the information himself, which ensures informational continuity.[36]
7 Coordination	means coordination within the care structure as well as cooperation with other health care providers; includes how the primary care team is structured, whether there are any other non-physician staff and how the distribution of tasks in the team is organised; cooperation with other health care providers including specialists and other public health employees; Coordination contains also the gatekeeping function as well as the competence to outsource care to specialists if necessary.[36] [35]
8 perceived quality of care	subjective assessment of the quality of care experienced by the patient

Table 3 Definitions of the main categories – excerpt of the category system

2.4.2 Analysing with the code system

When creating the code system, researchers were already able to begin the first steps of analysis by assigning quotations from the transcripts to the categories of the code system with the aid of MaxQDA, a computer program for qualitative content analysis. This means, the creation of the code system and the analysis were a kind of parallel process. In the first steps, the Swedish and German research teams performed the analysis in the local language. The German team also carried out the analysis of the content from Switzerland and Jersey. When the code system was ready, the analysis could go into the final round. The Swedish and the German research team participated in the analysis by populating the content from the interviews in a common document and thus sorting them according to superordinate topics. While the Swedish team was responsible for entering their own data, the German team, including this thesis dealt with the Swiss, British and German data. At the end of the analysis, a joint, trans-national document with summarized statements on the basis of the category-based method of content structuring qualitative content analysis was produced within the scope of this doctoral thesis and could be used for the subsequent evaluation and interpretation.[51]

3 Results

Altogether data of 22 patients was collected in Germany (9), Sweden (7), Switzerland (3), and Jersey (3). All patients were interviewed, as described in the methods using the semi structured questionnaire. The resulting data allow the following assertations and interpretations to be drawn, which are presented thematically and category-based below. The result of our research was also the category system, which is illustrated in the following chapters using code trees. Established topics were: Patient centeredness, coordination of care, continuity, and access. It was possible to cluster patient experiences around process characteristics. This finding indicates that patient experiences from different countries can be grouped together based on common processes and structures. It is important to emphasize, that the following chapter on the results is structured according to the main categories. There is no sub-chapter for each sub-category. This is because, results of subcategories were sometimes summarized or often overlap. Nevertheless, the emerged category system is presented using the code trees, as it is also part of the results. The entire code system including code definitions and examples can be viewed in the appendix.

When looking at the quotes in the results section, one will notice that there is an imbalance of interview quotes in favor of German quotes. There are several reasons for this: It seems that the most detailed interviews were conducted in Germany. In addition, Germany simply interviewed the most patients by far (with the exception of Sweden). Only in Sweden were nearly as many interviews conducted (7), but there the language barrier may have resulted in a loss of content and/or quotes. The imbalance in favor of German quotes was nevertheless left as it would have been a loss not to include important patient statements simply because of the imbalance.

3.1 Patient centeredness – communication is key

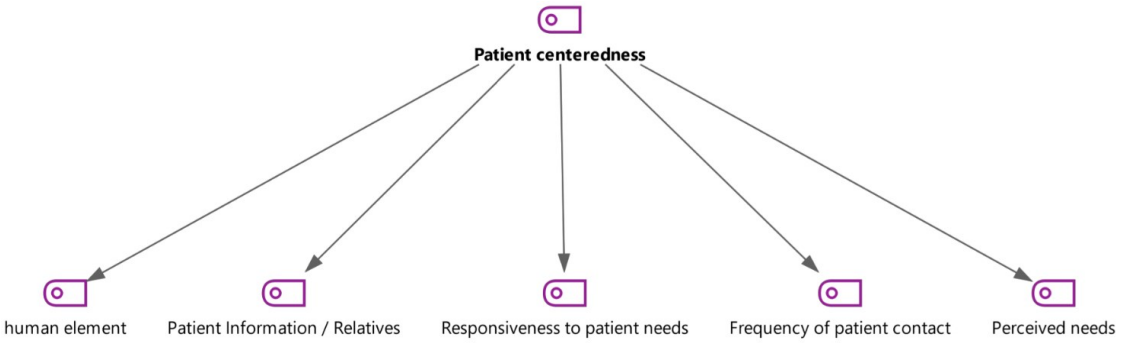

Figure 2 Code tree of the category "Patient centeredness"

It was particularly interesting to observe, that in the open questions about positive and negative examples of the health care process, several patients talked about situations, that either contributed or had a negative impact on patient centeredness. The results, which apply to both inpatient and outpatient care are described in the following.

3.1.1 Informing patients

Overall patients felt cared for if the flow of information between the medical staff and themselves worked out. This applies to both outpatient as well as inpatient settings. It contains both the involvement of the patients and their relatives in the care process and related decisions (GER7) as well as the physicians' ability to explain the underlying causes and effects of the disease in lay terms (GER8, GER9, SWE7). It is therefore a matter of simply informing the patient and his or her family, as well as doing so in a comprehensible manner.

> **Interviewer**: "What exactly did you like about the hospital? [...]"
>
> **GER7**: "[…] that you weren't standing around somewhere thinking, what's going on? You were informed, you were looked after. Yes, it was good all around." *(LI. 49-50)*
>
> **GER9**: "And this [the cardiologist] was the first person, who was probably also active in science and research in the past, who could explain this [the heart attack] to me or explain in simple terms why these things [heart attack] come so suddenly." *(L. 130)*

> **GER8**: “I plan to make an appointment with my GP, where he will explain everything what the final report from the hospital says. Yes, because one is also a bit curious oneself about all the examinations and why they were made […] and I would like to talk to my family doctor about it again.” *(L. 107)*

> **SWE7**: “Now I have a different doctor, and he actually took the time to talk through everything. From the first day we sat there, we really went through everything, and it was really nice to meet him, and it gave me some peace of mind to meet him.” *(/)*

Moreover, being informed about the procedures of inpatient medical examinations had also a calming effect on a German patient, who was frightened of a coronary angiography (GER6).

> **GER6**: “[…] I was really scared [of the cardiac catheterisation], of course, because I didn't know what they were doing. But they really reassured me, so it all went well. […] they [the doctors] were also very nice and explained everything. So, there is nothing to say.” *(Ll. 79-85)*

The importance of patient-centredness and talking medicine can also be transferred to the involvement of the patients’ relatives. The need of being informed about the disease itself, therapy options and care processes was found across sectors in both Germany and Sweden, independent of the care setting (GER7, SWE3).

> **SWE3**: "…. The [my] wife was there once when I had a meeting with her because she also wanted to express how she felt about this." *(/)*

Not only the positive examples allow conclusions to be drawn. In terms of patient centeredness and flow of information, negative examples were also mentioned. Thus, one German patient (GER7) with a stroke stated, that the information flow

between the treating hospital and her husband was disturbed, although she was assured of the same. After being admitted to the hospital by her GP, she went from the emergency room to a neurological ward. Because she couldn’t call her husband well because of the stroke, she repeatedly asked the hospital staff to inform her husband about her condition.

> **GER7**: “The only disadvantage was that my husband didn't get any news from Friday to Monday about what was going on with me [in the hospital]. I had a bit of trouble speaking, it was hard for me to talk on the phone […]. The nurse said, yes, your husband knows, but he didn't know anything. That was the only disadvantage in the clinic, otherwise the care there was good for me. But those at home [her relatives] almost went crazy with worry because they didn't hear anything. It was always said that the head doctor would call back, but he never did.” *(Ll. 44-46)*

Another patient (GER9), who initially presented to the GP practice with back pain and ended up suffering a myocardial infarction, described how he was not informed by the hospital staff. He perceived the lack of explanation, provided by the staff about his final diagnosis and its severity as negative.

> **GER9:** “[…] I didn't wake up again until the next day and until then I still thought that there was a pinched nerve somewhere. […] I wasn't told much about what it [the diagnosis] was. Or why it was suddenly so urgent. […] In any case, I didn't get it, or it wasn't said clearly or openly what the new suspicion was. I woke up the next day and was really shocked about my condition. I didn't expect my chest to be opened, that I'd had a heart attack at all.” *(Ll. 16-18)*

In summary, it can be said that an appropriate and balanced transfer of information to the patient and his/her relatives plays a major role for patients. This applied to outpatient and inpatient care. In Jersey and Switzerland, neither positive nor negative examples were reported. Patient and family involvement and lay friendly explanation seem to be an essential component for a good care

experience for patients. This is since patients from Germany and Sweden (GER1, GER6, GER7, GER8, GER9, SWE3, SWE7) independently reported its presence as a positive experience respectively the absence as a negative experience. This applies to both outpatient and inpatient care, as patients consider it relevant at both levels.

The information transfer between healthcare professionals and patients not only contains information about the further procedures in the acute situation and the patients' condition, but also elucidation about the following long-term care. Patients in Sweden and Germany (GER1, GER6, GER9, SWE3) felt a lack of information about follow-up, psychological guidance after heart attack and prevention of further similar events.

> **GER9**: "[…] How to deal with it [the heart attack]. And I was expecting not only psychological tips, but also tangible tips, that people would say, yes, you made this […] mistake […], or didn't you pay attention to these signs? Pay attention to that in the future. That this and that comes, so I continued to have the feeling of being completely at the mercy of this heart attack." *(L. 74)*

> **Interviewer**: "[…] you would have liked even more training and education on how to protect yourself even more?
>
> **GER9**: "Yes! In fact, that would have been the most important thing for me." *(Ll. 185-186)*

> **Interviewer**: "[…] And did you get recommendations on how to change your lifestyle or how to deal with your blood pressure?"
>
> **GER1**: "Yes, they just said to lose weight. […] Eat less."
>
> **Interviewer**: "Yes. Ok […] but […] no other support with that?"
>
> **GER1**: "No. […]" *(Ll. 61-64)*

> **GER6**: “No one told me what I should or shouldn't do or what I should refrain from [when discharged from the hospital]. And the doctors don't have any time, that's the problem. […] I would have liked that [more clarification], that I should at least know what I am still allowed to do and what not.” *(Ll. 65-69)*

> **SWE3**: "Well, I don't really know who to contact, maybe you should get help with that as well, so you can get information on what to do, maybe a break." *(/)*

> **SWE3**: "[…] regular contact with the doctor […] would be good, then maybe you can feel this way and maybe talk to the doctor if he or she has other ideas, other medications or something like that […]." *(/)*

While patients in Sweden and Germany (GER1, GER6, GER9, SWE3) perceived a deficiency in information about follow-up, psychological guidance after drastic medical events, and prevention of further similar events, a Swiss patient (CHE1) reported the positive and reassuring effects of behaviour change education.

> **CHE1**: “And she [practice nurse] took away my inner fear a little bit and talked to me. What I could change in my life, what I have to pay attention to, what I am allowed to do. She's always looking out for me.” *(L. 1)*

The expressed lack of information about further care overlaps with coordination of care, as patients wished for more guidance and help in organizing further care. Therefore, this intersection is further presented in chapter 3.2.

3.1.2 Impact of workforce resources on patient centeredness

Time constraints can affect the patients‘ experience

The quality, quantity, and type of the available health care labour affect patient centeredness in different ways.

A lack of resources was reflected in different settings and countries. Jersey and Swedish patients complained about longer waiting times (SWE5, JER2) and feeling the shortage of staff in the sense of feeling the time rush (JER1). They grew the feeling, that PC staff were working beyond their breaking point and therefore did not have enough capacity for all patients.

> **SWE5**: “Yes, it's clear now, surely it wasn't the same when there was a shortage of staff... last time I had to wait, let's see now, five days I think.” *(/)*

> **Interviewer**: “Ok. Have you had any problems with waiting times, for appointments and things?”
>
> **JER2**: “[…] I was waiting in the hospital, but you know you got to wait […].”
>
> **Interviewer**: “[And] for follow-up appointments? Is [it] delayed often?
>
> **JER2**: “Yeah. You [the GP] are bound to be busy.” *(Ll. 149-150, 153-154)*

> **JER1**: “I think […] [the GP] got pressure on [him], [he] can’t read up. And you only get 15 minutes in the primary care. And that’s a joke, you know?”
>
> **Interviewer**: “So it’s too short time. […] But you feel that […], from what you’re saying, that […] sometimes the consultations are a bit rushed and there’s not enough time?”

JER1: “Yeah.” *(Ll. 193-194, 196-197)*

Patients from Sweden, Germany, and Jersey (GER3, GER6, GER9, JER1, SWE5) reported that medical staff gave the impression of being under time constraints.

The important components of a realized patient centeredness in the sense of a maintained flow of information which was described in the previous chapter cannot be preserved under the circumstance of a lack of personnel resources, as can be deduced from the following quotations.

GER3: “Yes, it all happened so quickly. [...] I said [begging] I had to go to the toilet. Then she pushed this [...] bowl under me so that I couldn't breathe at all. And rushed past me. [...] And then I said: When is the doctor coming? [...] And then the [nurse said]: Do you think I have nothing to do? And I saw how she ran and how busy everyone was. But there's another way to say it. That hurt me. [...]”

Interviewer: “So you would have liked people [physicians and nurses in hospital] to take a bit more time for you?”

GER3: “Yes, yes.” *(Ll. 401-408)*

GER6: "The only thing that always bothers me is that the doctors don't talk to the patients. [...] I was discharged from hospital. Nobody said anything about what I should do [...] or what I shouldn't do. And the doctors have no time at all, that's the problem." *(Ll. 63, 65)*

Interviewer: “[…] What do you discuss with him? Would you also discuss private problems with him?”

GER9: “Ok. Because these general practitioners don't really twiddle their thumbs, they would tell me something if I came to them with any stories. The throughput [of patients] must be right.” *(L. 228)*

Like before, this issue occurs independent of the care sector (outpatient or inpatient) or the country (GER3, GER6, SWE5, JER1), the patient lives in. Nevertheless, it must be said, that not all patients from Germany, Sweden, and Jersey described time pressure as such. There were also positive examples, in which patients from Germany, Jersey, and Sweden (SWE7, JER1, GER8, GER9) felt that the staff took the time to listen to the patients' symptoms. Therefore, it cannot be generalized that there is a shortage of staff in all areas. It can only be concluded that if there is a lack of staff or time pressure for other, unknown reasons, patients may very well feel the consequences of time limitations. These can be longer waiting times for appointments, missing communication between staff and patients or a general feeling of time pressure (GER3, GER6, SWE5, JER1).

> **SWE7**: "Now I have another doctor and he actually took the time to talk through everything. From the first day, […] we sat there, we actually went through the lock, stock, and barrel, and it was actually really nice to meet him, and it gave a little peace and quiet to meet him." *(/)*

> **Interviewer**: "Was there anything negative where you felt people weren't listening to you or didn't care for you?"
>
> **JER1**: "No, no. Like I said, they were very caring." *(Ll. 87-88)*

> **GER8**: "[...] two days later the doorbell rang. [...] I opened the door and there was Dr. H. [GP] at the front door. [...] then I invited him in and [...] he asked how things were going [...]." *(L. 27)*

GER9: "But from the patient's point of view [it was] very professional and actually nothing was lacking. I think it went quite well [...] for the fact that it's such a mass operation in the hospital." *(L. 30)*

Positive effects of non-physician staff

Furthermore, it has become apparent, that non-physician staff can have a reassuring effect on patients. This was reported in Switzerland, where advanced practice nurses could take away the patient's fear (CHE1). Swedish heart failure nurses (SWE2, SWE4) and German practice nurses (GER2) managed to offer the feeling of being cared for, seen, and heard. In Jersey, it was also the non-physician staff about which patients expressed a positive opinion (JER1, JER2). In this case the continuous presence of nurses had a nurturing impact.

CHE1: "[…] …yes, the closest, really the closest, was always Mrs. W. [practice nurse], who talked openly with me about it. And she actually took away my fear of everything. […] she really helped me and still helps me now, I come here about once a month." *(L. 7)*

CHE2: "First and foremost, we talk. A lot of talking. Because there are so many things, I can discuss with her [the APN]. I can confide in her almost the same things as I do with a psychological counsellor. I can talk to her about everything." *(L. 12)*

JER1: "Alright. Well, the care that I received [in the hospital] was A1. It was very good. The staff was brilliant." […]

Interviewer: "[…] Are you alluding to the interpersonal things, the human element? Is that what you liked about it, how the nurses ..."

JER1: "Yes. She was nice and caring." *(L. 10)*

JER2: “Yes. They [the nurses] were terrific. I’ve never been in a hospital in my life. That was the first time I’ve been in a hospital bed.”

Interviewer: “[…] but why did you find their care to be particularly helpful?”

JER2: “Well, they were there all the time.” *(Ll. 45-54)*

SWE2: “They [heart failure nurse] know exactly what to ask and so on, how I live and how it feels and all that, and how I experience it all today so that, I think, it works just fine.” *(/)*

SWE4: "Well we can talk about things and how I feel and yes she [the heart failure nurse] wants to help me all the time because I've had a bit of trouble after." *(/)*

Interviewer: “[…] you just said that the practice here […] has such a familiar atmosphere. Would you also talk about non-medical things? Somehow private problems […]?”

GER2: “Yes. I can definitely chat about it with N. [practice nurse].” *(Ll. 147-148)*

The continuous and regular contact between the patient and a non-physician health care professional appears to have a positive impact on patients, especially on the ones with a chronical illness. Again, these observations apply regardless of the setting and country of the survey. In Germany this special connection between practice nurses and patients was indeed reported, but not to the same extent as in the other countries. In Germany, it was the primary care physician rather than non-physician staff from whom patients reported a private relationship

tinged with trust (GER5, GER6, GER7, GER8). In Germany, four out of ten German patients reported, having a personal connection to their GP.

> **GER5**: “If I have a problem, even if it is only a moral or psychological problem […], you can talk to him about anything.” *(L. 170)*
>
> **GER6**: “Okay. You probably trust him a lot, don't you?”
>
> **Patient**: “Yes, yes. Yes, you have to have a certain trust in a doctor.” *(Ll. 198-199)*
>
> **Interviewer**: “[…] would you […] also bring up things with the family doctor, like non-medical things? So any private matters, if you need help there or something?”
>
> **GER7**: “I would do that, yes.” *(Ll. 135-136)*
>
> **GER8**: “[…] I always say that you have to be lucky enough to get into the right hands, and that's a big plus. The relationship between the patient and the doctor, that also has to be right. Otherwise, everything else is useless. […] It's the personal thing. If I find a person sympathetic, then that's fine. […] And then that plays a big role, that you feel sympathetic towards each other.” *(Ll. 199, 205)*

It seems that while personal access by the physician in the form of trust is very important to patients, non-physician personnel like APNs or heart failure nurses have the opportunity and primarily the capacity to operate on a different level. This includes, for example, the amount of talking and psychological effects reported by patients in relation to non-physician staff. The impression, that patients are more accessible to non-physician staff on a personal level hardens,

as a patient in Germany (GER9) reported not sharing personal information due to the fear of becoming a burden to the GP.

> **Interviewer**: "[…] What do you discuss with him? Would you also discuss private problems with him?"
>
> **GER9**: "Ok. Because these general practitioners don't really twiddle their thumbs, they would tell me something if I came to them with any stories. The throughput must be right." *(L. 228)*

The feeling of becoming a burden was also reported from another German patient in relation to hospital staff (GER6).

> **GER6**: "[…] the only thing that always bothers me is that the doctors don't talk to the patients. […] I was discharged from hospital. Nobody said anything about what I should or shouldn't do. And the doctors just don't have any time at all, that's the problem." *(Ll. 63, 65)*

Non-physician practice staff in Germany, Switzerland, Jersey, and Sweden acted as a low-threshold and continuous contact option that was well received by patients (CHE1, GER2, JER1, JER2, SWE2, SWE4).

Unchangeable characteristics of the healthcare personnel

Certain unchangeable characteristics of the personnel can influence the trust placed in the same. One patient reported (JER1), for example, that he had the feeling, that young GPs were more up to date or listened more closely.

> **JER3**: "[…] I prefer to see you because you're young. And you're probably more up to date with things. Whereas [the physician] next door is a bit older, and he's very good. I'm just saying that you're young and so you're more up to date. […]" *(L. 116)*

Furthermore, a female patient (GER1) from Germany would have preferred a same-sex caregiver for replacing the urine catheter in hospital.

> **GER1**: „[…] I wondered if they would put a [urinary] catheter in me. [...] And then it was […] a male nurse. [...] I felt a bit embarrassed with the

men. [...] But one is just like that, one feels a bit ashamed.“ *(LI. 82, 84, 86)*

In summary, regardless of the nation and type of setting, patient-centeredness encompasses several important aspects from the patient's perspective. Firstly, it requires an established flow of information between patients (or their relatives) and healthcare staff, specifically regarding the disease, therapy, and long-term options. Lay-friendly communication facilitates this. Additionally, the characteristics of the health care staff, like sex, age, capacity, and the presence of non-physician staff play a role. Non-physician staff can function as a low threshold contact option and support information flow or reassurance of patients.

3.2 Coordination of care – guidance is fundamental

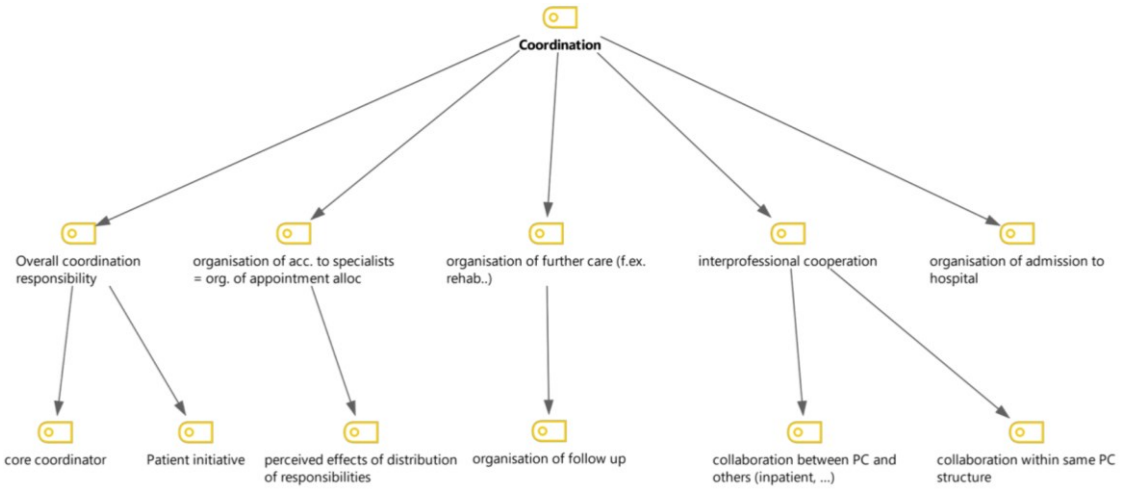

Figure 3 Code tree of the category "Coordination"

The patients were asked about how their care situation is organized and how the different care givers cooperate. Concerning the organisation and management of care on the one hand and the informative, advisory role in the sense of guidance on the other, the following results can be derived.

3.2.1 Core coordinator

It was interesting to note that even in countries with gatekeeping, where GPs function as core coordinators, no connection between the presence of gatekeeping and better reports of coordination through the health care system

could be demonstrated. All patients from Jersey (JER1, JER2, JER3) reported to have no one who assisted with advice on further steps. Another patient from Sweden (SWE6) indicated the need to have a main coordinator in the background when needed.

> **Interviewer**: "[…] Is there anybody that really guides you through the care system or helps coordinate that for you?"
>
> **JER1**: "Not really." […]
>
> **Interviewer:** "Ok. So, who is responsible for coordinating your care […]?"
>
> **JER1:** "Myself." *(Ll. 143-144, 198-199)*

> **Interviewer:** "Ok. […] who guides and supports you through the system?"
>
> **JER2:** "B., my partner." *(Ll. 199-200)*

> **Interviewer:** "[…] is there anybody that guides you, coordinates you through the system […]?"
>
> **JER3:** "No." *(Ll. 107-108)*

> **SWE6**: "Yes there are many people. […] I would like to be sure that this is my doctor, that he'll be there when I need him." *(/)*

There were also patients, who were satisfied with the extent of coordination whether with or without a gatekeeper system.
In Switzerland and Germany, where no gatekeeping exists, patients (CHE1, CHE3, GER1) described the medically necessary referral to the specialist, which in this context can be described as coordinating, as satisfactory.

Interviewer: "Are there other specialists that are important in your health care? So other specialists that you see?"

CHE3: "Yes that worked. He [the GP] immediately referred to the relevant specialist." *(LI. 40-41)*

Interviewer: "And will that [the need to go to a specialist] be discussed with the family doctor when you see [a specialist]?"

GER1: "Yes, I need a referral. I get a referral and then I go there." *(LI. 111-112)*

CHE1: "So, he [the GP] had to do everything with registration and referral etc."

Interviewer: "But is the GP the control centre, so to speak, who controls or coordinates? […] Was [the coordination between different institutions of the health care system] simply done here in [the] practice?"

CHE1: "Yes, exactly." *(LI. 55-56)*

In Jersey, where gatekeeping exists, the impression emerged that the requirement for GP referrals was perceived as rather burdensome by patients (JER1).

Interviewer: "[…] you've already […] answered how you see the specialist. […] You've got to see the GP […]. Does this work for you […] and how do you perceive this situation? […]"

JER1: "That is rather difficult […] really, because you can't really leave out the middleman […]. The first man that you see is a doctor. […] The GP, you can't really leave him out. So what do you do? […] the system is: they won't look at you unless you're being referred to by a doctor. I

> couldn’t have gone up to ENT [Otorhinolaryngologist] and say: I want to see Mr. DC? […] You got to see the GP [first].” *(LI. 135-142)*

In cases in Germany in which patients described the GP as their core coordinator or first point of access, they stated that this was due to the generalist approach (GER3), the short access route (GER9), but also the trust in his or her competence and diagnostic skills (GER6, GER9) and the fact that the GP receives a report from the specialist (GER8).

> **Interviewer**: “[So can it be said that] he [the GP] takes on the role of a coordinator for you, who would refer you or send you to other doctors?”
>
> **GER3**: “Yes, I think so. And he also has an eye, I have the impression, on both of us, on my husband and me with an old people's home possibly, you know. He would help me, he said, if there was ever a need. […] Well, I think that's the be-all and end-all. I like going there.” *(LI. 364-365, 367, 372-375)*

> **Interviewer**: “Does the family doctor play […] a coordinating role for you? Does he […] have an overview of what needs to be done?”
>
> **GER6**: “Yes, he does.”
>
> **Interviewer**: “Okay. So, he reminds you when you need to go for a check-up or something like that?”
>
> **GER6**: “Yes, exactly.” *(LI. 172-173, 176-177)*

> **GER9**: “[…] normally that [the GP practice] is the first port of call, because I think he's competent and I've chosen the GP because I think he's capable. […] I prefer to go to someone I trust.” *(L. 230)*

Interviewer: “You had said before [...] that your wife had asked [Dr. S., GP], if he could come by [when you had the first symptoms of a stroke]. How far away is he then [from your home]?”

GER9: “From our home? About 200 meters.” *(Ll. 95-96)*

Patients also described their GP to be someone who helps organizing further steps or who is on hand with advice (GER1, GER4, GER7, GER8).

Interviewer: “So if you said you wanted rehab. Now you have said that you would probably ask your family doctor, right?”

GER1: “Yes, I would ask [for advice] then.” *(Ll. 89-90)*

Interviewer: “Yes. But if you had another problem, if you needed another specialist, would you go there directly or would you ask Dr. O. [GP] first?”

GER4: “I once had a colonoscopy, that was two or three years ago, and I had the idea that I could have a colonoscopy. And then Dr. O. [GP] chose a doctor close to my home.” *(Ll. 243-244)*

GER8: “I am satisfied with it. [...] if I need a specialist, for example a cardiologist or a dermatologist [...] then the GP says to me, go there or there or there. [...] And the specialist will then give him a report on what he has done and what he recommends.” *(L. 191)*

Interviewer: “And if you needed a new specialist for some other "problem", would you look for one yourself or would you ask your family doctor to help you?”

GER8: “I discuss things like that with my family doctor or my son-in-law.” *(LI. 144-147)*

Interviewer: “So he also helps with organizational things if needed?”

GER7: “Yes, definitely.” *(LI. 139-142)*

Interviewer: “Ok, great. And if you needed help at some point? Would you know how you would organize that? […] Would you consider asking the family doctor for help as well? […]”

GER8: “Yes, everything to do with illness only goes via our GP.” *(LI. 92-97)*

However, it must be emphasized that the need for guidance is not synonymous with organizational help. There were patients in Germany (GER6, GER7, GER9) and Jersey (JER3) who felt comfortable organizing their own follow-up or specialist care. Some others from Germany (GER6) enjoyed, having their follow-up or specialist care organized by the hospital or their GP or disliked the fact that the initiative for further examinations and referrals had to come from himself (GER4). It can therefore be stated that the need for guidance and advising cannot be generalised. In this context a compulsory need of GP referrals in some German contexts was disliked because of the feeling of paternalism.

Interviewer: “And if you need a specialist […], do you organize that yourself?”

GER7: “I've always organized that myself.”

Interviewer: “So the family doctor is not involved?”

GER7: “[…] what I can do myself, I do myself. […]” *(LI. 105-106, 108)*

GER9: “Yes. That's an issue with our health care system. I don't know if it [the need for transferals is] necessary, but I feel patronised. […] I feel incapacitated. […] I would like to tell you that this is often not so nice from the patient's point of view.” *(L. 216)*

Interviewer: “[…] is there anybody that guides you, coordinates you through the system? […]”

JER3: “No.”

Interviewer: “So you feel that you have to guide yourself or find the way yourself?”

JER3: “I’m an independent person. […] I don’t need anybody really.” *(Ll. 107-110, 112)*

Interviewer: “And about Crohn's disease? How does that work?”

GER6: "Dr. O. [GP] has already called the hospital I usually go to, a few times, and he also makes the appointments [for] colonoscopy. […] In this case he [makes the appointments].”

Interviewer: “And how do you feel about that? Is it good for you that he does it for you or would you rather do it yourself?”

GER6: “No, that's fine. Because they're colleagues, they can do it better together.” *(Ll. 184-185, 187-189)*

Interviewer: “Ok. So that works quite well for you with the coordination [of follow-ups and referrals] by Dr. O. [GP], doesn't it?”

GER4: “Yes. However, only after I have drawn his attention to something.”

Interviewer: “Ah ok. The initiative then comes from you.”

GER4: “Yes, of course.” *(Ll. 251-252, 255-256)*

3.2.2 Guidance: help in an advisory and informative way

The difference between guidance and organizational help is reflected in the following quote (GER6). The patient seeks for guidance by consulting the GP as a core coordinator but feels comfortable in organizing the specialist appointment alone.

GER6: “[…] I went to a lung specialist and Dr. O. [GP] recommended him to me […]. He does [refer me]. There is no problem at all.”

Interviewer: “Ok. And did you make the appointment with the lung specialist yourself or does he do it?”

GER6: “No, I do it myself […] and am [satisfied with that].” *(Ll. 111, 113-117)*

The need for guidance was expressed especially in the thematic field of additional care and prevention services such as heart sport groups, self-help groups and rehabilitation.

Patients from Jersey (JER1, JER2, JER3), who come from countries with a gatekeeper system, noted the need for more guidance through the health care system to the same extent as German and Swedish patients (SWE3, GER2, GER4), who come from a country without gatekeeping system.

Interviewer: “[…] do you somehow have someone who […] makes a complete plan for how you should look after yourself now that you've had a heart attack?”

GER2: “No, I don't have one.” *(Ll. 61-62)*

GER4: “Yes, yes, yes. Nobody told me anything [about the cardiac sport group]. O. [the GP] said: Yes, then look on the internet under

heart sports group. I said: Yes. I mumbled to myself: I've already done that. It's all difficult for me to reach, isn't it? […] First of all, because of the distance, and then most of them were already fully occupied." *(LI. 116, 118)*

SWE3: "[…] I don't really know who I should contact, maybe I could use a little help with that […] and get information on what to do […]." *(/)*

Interviewer: "[…] who guides and supports you through the system?"

JER2: "B., my partner." […] I suppose I'm alone […]." *(LI. 199-200, 202)*

3.2.3 Interprofessional cooperation

While the presence of a gatekeeping system apparently has no influence of the satisfaction about guidance and coordination, it does have an impact on satisfaction with cooperation between professionals. Patients were dissatisfied with the extent to which the GP was informed about specialist care rather in Germany as an example of non-gatekeeping systems than in other countries. Five out of ten German patients (GER3, GER5, GER7, GER9) reported that their GP receives reports about hospitalization or the specialist care and medication strategy only via the patient himself.

Interviewer: "Who gets the letters then? Does the family doctor get them directly from the hospital? […]"

GER3: "I got them home with me, yes, when I got out of the car, when I drove home, I got the papers, and our helper [of the family] took them back to Dr. O. [GP]." *(LI. 554-555)*

GER5: “I do that [, pass the findings and results on to the GP.] Yes. That it is passed on. […] He [the orthopaedist] wouldn't do it automatically […].” *(Ll. 182, 184)*

GER7: “99.9% of the time I get a doctor's report and there is one for me and one for the GP. And I pass it on.” *(L. 148)*

GER9: “I have to say, in computer times, it could […] be different from the patient carrying the paper [the specialists’ report] from A to B. […] And that this information is stored somewhere in the database or somehow gets to the other […] [physician] electronically and is available there. I've also had to deal with the transfer of data between clinics and GPs, so that seems to be a huge disaster here in Germany.” *(L. 250)*

Nevertheless, there were also positive examples of information transfer in Germany (GER4, GER6, GER8). One patient reported that it has a positive influence on the information transfer between specialists and the GP, if there was a referral beforehand (GER4).

Interviewer: “[…] when you see your GP […], does he also have all the information from the other specialists?”

GER4: “Yes, of course. […] from the orthopaedist I don't think so, because […] I did that separately [without a referral], whereas from the bowel specialist, he should have that too. […] [and from the cardiologist] anyway. Because there was always a referral.”

Interviewer: “So you have the feeling that Dr. O. [GP] is well informed and they [the specialists and the GP] also communicate well.”

GER4: “I think so, yes.” *(Ll. 261-262, 264, 266-268)*

Interviewer: “[…] did the GP then also receive all the information about the story [after you were discharged from hospital] , i.e. did he receive letters […]?”

GER6: “Yes, he received all the reports from the hospital.”

Interviewer: “So did you have the feeling that the GP was informed?”

GER6: “Yes.” *(LI. 58-61)*

GER8: “[…] then he [the GP] gets a report from the specialist afterwards about what he has done and what he recommends. […]”

Interviewer: “So you have the feeling that your GP is also well informed when you have seen a specialist?”

GER8: “Yes, yes.” *(LI. 191-193)*

Although one Swedish patient (SWE6) wished for better cooperation between his GP and specialists, it was not denounced as frequently and clearly in Switzerland, Jersey, and Sweden as in Germany.

SWE6: “[…] I feel it [the care process] is a bit too compartmentalised, there should be more collaboration [with the neurologist]. […] of course, it's a bit difficult that there are different doctors, and they say different things, it can be a bit difficult.” *(/)*

In Switzerland, Sweden and Jersey, most patients (CHE1, JER1, JER2, JER3, SWE7) pictured the cooperation within the primary care team and the communication between their GP and others, such as heart failure nurses, cardiologists, and hospitals as sufficient. In an example in Sweden where the GP didn’t automatically receive the letter from the specialist, he took responsibility for it himself. The transfer of information between GP and specialist was not, as in Germany, the patient’s responsibility.

Interviewer: “How do you find that the different people involved in your care communicate and collaborate? Do you feel that they do communicate?”

JER1: “Yes.”

Interviewer: “So you feel that their communication is good, between [e.g.] the hospital and your GP?”

JER1: “Yes.” *(Ll. 216-219)*

Interviewer: “And do you feel that your providers are well informed about you and your condition?”

JER2: “I think so.” *(Ll. 219-220)*

Interviewer: “Ok. And do you think the people involved in your care, e.g. [the] hospital and your primary care, nurses, doctors […] communicate and collaborate well? Do you get that sense?”

JER3: “Yes. I think that they know what [they]’re about.”

Interviewer: “So you get the sense that the communication seems adequate or good?”

JER3: “Yes.” *(Ll. 129-132)*

SWE7: “Yes, first, what did I say to R. [GP], you have received records, right? No, I can't find anything – he said – from the doctors [specialists]. So, he contacted them himself and then found out about things. […] He called different doctors because he might not be familiar with everything. And he knew who to look for. He looked up many specialists – he said – and wanted to talk to them about [me].” *(/)*

Interviewer: “And do you understand how the exchange of information takes place, i.e. [...] between nursing and doctor?”

CHE1: “I think that's pretty good. Because everything is entered in the portal, and I think everyone has access [...] to the information.”

Interviewer: “So you don't have the feeling that the doctor doesn't know what was discussed beforehand?”

CHE1: “No [...] it's in the portal.” *(LI. 45-48)*

Especially in Germany the information transfer from specialists to GPs and, consequently the GPs’ knowledge about the patient was described as insufficient and unsatisfactory. At this point, the bridge can be built to the topic of informational continuity, which is dealt with in the following chapter.

In summary, results can be divided into topics concerning the organization and management of care on the one hand and the informative, advisory role in the sense of guidance on the other. Patients benefit from both having a core coordinator and guidance in the sense of advisory functions. According to these results, the presence of a gatekeeping system has no influence on the degree of coordination and guidance in a health care system. Nevertheless, gatekeeping can affect the degree of satisfaction with communication between professionals. Patients were dissatisfied with the extent to which the GP was informed about specialist care rather in Germany as an example of non-gatekeeping systems than in other countries. Patients in Germany were, in contrast to the other countries, very often responsible for this transfer of information.

Patients benefit from guidance and counselling. Apparently, there is need for improvement in advisory functions for informing the patient about further supply and preventive options, such as heart sport groups, self-help groups, and rehabilitation.

3.3 Continuity – Long-lasting relationships and transfer of information

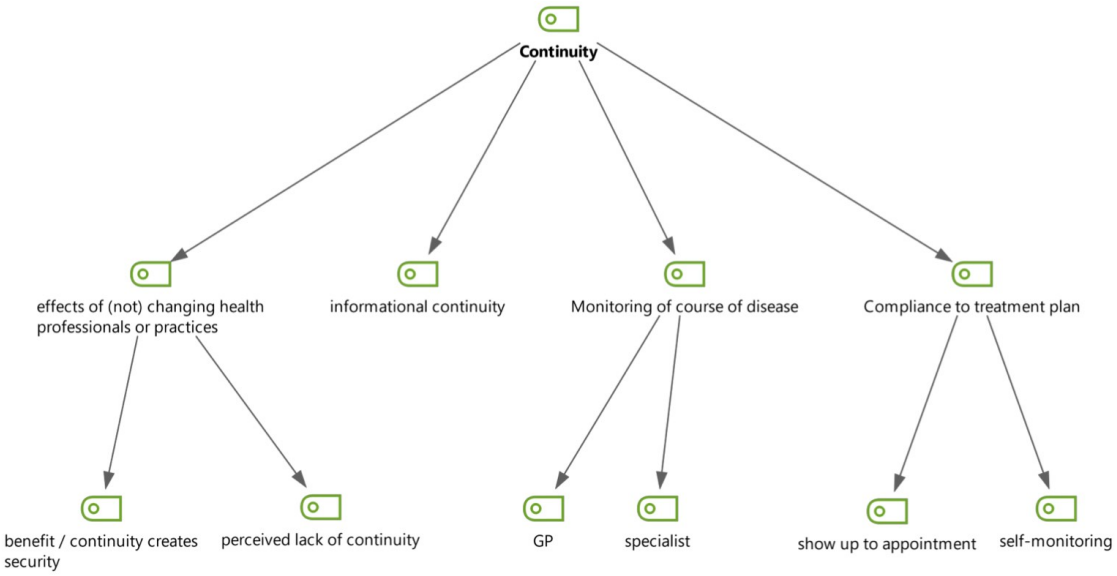

Figure 4 Code tree of the category "Continuity"

The overlap between coordination and continuity is obvious. The previous chapter dealt with interprofessional cooperation between different care givers. This automatically leads, via informational continuity to the issue of continuity of care. Both, informational and personal continuity are the two main themes that emerged from the data collection. The topic of continuity was mainly present in the GP sector.

3.3.1 Informational continuity

> **Interviewer**: “And do you know how the exchange of information takes place [within the GP practice], basically between the nursing [APN] and the doctor?”
>
> **CHE1**: “I think that's pretty good. Because everything is entered in the portal [electronic patient file] and I think everyone has access to it […] the information.”
>
> **Interviewer**: “So you don't have the feeling that the doctor doesn't know what was discussed beforehand?”
>
> **CHE1**: “No [...] it's in the portal.” *(Ll. 45-48)*

Interviewer: “And do they also exchange information with each other [within the joint practice]?”

GER1: “Yes.”

Interviewer: “So you have the feeling that it doesn't really matter who you were with. [...] So even though they are at different locations [joint practice with different locations].”

GER1: “Yes.” *(LI. 145-150)*

Interviewer: “[…] there are several doctors here [in the GP practice], aren't there? Do you always see the same one [or] do you also see the other two?”

GER2: “I also see the other one. [...] He's also ok [...] I get on with him too. He knows everything about my illness. [...] Even if there is always a change [between the GPs], I get along with all of them.” *(LI. 123-124, 130)*

Interviewer: “And what is it like for you that the GPs change [within the practice]? [...]”

GER4: “Oh, well, that's not so bad. [...] He [the GP] has all the documents, such a package of stuff about [...] all the stories there.” *(LI. 213-214, 218)*

Interviewer: “And do you have the feeling that the other [doctors within the practice] know about [you when you are cared for by different doctors]? So can they read about [you] somewhere […]?”

GER8: “Yes, yes. When I go to the doctor, he gets a file with all the reports […]. And the doctor […] reads it beforehand and then knows what it’s about. But as a rule, if it is important, even the other [employed] doctors say, we will do it with doctor H. [GP], because he is informed about everything.”

Interviewer: “[…] Are you satisfied with that?”

GER8: “Always.” *(Ll. 172-175)*

While the communication within care structures, such as GP practices was reported to work well in Germany and Switzerland (CHE1, GER1, GER2, GER4, GER8) patients in Germany were dissatisfied with the extent to which the GP was informed about the care provided by specialists and hospitals. This is also touched in chapter 3.2.3 on interprofessional cooperation. As almost half of the patients in Germany (GER3, GER5, GER7, GER9) were responsible to establish the information transfer between hospitals or specialists and the GP themselves, and GPs didn’t automatically receive reports of the provided specialist care, this is an obvious weakness in the maintenance of informational continuity. In a case (GER9), where reports were offered to be sent automatically to the GP, letters did not arrive, and the patient had to bring the GP up to date. In total, patients in Germany sometimes seemed to be overwhelmed with the task of maintaining the information transfer and expressed the wish for a technical solution for the exchange of medical information between physicians.

GER9: "Also from the hospital, the final reports have [...] also been sent to the GP officially and some of them have probably arrived, but some have not.”

Interviewer: “Okay. So, you actually take over the communication between the [institutions] for safety's sake.”

GER9: “For safety's sake, exactly. [...] I don't want to leave it to chance.” *(Ll. 274-276)*

GER9: “[…] the other day this report [from the cardiologist] didn't arrive at the GP practice, it wasn't sent somehow […]. He [the GP] said it still hasn't arrived and I was at the GPs for a consultation […]. He [the GP] had to rely […] on me as a patient, as an unreliable source and certainly not knowledgeable with special terms and so on. […] But I think it [the report] disappeared until today […] Well, that doesn't work!” *(L. 258)*

Germany was the only country where informational continuity was described so poor to this extent. In Jersey (JER2, JER3) the information transfer between institutions was reported to work better. In Sweden and Switzerland no detailed information was gathered on this topic.

The importance of informational continuity for patients is also reflected in the fact that patients generally appreciate it when their longstanding GP has all the information about their medical history (GER5, GER9). In some cases, informational continuity is even the reason for a patient to stay with the same GP over many years (GER5, GER8).

GER5: “He only gets the findings.”

Interviewer: “[…] But then do you also have the feeling that the family doctor knows everything about what the others have done?”

GER5: “Exactly. That is actually important.” *(LI. 188-190)*

Interviewer: “Do you always see the same doctor [GP] or do you see different ones?

GER9: “I always see the same GP. There are also reasons why, if my whole history is filed there, he also has a complete or potential possibility to assess everything that is wrong with me. And if I were to do this via two or three doctors, then I would be busy comparing the data.” *(LI. 237-238)*

GER5: “So it [the practice setting] is a big family. That's why you don't change something like that. […] [Staying with the same GP for as long as possible] is actually the most important thing because he has had my data for 40 years. If he looks in the archive, he has all my data in there. So, he can read from it, and I think that's actually important.” *(L. 144)*

Interviewer: "Ok. And is it also important for you that you have [...] a long-standing relationship with your GP?"

GER8: "Yes. I always find that good. [...] If I go to another doctor […], I'll be asked again, what do you have [and] how long have you had it […]. And that's not necessary if I have a family doctor. He already knows from the ground up, he has all my papers [...] and […] searches through them. Or you talk about the illnesses you [had] at the beginning and then the doctor already knows how to assess the situation." *(Ll. 186-189)*

Unfortunately, no data about this was conducted in the other countries. Nevertheless, it can be deduced from the German quotes that informational continuity is apparently perceived better by patients if longitudinal continuity is established, means seeing the same GP over a longer period. This leads us directly to the next chapter.

3.3.2 Temporal continuity

Longitudinal/interpersonal continuity – Patient-Physician Relationships: Fostering Security and Trust

The collected data leads to the conclusion, that patients perceive a long-term relationship between physician and patient as more secure regarding the patients’ health care process. On the one hand, this is due to the fact that informational continuity, in the sense of the practice or GP having all relevant

information about the patient's medical history, leads to longitudinal respectively interpersonal continuity and thus security among patients. On the other hand, interpersonal factors also play a role in maintaining longitudinal continuity. Nine patients from Jersey, Sweden, Switzerland, and Germany (CHE3, GER2, GER5, GER7, JER1, SWE2, SWE4, SWE6, SWE7) stated that trust, security, and the feeling of being well cared for, are a result of having the same general practitioner over a longer period of time. In this context it was also reported that patients dread the moment when the GP retires (GER2, GER7).

> **GER2**: "Right, yes. It's actually familiar, the practice."
>
> **Interviewer**: "And is it also important to you that you stay in the practice? Or do you think that the main thing is the family doctor [and] wouldn't care if it was someone else [, i.e. the GP changed]?"
>
> **GER2**: "No, I have to say that they also care about it. They are also like family. […] So, I've never had any problems."
>
> **Interviewer**: "So if they were to close now, suppose you were..."
>
> **GER2**: "Disappointed, yes. Because you rarely find a family doctor like that, I have to say. Even though there is always a change [within the joint practice], I get along with all of them." *(LI. 126-130)*

> **SWE2**: "It feels safe that I have had the same doctor many times. […] It is important to have the same doctor because you get the impression that […] we kind of know each other and […] with heart failure he has everything under control, I think." *(/)*

> **SWE4**: "I have been lucky that he [the GP] has stayed, that you get the same [doctor], that's it." *(/)*

SWE7: “I kept the same doctor 100% of the time.” *(/)*

In contrast, frequently changing doctors tend to unsettle the patient (CHE3). However, in joint practices, patients were fine with changing doctors (JER1, GER1, GER4, GER8), even if some still reported having a favourite physician, especially when it comes to important matters (JER1, GER8). A patient from Jersey reported aiming to see the same GP within the practice, which, to his regret, was not always possible (JER1).

CHE3: “Yes, we felt safer with the family doctor. The question was always yes, is this person [in a setting where physicians changed daily] really trained enough when decisions were made regarding medication. There was a certain uncertainty.” *(L. 53)*

Interviewer: “And you don't think it's a bad thing that you have two doctors [in the joint practice] who talk to you?”

GER1: “No. No.” *(Ll. 157-158)*

Interviewer: “Ok. So, the main thing is that you have a family doctor [and are not without one]. It doesn't matter if it's someone else now and then.”

GER4: “That's not so important to me.” *(Ll. 215-217)*

GER8: “No, there are several doctors in the practice and also two female doctors. And when it comes to important things, then of course only Dr. H. [GP] is an option for me, because he knows the course of my illnesses. Whereas the other doctors first have to deal with it and look up what I had […]. If it's something minor, I go to a substitute doctor [in the same practice].” *(Ll. 172-173)*

JER1: “I try to see the same one.”

Interviewer: “[…] within the practice, you try to see the same doctor but sometimes you find it difficult, so you have to see different ones.”

JER1: “Yeah.” […] Well, everybody’s got their favorites, like the GP. […] I used to see S. [one of the GPs in a joint practice]. He left. […]

Interviewer: “So the turnover of GPs is a problem.”

JER1: “Yeah. […] you can [see the same GP]. You just wait.”

Interviewer: “So it depends on who’s available, yeah.” *(LI. 155-156, 173-174, 176-178)*

When the period of treatment by the same GP was queried, the patients who reported this personal relationship to their GP, resulting in trust, security, and familiar atmosphere, mostly had the same GP for at least twelve and up to 40 years (CHE3, GER5, GER7, GER8).

CHE3: “One had a personal, a very personal relationship with the family doctor. And above all, he knew the whole family. Our two children will soon be 60 years old. He knew them and all the problems and so on that were coming up. […] Right, he knew everything.” *(LI.7-8)*

Interviewer: "Now you also said that it's important to you that you stay with the same [GP] for as long as possible and that you talk about it and that it's like a family, you said.”

GER5: “That's good. That's the important thing. You have a relationship of trust with the doctor. [...] I've been in the practice for 40 years.” *(LI. 157-158, 106)*

Interviewer: “And how important is it to you that you always have the same one? You have now said that you have been there for 18 years.”

GER7: “It is important for me. Not always something new. I don't want that now. That is important.”

Interviewer: “Yes, also with the personal relationship and so on.”

GER7: “Yes. Yes. Yes.”

Interviewer: “Then it's probably like a kind of relationship of trust, isn't it?”

GER7: “[…] yes. He is not allowed to stop either. Because of his age, we said, it's not possible, he's not allowed to stop.” *(LI. 199-204)*

SWE6: “Yes, there are many people. I would like to be sure that this is my doctor, that he'll be there when I need him.” *(/)*

Interviewer: “Ok. And how long have you had the family doctor?”

GER8: “Since we moved here. That was […] 12 years [ago].”

Interviewer: “[…] is it also important to you that you have such a long-standing relationship with your GP?”

GER8: „Yes. I always think that's good.“

Interviewer: “So there's a kind of relationship of trust between you and the GP, isn't there?”

GER8: “Yes, but of course. You can't do without him.” *(LI. 182-187, 278-279)*

In Germany there were also patients, who had the same GP for only two to five years. One of them (GER3) expressed a feeling of trust towards the GP, even though she had only been with him for five years. Nevertheless, it was more common for patients who reported trust to have been with the same GP for over 12 years.

> **GER3**: “I just have trust, you know. […] I've probably been with Dr. O. [GP] for three, […] maybe five years […].” *(Ll. 343, 527)*

Patients from Sweden (SWE7) and Germany (GER8), who were neutral about changing professionals, stated that this only applies on the condition, that good personal contact and informational continuity were established. There can be a sense of security if the GP takes the time to get to know each other and find out about the patient’s health history (SWE7).

> **SWE7:** “Now I have another doctor and he actually took the time to go through everything from day one, the day we sat there we went through everything that was involved and it was really nice to meet him [the GP], and it gave me a bit of confidence to meet him.” *(/)*

Nevertheless, it is not exclusively about having the same GP over many years, but it must also work on a personal level. This hardens, as two German patients (GER6, GER9) declared that they were planning to change their GP in consequence of the lack of a personal level, even though being patients of their GPs for many years. Another patient (GER4) reported that a lack of initiative by the GP can also go at the expense of longitudinal continuity.

> **Interviewer**: "And what made you decide to change [the GP]? […] what did you find better about him [current GP] than your [previous GP]? Can you describe that?"
>
> **GER6**: "Yes, she was so terribly moody. When she was in a bad mood, she took it out on the patients and when she was in a good mood, she did everything right. But I don't need that when someone is so

unstable. […] She also sometimes talked to me in a stupid way, so I thought to myself, I don't really need that anymore."

[…]

GER6: "Yes, I do [have trust towards the current GP]. Yes, you have to have a certain trust in a doctor."

Interviewer: "[…] You probably didn't have that much trust in the predecessor [of the current GP], did you?"

GER6: "No." *(LI. 134-135, 137, 198-201)*

GER4: "[...] He [the GP] just reacted. [...] That's not so funny. [His] predecessor […] was different. [...] He did examinations straight away, he did a lot on his own initiative. [...] [Don't] smoke or do your exercise [...] He asked all sorts of questions. [...] Or measuring [the] blood pressure or anything. He [the current GP] doesn't do any of that. [...] So that seems strange to me. [My sisters] said I should change [the GP]. Preferably to the cardiologist, because he's also an internist."

Interviewer: "And are you considering that?"

GER4: "Yes, in the near future. When the tablets run out again, then I'll go over to the [cardiologist], make an appointment and ask him if I can stay with him. [...]"

Interviewer: "So that he [the cardiologist] becomes your family doctor."

GER4: "Exactly." *(LI. 327-330, 332-336, 340-348)*

GER9: "Yes. I had a [different] family doctor and she was already very old […]. I think I was with her for 35 years and then she only worked

part-time. It was difficult then, it's no excuse for me to leave now, but it was difficult to meet her or to get anything at all within a certain time frame." *(L. 244)*

Bridging gaps in follow-up care

The establishment of the follow-up care respectively the monitoring was experienced as disappointing when the GP didn't take enough initiative for follow-up and check-up examinations. In one German case (GER4), the GP only referred the patient to another care provider (cardiologist) and did blood tests upon the patients' initiative.

GER4: "[…] I was at the [GPs], I had to get some pills, so I asked him: Tell me, don't I have to go to the cardiologist again? He said: Yes. Yes, we can do that." *(L. 200)*

Interviewer: "That's also what you missed a bit with Dr. O. [GP], isn't it? That he didn't ask questions and didn't take the initiative."

GER4: "Yes, yes and if I hadn't been at the university hospital, had a main examination there with all sorts of things, then I wouldn't have known what to do. [...]

Interviewer: "Yes. But you also took the initiative and asked Dr. O. [GP] whether you should go again."

GER4: "Yes, yes. I drew his attention to it and then he said: Oh yes, we can do that. Yes, what's that all about? […] The [...] predecessor [of the current GP] was different. He said: Mr. K., we did the last blood test six months ago. You're actually due again. When do we want to do it? [...] Dr. O. [current GP] doesn't do that […]." *(Ll. 556-557, 561-565)*

Patients perceptibly wish for more initiative from their doctors when it comes to their follow-up care after experiencing acute incidents such as stroke or

myocardial infarction and appreciate regularly check-ups by GPs. Apparently, patients, no matter which country or system they come from, appreciate regular check-ups after an acute illness such as stroke or heart attack. No uniform opinions on the satisfaction of the check-ups could be mapped within the countries. For example, one Swedish patient (SWE3) criticised the lack of check-ups, while another patient in Sweden (SWE7) reported that he had regular check-ups at the GPs. It can therefore be concluded that ensuring regular check-ups is not dependant on system-dependent structural features, but rather depends on the individual practice setting.

> **SWE7**: “He [the GP] used to call me up and send me down for tests and keep an eye on me all the time like […] every 3 months, sometimes every 14 days […].” *(/)*

> **SWE3**: “But maybe you should have some regular appointment [with the GP] that you would get so you don't have […] to be reminded of it, but it would be one every six months or every year.” *(/)*

> **GER7**: “Now he [the GP] comes by every fortnight to see how I'm doing.“ (*L. 142)*

> **Interviewer**: “So you have regularly scheduled appointments. And if something comes up in between?”
>
> **CHE1**: “Then I can get in touch at any time. That's what they keep telling me, that I should get in touch if there's anything, get in touch immediately, not later.” *(L. 26)*

Furthermore, it was reported as positive, that the regular follow-up was taken over by advanced practice or specialist nurses in Switzerland, Jersey and Germany (CHE1, GER2, JER1).

Interviewer: “[…] was there a situation or a behaviour of certain persons that you liked or noted positively since the heart attack?”

GER2: “[…] I have to say that N. [practice assistant] calls me regularly to ask me how I am and whether everything is all right with my tablets and to take blood samples. She calls quite often.” *(Ll. 81-82)*

CHE1: “And yes, she [Mrs. W., APN] really helped me and still helps me now, so once a month I come here.” (L. 7)

JER1: “[…] I used to have somebody that used to come every two months. […] A nurse. She used to come and checked over.”

Interviewer: “[…] do you think your condition is taken good care of? Do you think there’s good support for you after the stroke and rehabilitation […]?”

JER1: “Yeah. To me it was adequate.” *(Ll. 205, 207, 210, 213)*

Continuity of further care respectively follow-up care may be disturbed when responsibilities are not clearly divided between different providers. One patient (GER4) shared that his GP missed monitoring blood lipid levels, although it should have been done by the GP. This was then noticed by the cardiologist, who was surprised and had the values determined himself.

GER4: “[…] I went to see a cardiologist about three weeks ago and [the cardiologist] asked me: What has been your [cholesterol] status lately? […] I say: I don't have any, it was half a year ago, at the university. [The cardiologist] says: Oh, come on. I noticed from his reaction that he […] didn't find it funny. […] then he said: Then we'll take some blood right away and see what's going on. And he did the examination. Promptly there were [the results] and I had to increase the [Cholesterol-lowering drugs]. […] The GP did not take the initiative.

> He should actually have done it. If he sends me to a cardiologist, then he has to do the blood tests first. I don't understand it. [...] *(LI. 300, 302, 304, 306)*

The quote highlights an issue of perceived insufficient follow-up care and monitoring due to a missing examination, that is very relevant for patients after myocardial infarction. In this case, the division of tasks between the specialist and the GP were not clearly defined.

In summary, continuity involves two main issues: informational and longitudinal respectively interpersonal continuity. Regarding informational continuity, Germany was the only country where the same was described as so poor: the extent to which German GPs were informed about specialist or hospital care was criticized. Patients themselves were often responsible for maintaining informational continuity between providers. As far as longitudinal continuity is concerned, a long-term patient-physician relationship results in more security regarding the patients' health care process: interpersonal factors play a role in maintaining longitudinal continuity. Trust, security, and a feeling of good care result from interpersonal continuity, while changing doctors may confuse patients. Either a long-lasting patient-physician relationship or contact on a trusted basis create an atmosphere in which the patient feels secure and well looked after.

Responsibilities must be clearly divided, and the distribution of tasks must be unambiguous between different providers in order to establish satisfactory follow-up care and monitoring.

3.4 Access

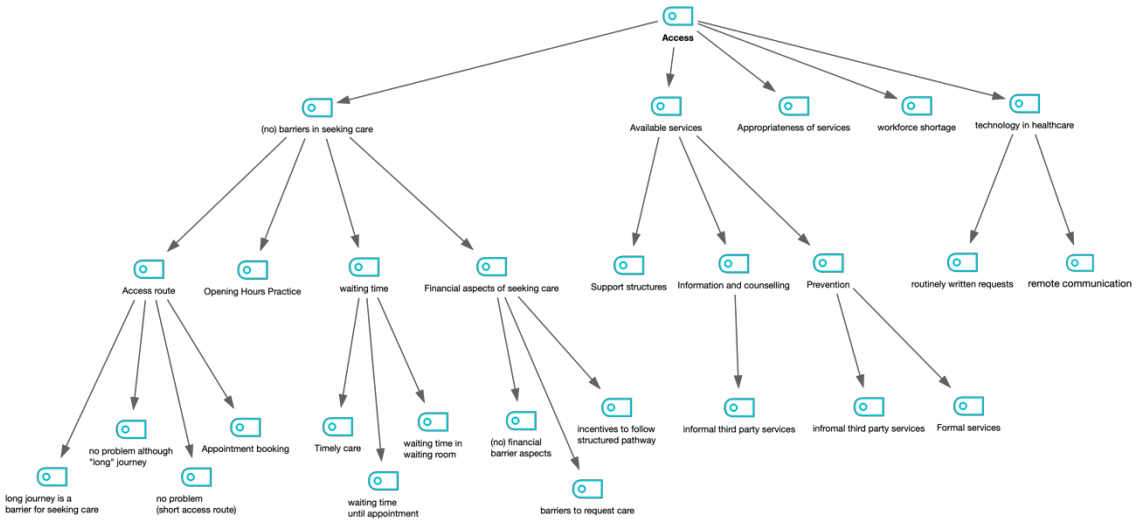

Figure 5 Code tree of the category "Access"

When asked about the reachability of GPs, specialists, and other care services, patients described the following circumstances that affected the access to the different health care institutions they needed. These include the lack of availability of care services as well as other barriers such as opening hours, waiting times, access routes and technical and financial hurdles.

3.4.1 Available professionals

It was helpful for patients to have a first contact person for situations in which their health deteriorates (CHE1), whereby it was not mandatory that this had to be a doctor. Other health professionals, such as heart failure nurses in Sweden or advanced practice nurses (APN) in Switzerland can take on this role of the first contact person (CHE1, SWE2). For the patient, whether they contact non-physician or physician staff depends on how severe the situation is (CHE1). In connection with this calming effect of an accessible person in the background, it is particularly important that this contact person or institution can be reached promptly.

> **CHE1**: “Then [when health deteriorates] I can get in touch at any time. That's what they keep telling me, that I should get in touch if there's anything, get in touch immediately, not later.”

Interviewer: “And would you rather report to Mr. S. [GP] or to Mrs. W. [APN]?”

CHE1: “So it's more likely to be Mrs. W. [APN]. Unless I really keel over, then I think it's Mr. S. [GP].” *(LI. 26-28)*

SWE2: “Then I […] have a number for the cardiac care nurse when I think about asking, I have paper at home, I think it's so that I can reach her directly, that's it. […] As for the doctor's visit itself, I have to go in or call and make an appointment for a consultation, but I'll mostly talk to the nurse.” *(/)*

In Jersey, everyday support, offered by home care nurses was described as positive (JER2).

Interviewer: “[…] what did you find very effective?”

JER2: “After I’ve come home [after the hospital], the nurse came to [my house], so I was alright.” *(LI. 21-22)*

Patients not only missed the counselling and information about further care offers (GER1, GER2, GER4, GER5) which is described in chapter 3.2.2, but also concrete offers, such as physiotherapy (GER2), heart sport groups (GER2, GER4) and self-help groups (GER2). In more general terms, a missing network of care was reported, especially by German patients. It was the case in rural areas as well as in large cities.

GER2: “Well, counselling centres actually. Where you can go and say, I have this problem, what can we do? That's what's missing.” *(L. 157)*

GER2: “[...] I had three [rehab clinics] to choose from. [...]”

Interviewer: “And did someone recommend the best one to you or did you choose it yourself?”

GER2: “No, nobody recommended which one should be great, they said I should choose which one I wanted.” *(Ll. 104-106)*

GER4: “[…] the search to find a cardiac sports group. That was very, very difficult and bad. Dr. O. [GP] didn't help me at all. I told him it was so difficult to find something like that [here; patient lives in a large city]. He says: Yes, yes, that's how it is. [I would have liked] someone who could help me a bit […] and so I just poked around on the internet, for hours, until I found something.”

Interviewer: “[…] some kind of counselling centre would be good […].”

GER4: “Yes.” *(Ll. 116, 384, 387-388)*

GER2: “But it's difficult to find one [heart sport group] in the area. You actually have to drive quite far.” *(L. 110)*

GER2: “Sure, that's just the topic, [...] whether heart patients could also meet and exchange ideas […] without doctors.”

Interviewer: “A kind of self-help group. [...]”

GER2: "[...] talk in private in a different way than with a doctor. [...]”

Interviewer: “There are certainly many people who have the same problems that no one knows about.”

GER2: “Right, yes. This usually remains under the radar. Nobody really knows except the GP and the hospital because they don't talk about it. [...] Yes, that would actually be appealing, to do something like that or set it up.” *(Ll. 163-165, 168-171)*

Although it was reported that it was hard to find aftercare and rehabilitation services in both rural and urban areas, one German patient reported that the range of rehabilitation facilities was comprehensive in his urban area. So, unless all the groups were overcrowded in urban areas, there were more offers in the urban area than in the rural area. There, it may be difficult to find a suitable offer that is accessible in an adequate time frame.

> **GER9**: "[…] I looked for the rehabilitation clinics that are close to me and I was actually lucky that here near [my city; large city] we have quite a lot. And then I also found a rehabilitation clinic in the neighbouring municipality, where I can even get to by bike." *(L. 92)*

> **GER2**: "Well, it [network of care] leaves a lot to be desired, especially because of fitness and everything. From that point of view, there's nothing up here [Swabian Alb, a rural region in Germany]." *(L. 151)*

While counselling or referral centres for aftercare, sport and rehabilitation services were missing especially in Germany, pharmacists and information leaflets, which patients in Jersey (JER1, JER3) received from the local stroke recovery services, could provide a source of information.

> **Interviewer**: "[…] you've had a lot of information [about your illness and further care possibilities] come through?"
>
> **JER1**: "Yeah. Stroke recovery service."
>
> **Interviewer**: "Stroke recovery sending you information […]. Ok."
>
> **JER1**: "[…] I'm going to say, […] I've got it all, but I don't really look at it, do I?" *(LI. 81-83, 86)*

> **JER3**: "Well, because they [the pharmacists] are always helpful." *(L. 156)*

3.4.2 Barriers in seeking care

Opening hours

The opening hours of GP practices were reported to have an impact on patients' experiences such as their perception of safety. In Switzerland, the extended opening hours in the form of practices opening early and additional evening consultation hours were depicted as positive.

> **CHE1**: "[…] if it's something bad, [one can get an appointment] immediately. If it is something where you can wait, you should schedule about a week's [waiting time]. [...] Then I always check after work and so far, it's always been [good]. And if it doesn't work with the normal hours, they also have evening hours. I've already been able to use them." *(L. 32)*

> **Interviewer**: "What did you actually need the GP for?"
>
> **CHE3**: "[…] actually for emergencies I would […] say. […] Yes, you could call Dr. H. [GP] around the clock. Be it in the middle of the night or over lunch." *(LI. 9-11)*

On the contrary, patients don't feel well and safely cared for, when opening hours are short or even untransparent. As GP practices are reported to be the ones to guide the patient through the health care system, which is described in the chapters on coordination and patient centeredness and are the first point of access in emergency situations (see chapter 3.5 Pathway) in most interviewed cases in Germany, scattered or untransparent opening hours don't match the patients' needs. For example, one patient (GER8) described that scattered opening hours of 8am to 12am and from 3 pm onwards are fine for trivial matters such as picking up prescriptions but are not suitable in serious situations.

> **Interviewer**: "[…] And do you find the opening hours of your family doctor appropriate?"

> **GER8**: “Yes, you know, I'm not like that, I know that I can go to the doctor from 8-12 or in the afternoon from 3 p.m., […] but I've been very lucky so far that nothing major has happened, so that when I go to my doctor now, I just pick up a prescription for my medication.” *(Ll. 124-129)*

Another patient (GER9) reported that he had changed his longstanding GP in the past because of the obscure opening hours. In this case, longitudinal and even informational continuity was at the expense of unsatisfactory opening hours.

> **GER9**: “[…] I had a family doctor, […] I was with her for a long time, […] since the 80s, I think I was with her for 35 years and then she only worked part-time. It was difficult […] to meet her or to get anything at all within a certain time frame. And then she wasn't there at all, so that was too much effort. […] I looked for someone else […].” *(L. 129)*

It is noticeable that unsatisfactory opening hours of practices were only described in Germany and positive examples for opening hours of GP practices were only reported in Switzerland. Patients in Sweden (SWE1, SWE2, SWE4) weren’t dissatisfied with the general practitioners opening hours, but often couldn’t reach the heart failure nurse due to limited phone opening hours. As a result, several Swedish patients (SWE1, SWE2, SWE4, SWE5) experienced an aggravated access to physicians and heart failure nurses. Patients from Jersey made neither positive nor negative statements regarding opening hours.

> **SWE4**: “Even if you call at seven in the morning, they may say that it is already busy and, as I don't have a direct number for her [heart failure nurse] either, I must call via the health centre. It has sometimes happened that I can't get there until the afternoon and she is gone home by then.” *(/)*

SWE1: “I tried to call them, but I was kept on hold. It was impossible to reach the health centre. […] If you want to go there, you must call at eight in the morning just to get through.” *(/)*

SWE2: “Then I call the health centre. But then it has been really hard to get through. You must get up before seven of course.” *(/)*

SWE5: "[It is] very difficult to get through to our health centre because you have to go through […] and then they wanted all the details and bank ID and all that and I couldn't do that then." *(/)*

Access route

Besides the opening hours, another modifying factor, belonging to the access category is the geographical access route. Patients in Germany and Jersey felt that a short distance to the GP or in some settings also community healthcare workers facilitated the care. Most of the patients in Germany and Jersey were satisfied with their access route.

Interviewer: “How satisfied are you with the way you can reach the GP? [Related to the] route?

GER7: “[Regarding the route] five minutes at most. […]” *(L. 92)*

Interviewer: “[…] And how satisfied are you with the way you can reach the family doctor?”

GER8: “We live 10 minutes away from the [GP] practice [by car].”

Interviewer: “And is that good for you? [Do] you think that's within reason?”

GER8: “Yes, it is very good.” *(Ll. 108-109, 112-113)*

Interviewer: “OK. And how far is it from your home to the GP?”

GER4: “Oh, two stops by underground. So, no problem.” *(LI. 359-360)*

Interviewer: “How far away is [the GP] then?”

GER9: “[…] About 200 metres.” *(LI. 95-96)*

JER3: “It took me about 15 minutes to walk. I live in [X] which is just down the road.” *(L. 14)*

Only one patient in Germany stated, that a journey to the GP of 30 minutes is too long and therefore a problem, whereby it was solved by the GP offering home visits.

Interviewer: „[…] is his [GP] practice far away from your home?”

GER6: “Yes, it's about 8 stops by tram.”

Interviewer: “Ok. So probably about half an hour? […] Is that too long?”

GER6: “Yes, it is. […] He has come to my house several times when I was feeling so bad that I couldn't go.”

Interviewer: “That is probably a relief for you if he also makes house visits, isn't it?”

GER6: “Yes.” *(LI. 89, 104-109)*

A distance to the GP as short as possible is thus very important, although it was not a problem in any of the cases surveyed. While distances to the GP were either justifiable or were overcome by home visits, distances to further care services, like heart sports groups were rather problematic. This is, against expectations both the case in urban, as well as in rural areas. Both in city 1 and in city 2, a small rural village, patients couldn’t find continuing offers in their immediate

environment. In one case in a German rural area, the attendance of sports groups or rehabilitative measures by an actually motivated patient came at the expense of the long journey of over 30 minutes.

> **GER2**: “But it's difficult to find something [like a cardiac sports group] in the area. You have to drive quite far.”
>
> **Interviewer**: “Exactly, but if there was theoretically something within 5 km. Let's say there is something opening now.”
>
> **GER2**: “I would grab it immediately. Of course, I would. […] Yes. But if I must drive half an hour. That's just too far for me.” *(LI. 110-114)*

> **Interviewer**: “OK, now you just said you were looking for a cardiac sports group. Did you find one?”
>
> **GER4**: “Yes. I found one in P. [suburb of the state capital from which the patient comes]. But that was a bit far for me, because I live here at the Olympic site, and […] that was always an hour's drive for me.” *(LI. 103-104)*

In summary, the tolerable limit for patients for commuting times seems to be 30 minutes, both for the GP and to other healthcare facilities such as rehabilitation services or heart sport groups.

Waiting time

The reports on waiting times cannot be reduced to a common denominator. Both short and long waiting times for GP and specialist appointments were reported in the participating countries. The only country without long waiting times as a reflected problem was Switzerland. Long waiting times until appointments with GPs as well as specialists are perceived by patients as aggravating factors. One patient from Germany even talked about changing the GP because of an unacceptable waiting time of two to three weeks, although apart from that he was completely satisfied with the GP.

Interviewer: “How long do you usually have to wait until you get an appointment [with the GP]?”

GER5: “[…] 14 days, three weeks already.” […]

Interviewer: “So if you now call normally and say you have the flu or […] some kind […] Then you will [get an appointment] after 14 days? […]”

GER5: “Yes, exactly. […] That's crazy. […] you consider, […] whether you shouldn't choose another doctor. [...]. I've been going there for 40 years, and I've noticed before that it is always difficult for me to get an appointment.” […]

Interviewer: "To sum it up again, nothing really bothers you except the long waiting times."

GER5: "With the long waiting times for appointments, yes." *(LI. 106, 107-116, 249-250)*

While waiting times for GP appointments do not seem to be a big problem, waiting times for specialist appointments were reported to be a problem. Long waiting times for specialist appointments were reported by patients from Sweden (SWE6) and Jersey (JER1). In Jersey, these were reported to be up to six months. As a result, a patient (JER1) reported, seeking help in emergency rooms to prevent long waiting times for specialist appointments.

Interviewer: “So what I suppose you’re alluding to is how it’s difficult to try and access healthcare sometimes? […]”

JER1: “Well, yeah. This is a prime example. I’ve got to go to a clinical investigation. It's in August.”

Interviewer: “[…] it’s about six months from now.” *(LI. 105, 108-109)*

SWE6: “It's been a long time since I've been to a doctor in T. [town in Sweden]. It's [due to] waiting times.” *(/)*

Interviewer: “Do you think, maybe sometimes it’s easy just to go to the emergency department or something like that?”

JER1: “Well, I think so. If you can call the emergency as well as [the] casualty [department], I think you can get looked at straight away.” *(L. 114)*

When patients were satisfied with the waiting time for a GP appointment, these were periods of one to three days. This was reported regardless of the country and system in Sweden, Germany, Switzerland, and Jersey. One patient from an urban area in Germany even reported, not needing an appointment to go to the GP.

GER3: “[…] If I call [the GP practice] on Tuesday, I'm sure I'll get an appointment by Friday. […] I usually get them pretty quickly and fast.” *(L. 435)*

Interviewer: “[…] in general, when you need an appointment with your family doctor, how quickly do you get one?”

GER4: “Oh, relatively quickly. Actually, I don't need an appointment. He doesn't have many patients. You just go there, wait a quarter of an hour, and then it's right away. It's not overcrowded.” *(Ll. 349-350)*

Interviewer: “And if you need an appointment [with the GP], how long is your waiting time?”

GER6: “Oh, I usually get it the next day. […] there is no problem. If I call the day before, I always get an appointment.” *(Ll. 92-93)*

Interviewer: “Are there waiting times [for an appointment with the GP] that are particularly long?”

GER7: “No! Normal. Sometimes three days, sometimes a week, maximum. […] it also depends on whether it's a vaccination appointment […] or if it is urgent, it is also on the same day […] *(LI. 97-98)*

Interviewer: “Yes ok. And how easy is it to get an appointment, so if you call now, how long does it take?” […]

GER9: “[…] actually 80% within 24 hours.” *(LI. 199, 204)*

Interviewer: “And how long does it normally take to get an appointment [with the GP]?”

CHE1: “So if it's something serious, immediately. If it's something you can wait for, you should allow a week or so.” *(LI. 31-32)*

SWE2: “It took some time, maybe not the same day, it depends on your ailment.” *(/)*

Interviewer: “So you just ring the [GPs] reception and you get an appointment? I suppose, seeing the GP seems easy for you?”

JER2: “Yeah, it’s quite easy.” *(LI. 189, 191-192)*

Timely care in emergency situations

In emergency situations, the access to emergency care was established quickly in all reported cases. Patients in Jersey, Sweden and Germany perceived access

to the hospital in less than 45 minutes as fast. Thereby, various factors played a role. Firstly, it was reflected as positive, that the GP is reachable around the clock and even comes immediately when called. In one case in Germany, the GP even brought the patient himself to the hospital. In addition, it was found to be effective and timesaving in several German cases, if the GP had already informed the emergency department about the arrival of the patient.

> **GER7**: “[…] And then […] the leg started to tickle and then the language came up. Then we called the GP, because he is located near us. He came straight away, didn't listen any further and said it was a TIA, a stroke, hung up, and in no time at all he was there. He gave me an infusion and called the ambulance and then I came to the hospital and it was a stroke. I was practically in the emergency room in the clinic in 3/4 of an hour. […] It worked like clockwork, yes. […] It was very good.” *(Ll. 20, 22)*

> **GER8**: “I […] wanted to get up and then I felt dizzy. […] And [there] was no strength left at all [in my hand]. […] Then we called my GP. He said I should come down immediately and then I went to the GP, and he took blood and did a few tests and then he said it would be better for him if I went to hospital. So, he got me a wheelchair and drove me personally to the hospital emergency room. [Before that] he called [in the hospital] and said he'd take me over.” *(L. 17, 55)*

> **Interviewer**: “But in the acute situation, when you first had the feeling of [chest] pressure, Dr. P. [GP] called the hospital for you and registered you?”
>
> **GER1**: “Yes, I was already registered then, I could walk straight in.” *(Ll. 99-100)*

SWE2: “Then I was up there for a visit and then the doctor said you shouldn't be here, but you should be in the emergency room, so they sent me straight up here [to the hospital].” *(/)*

JER3: “The attentiveness […] and the quickness of it from here [the GP practice] to the hospital. […] He [the GP] took one look at me and phoned for an ambulance.”

Interviewer: “[…] So you found that this measure was especially effective?”

JER3: “Yes. Very great service.” *(Ll. 18-20, 30)*

Secondly, in an emergency, the practice assistant established a rapid exchange of information between her and the GP, so that the GP was able to react adequately.

GER9: “[…] she [the wife] phoned the GP to ask if he could come and see me. She didn't get through to the doctor there, but to the receptionist. And she said that there was a lot going on and that she would pass it on. And then the doctor actually called her [the wife] back within a very short time. So that worked. […] I would say 5 to 10 minutes at the most.” *(Ll. 6, 8)*

Financial barriers

Financial barriers were pictured by patients who had to pay a practice fee to see a physician. This was only the case in Jersey. All interviewed patients in Jersey (JER1, JER2, JER3) reported that practice fees are a financial barrier to access health care. This led to a patient from Jersey seeking help in the emergency department to avoid costs.

Interviewer: “And do costs play a role? The expense?”

JER1: “Yes! […] every time you go to the doctor […] is on average 40 quid. Just to see the GP. And if I got to go three times in a month…”

Interviewer: “That's 120 pounds […]. And […] you don’t have to pay when you see a doctor in the hospital, do you?”

JER1: “No.“ (*Ll. 119, 122-124)*

Interviewer: “Were there any costs? Did the costs of the care play any role in the care you received?

JER2: “No cost at all.”

Interviewer: “[…] because it was free at the point in need, emergency care. It was free.”

JER2: “Everything was free.” *(Ll. 125-128)*

Interviewer: “[…] how does that affect you, the role of your GP […] when it comes to you accessing hospital care through your GP?”

JER3: “Well, obviously, because I have to pay to see the doctor here. If I could go directly, that would save money. That would be better. I’m on pension now.” *(Ll. 103-104)*

In the other countries there were no financial barriers reported.

CHE1: “No, not because of the money. Health is more important. Especially when you were at a point like I was, life or death, you don't look at the money that way. You're willing to pay a little bit more, but to live a few more years for it.” *(L. 36)*

Interviewer: “What role do costs play for you […]? So, have you ever said that you don't claim something because it was too expensive or something?”

GER5: “[…] not really, no. I [go along with everything that is suggested]. Exactly. And it is usually all paid for by the insurance company.” *(LI. 243-244, 246)*

In summary, access to different health care institutions may be affected by a lack of availability of care services as well as other barriers such as opening hours, waiting times, access routes and technical or financial hurdles. The lack of availability includes mainly physiotherapy, heart sport groups and self-help groups. In a nutshell, a missing network of care was reported especially by German patients in both rural and urban areas. Extended opening hours can create a feeling of safety, whereas short or untransparent opening hours have the opposite effect. The latter was reported in Germany in particular. Short access routes to health care providers are a facilitating factor, whereby home visits can provide alleviation. Long access routes, that exceed 30 minutes were particularly described in connection with rehabilitation offers, like heart sport groups. Long waiting times until appointments with GPs as well as specialists are perceived as aggravating factors. While waiting times for GP appointments do not seem to be a big problem, waiting times for specialist appointments were reported to be unsatisfactory in Sweden and Jersey. Satisfactory waiting times for GP appointments are one to three days. Financial barriers were pictured by patients who had to pay a practice fee to see a physician, which was only the case in Jersey. Practice fees can be a financial barrier to accessing healthcare.

Having a first contact person for situations in which patients’ health deteriorates can create security. In connection with this, quick contactability is particularly important. Patients in Jersey, Sweden and Germany perceived access to the hospital in emergency situations in less than 45 minutes as fast.

3.5 Pathway

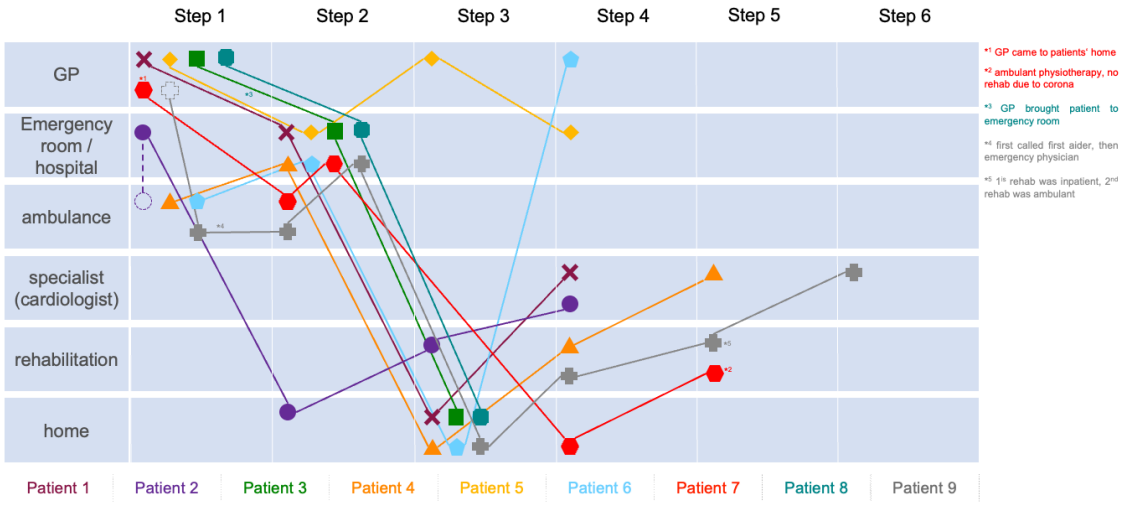

Figure 6 Patient pathway

In Germany, additional data was collected on the sequence of the patients' care stations. These pathways are plotted on a patient-by-patient basis in Figure 6. It was interesting to observe that more than half of the German patients contacted their general practitioner in an emergency, such as myocardial infarction or stroke, while none of nine patients used the emergency department as their first point of contact. Every patient who entered the health system at the GP level ended up in the emergency room or the ambulance.

3.6 Summary

Overall, the analysis of the data and the results showed, that the circumstances of the categories do not stand alone but influence each other. This is summarized in figure 7, where the interrelationships are shown.

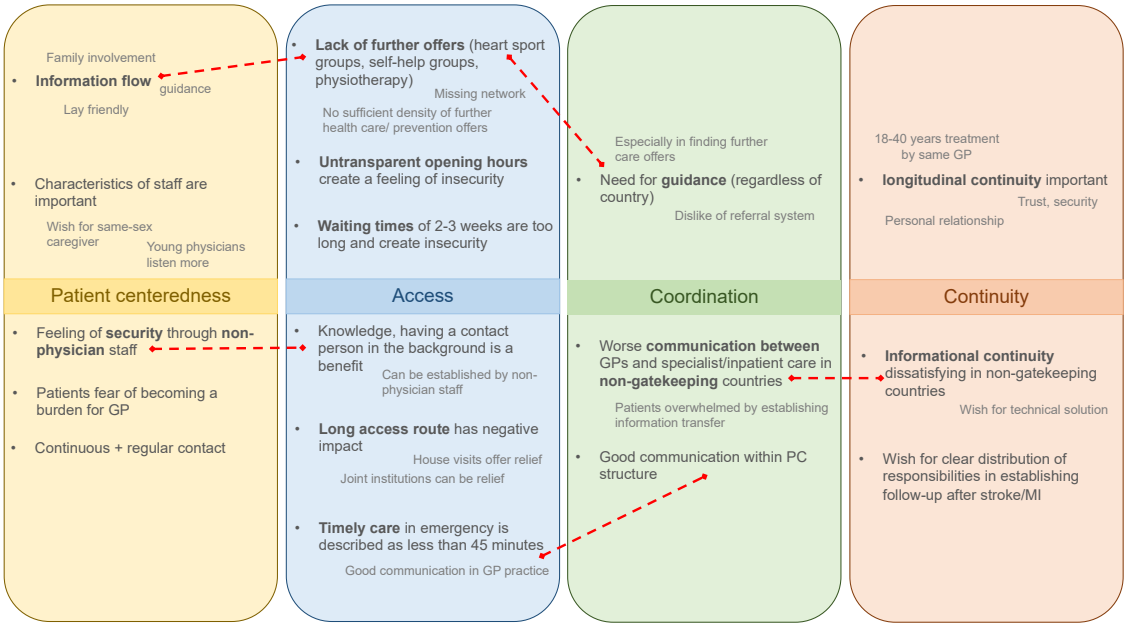

Figure 7 Summary of the findings

In total, it has become apparent, that talking and interpersonal medicine has a high priority for patients. Picking up the patient at his or her level of knowledge and explaining the disease pattern, risk factors and further procedures in a comprehensible and lay friendly manner conveys safety to patients with burdensome illnesses. The importance of this becomes clear above all when one considers that these characteristics of good care were raised by patients on the one hand transnational and on the other hand without explicitly asking for it. This means, that these features of patient centredness were strongly embedded in patients' memories. Although the importance of patient centred care and talking medicine is reflected in the chapter on patient centeredness, interpersonal skills even appear in several other chapters, that actually deal with structural conditions. It has thus been shown that human aspects such as sympathy are often more important than theoretically perfect structural conditions, such as long-standing continuity.

The further questions on access, coordination, and continuity led to other important points: patients suffer from a comprehensive lack of further preventive and supportive measures. The lack of these is reflected in different categories, such as in terms of access as well as in patient centeredness and coordination. Furthermore, untransparent opening hours as well as waiting times of two to three weeks and a long access route of 30 minutes can create insecurity among patients. In general, patients benefit from the knowledge of having a contact person in the background and longitudinal continuity, i.e. a long-lasting relationship between patient and provider. This creates trust on the one hand, but also better informational continuity on the other. On the impact of gatekeeping systems, it was found that they can improve informational continuity in so far that the GP has all the information about the care provided by other professionals, which was described as important for patients. Nevertheless, the poor informational continuity between specialists and GPs cannot only be attributed to a missing gatekeeping system, as the transmission of information in Switzerland was not described as poorly as in Germany, although both are non-gatekeeping countries. The weak transfer of information between specialists and GPs was especially unsatisfactory in Germany.

4 Discussion

4.1 Discussion of the results

Altogether the results allow multiple conclusions. Although the findings found in this thesis arose from an international comparison, the recommendations derived from it and described in the following parts refer primarily to the German health care system as a reference system. The recommendations are thus described from a German perspective.

4.1.1 Important elements of patient-centeredness

Maintaining the flow of information between patient and doctor

Patients from Germany, Sweden and Switzerland described the guaranteed flow of information between them and their doctor as very important. This included lay-friendly explanations as well as involvement in the sense of informing them and their relatives about treatment options, the patients' state of health, and preventive measures. It applies to all stages of the disease and treatment, ranging from acute to long-term treatment options. It also includes being informed about the personal condition, past mistakes of the patient in relation to health promoting behaviour, and lifestyle changes. All in all, patients indicated the feeling of benefiting from good health education. The importance of the topic was addressed through negative and positive examples in Switzerland, Germany, and Sweden, with no clear pattern emerging in terms of the patients' backgrounds. The presence or absence of information flow can therefore not be linked to certain structural features. The fact, that the topic has not been reported negatively or positively in Jersey does not necessarily mean that it is not important to patients in this area, since there was no specific question on this in the interview guideline. It can therefore be assumed that patient involvement including good and lay-friendly communication, is a relevant factor influencing the patients' experience, that is not depending on the national cultural background. This is underlined by the existing literature. A review from 2000 which summarized the empirical literature on patient-centeredness pointed out, that poor provision of information and insufficient education can lead to dissatisfaction with care among patients.[65] Also from the point of view of American doctors who were interviewed, patient-

centered care is most influenced by good communication between physicians and patients. In the qualitative analysis by Schuttner et. al.[66] from 2022, primary care physicians described good communication that contributes to patient-centered care as follows: Physicians should explain the circumstances in a manner adapted to the patient needs. Conversations should include family members under certain circumstances, for example end-of-life-care.[66] Both the lay-friendly nature of medical explanations and the involvement of family members are consistent with our findings.

One approach to optimise communication and patient education by doctors, and thus overall patient-centredness, would be the presence of well-trained staff. A randomized controlled trial from Germany compared communication skills of physicians before and after a structured communication skills training against an untrained group of comparable doctors. They were able to demonstrate a significant enhancement of communication skills in the group of physicians, who received an intervention in form of skills training.[67] Since the training also increased the degree of patient-centeredness[67], introducing compulsory training in communication skills among doctors could be a way to improve the quality of health care.

Time constraints affect patients' sense of safety and experience.

Our interviewed patients from different countries described, that they felt the workforce shortage directly e.g., as a lack of time especially among GPs or indirectly by excusing their unfulfilled needs by the workload of GPs. This was the case both in outpatient and inpatient settings and has been reported mainly in Germany and Jersey. Patients from Jersey talked about GPs being in a time rush, while German patients reported insufficient opening hours that were unable to meet the demand for care. It was felt that the opening hours were not sufficient to ensure care in severe cases. Especially in Switzerland the shortage of workforce does not seem to be as noticeable. Swiss patients gushed about a feeling of security because of extended GPs' opening hours and the possibility to reach the GP around the clock. This could be due to the fact that the percentage of GPs among all physicians in Switzerland (27%) is higher than in Germany (17%).[2] According to the outpatient capacity planning ("Bedarfsplanung") of the

German National Asscociation of Statutory Health Insurance Physicians ("Kassenärztliche Bundesvereinigung") almost 50% of 984 regions in Germany were manifestly or threateningly undersupplied with GPs in 2022.[68, 69] Our findings that time for attention and communication between health personnel and patients is essential for patients is consistent with the existing literature. An international study including 33 countries examined, how patients' experiences relate to GPs workload and the consultation length. It was discovered that patients of GPs with a higher average working time per week, and thus probably more extended opening hours, were more satisfied, regarding continuity and comprehensiveness of care.[70] Nevertheless, the literature raises questions in the light of our findings. While Swiss patients in our study tended to be more satisfied with their GPs' opening hours, German patients complained about them, despite the fact that average working hours per week was higher in Germany (49,6) than in Switzerland (46,5).[70] As a result, we cannot completely underline the conclusion of the study that patients of GPs with a higher working time per week are more satisfied. In other respects, however, our results are in line with the findings of the international study of Schäfer et. al.[70]. It also examined how patients' experiences are linked to the consultation length. The experiences concerning comprehensive care were more positive when the consultation duration with the GP was longer.[70] In Germany and Jersey, where patients from our study expressed the feeling that medical staff and especially GPs were under time pressure, the study of Schäfer et. al.[70] described the average consultation time (10,6 and 11,2 minutes) as significantly shorter than in Switzerland (19,5 minutes).[70] Swedish patients in our study didn't complain about the feeling of time pressure when meeting their GP. Sweden was the country with the longest average consultation time (23,9 minutes)[70], which fits well with our results.

It can be concluded that several measures could be taken in Germany. Firstly, it seems that the share of GPs among all physicians in Germany (17%) should be increased to a similar percentage as in Switzerland (27%)[2] to counter the undersupply of GPs.[68, 69] Against the background of our results in combination with those of Schäfer et. al.[70], it appears that increased time capacities of GPs due to a higher proportion of GPs among all physicians could rise patient

satisfaction. Nevertheless, it cannot be the sole solution to increase the share of GPs in order to release time pressure. Sweden, the country with the longest average consultation time (23,9 minutes)[70] has an even smaller proportion of GPs of 16% than Germany (17%).[2]

Consequently, increasing the proportion of GPs will not be the only approach to a solution. Secondly, already practicing, and prospective GPs could be trained to extend consultation durations and make them more patient-centered. Although Maatouk-Bürmann et. al.[67] were unable to demonstrate significantly higher physician-patient consultation duration after communication training in a group of physicians, they could show, that the communication can get more patient-centered very well.[67] They were able to prove, that a communication skills training of 20 hours was able to increase the degree of patient-centeredness in consultations significantly.[67] It may not be necessary to increase the length of the consultation anyway if patient-centeredness can be improved without an extension.

Non-physician staff as a possible solution for several problems

While the previous chapter was primarily concerned with the expansion and training of physicians and especially GPs, there are several indicators that suggest that non-physician staff is essential. Non-physician staff are proven to be important, relieving time constraints for physicians[71], serving as additional low-threshold contact persons[72], providing guidance and counselling[72], and enhancing a holistic approach of health care[71, 72]. Next to relieving time constraint of doctors, according to patients' experiences in our study, they are also often additional, very important confidants. In countries where physician assistants and advanced practice nurses (APN)/ nurse practitioners (NP) are already common (Switzerland, Jersey, Sweden), patients in our study reported having a good relationship and feeling safe having someone to contact in the background. In Germany, where non-physician staff as contact persons for patients are not that common, patients reported the fear of being a burden to their GPs if they brought up private problems. Nevertheless, one German patient reported to have the possibility to talk with the practice assistant about everything. Either way, offering

the possibility of a low-threshold contact person within GP practices could be a reason for establishing more non-physician staff within practices.

Another argument for the implementation of non-physician staff, who does not necessarily have to be tied to the practices, is the patients' desire for guidance and counselling in the area of other care services. As described before, patients regardless of their country of origin seek for guidance, especially when it comes to information about preventive services, sport group offers and rehabilitation services. Since physicians in Germany have time issues in the sense of overwork and short consultation times[70], non-physician staff could satisfy or at least alleviate the patients' need for information and guidance. As our results from Jersey, Sweden and Germany showed that the necessary guidance or advisory functions could not be offered to the extent required by patients, it could be a complementary solution to establish navigators. The need was mainly related to additional support and prevention. The German Managed Care Association (BMC) deals with this problem and idea of this needed navigator function, as so-called "Gesundheitslotsen" which will be translated as health navigators in the following. The need for this profession is described in their position paper.[45] They clearly suggest the establishment of such health navigators for the German setting and propose the following based on their analysis of the existing experience: health navigators are especially needed in complex care situations, such as those of the participants in our study. These health navigators act across sectors and function as a networking and guiding structure. Their tasks are informing patients about existing care offers, assisting in the organisation of these and designing individually coordinated care processes.[45] Proposals for the exact procedure for establishing and strengthening these health navigators in Germany will follow in chapter 4.2.3..

APNs, however, are able to take medical decisions, take on medical tasks and manage patient cases thanks to their extended training. They are also capable to plan and coordinate cases and are a possible first contact point for patients.[45, 73, 74] In a Swiss pilot study, in which APNs and GPs were interviewed, APNs were able to offer the just described and so often desired advisory, planning and managerial function.[72] This is interesting to observe, since our Swiss patients

didn’t complain about the need for guidance to the same extent as our patients from Jersey, Germany, and Sweden. It can therefore be assumed that patients’ experiences and the resulting wishes in this case are linked to structural conditions, namely the presence of non-physician staff, in this case APNs. It can still be discussed whether the above-described health navigators should act independently in a separate institution or be linked to GP practices. As the patients in our study had difficulties to navigate, it might be a solution to link the “health navigators” to existing GP practices.

The evidence from two Swiss qualitative studies examining the experiences of patients, APNs and GPs with this newly established profession point to several strengths. Patients indicated that APNs had more time for consultations compared to GPs[71], which was verified by Swiss APNs.[72] Besides this, APNs and patients mentioned, that APNs were more able to do home visits than GPs, which in turn brings the possibility to evaluate the patient in his or her social environment.[71] Nurse practitioners reported having more (time) capacities to coordinate other health care and social services and empower patients by explaining things[72], than primary care physicians, who often lack the capacity for such tasks. As a result, patients felt more likely to be seen holistically and in relation to their entire private environment, which, combined with a lower inhibition threshold, made them more likely to address private problems[72] in relation to their health with an APN.[71, 72] All these components seem to be important in building a lasting relationship between professional and patient and in facilitating better patient management after an acute illness or in chronic conditions. Since counselling on prevention and rehabilitation programs is what patients in our study asked for, the establishment of APNs in German GP practices seems to be a logical step. However, APNs are not the only professional group, that can provide counselling. The previously described health navigators are also able to offer this.[45]

By relieving GPs, who could devote more time to their original medical tasks[72], APNs could have an additional positive effect in counteracting the lack of general practitioners in Germany. Between 2000 and 2017, the OECD recorded a 15% decrease in the number of general practitioners in Germany. In addition, the

OECD study showed, many physicians from different OECD countries, including Germany are busy with tasks for which they are actually overqualified, which aggravates the lack of GPs even more.[75] The Swiss study of GPs' and APNs' experiences with the new concept, in which family physicians reported that APNs lightened their workload, can underline the statement. Furthermore, Swiss APNs stated to devote more time to the patient than GPs[72], which was confirmed by the Swiss patients.[71] Patients were open to APNs taking over certain tasks from GPs.[71] These advantages would meet the requirements regarding patient centeredness set by patients in our study. The Federal Association of Nursing Management (Bundesverband Pflegemanagement) and the German APN & ANP Network (Deutsches Netzwerk APN & ANP) state the same in their position paper and recommend the establishment of APNs as an important interface to the physician profession with positive effects on quality of life and satisfaction with health care.[76]

In summary, the degree of patient-centeredness is influenced by a variety of factors, including the **flow of information**[65, 66], the **provision of time capacities**[68-70], and the establishment of alternative, **non-physician groups**.[45, 71, 72, 75, 77]

Guaranteed flow of information includes **lay-friendly** explanations and **informing** and **educating** patients and their relatives about treatment options and preventive, health promoting measures.[65, 66] This seems to be important for patients regardless of the country.

As it has been shown that physicians' communication skills and the degree of patient centeredness can be enhanced through **communication training**, one approach to optimise patient centeredness could be to train physicians.[67]

If there is a **lack of workforce**, patients can perceive this. This can manifest itself in German hospital physicians not speaking to patients, as well as GPs insufficient opening hours in Germany. The degree of comprehensive care and patient satisfaction was shown to be higher when GP consultation duration is longer.[70] Since a lot of regions were manifestly or threateningly undersupplied with GPs in 2022, it seems that the share of GPs among all physicians should

be increased in Germany.[68, 69] Increased time of GPs due to a higher proportion of GPs among all physicians could rise patient satisfaction.[70]

In synopsis, **non-physician staff** could be an approach to solve the lack of GPs[71, 75], strengthen holistic approaches of health care[71, 72], meet the patients' need for guidance[72] and satisfy the patients' wish for a low-threshold contact person.[72] Two different, non-physician groups (**APNs and health navigators**) were presented to establish the described advantages: **APNs** within GP practices could serve as an easy, highly trusted contact person.[72] **Health navigators**, acting independent of GP practices in larger institutions[45], could be suitable to assist the patient with advice, guidance, and information.[45, 77] Both can play a role, especially in view of the increasing shortage of general practicioners.[75]

4.1.2 The two dimensions of continuity: Informational and longitudinal continuity

Informational continuity – Establishing the transfer of information between different facilities and providers

Established informational continuity between different health care providers can create trust and a feeling of security and good, holistic care, especially among chronically ill patients, as stated in a review, which dealt with factors influencing patients perceptions on continuity of care.[78] In our project it was observed that well-implemented informational continuity has a positive impact on patient's experiences and by contrast, German patients reported on the deficiency of informational continuity: Four out of ten German patients reported that their GP receives reports about hospitalization or the specialist care and medication strategy only via the patient himself, which shows the fragmentation of informational continuity. Informational continuity seems to be perceived more positively in the other countries. None of our patients from Jersey or Switzerland stated problems, that were reported in Germany. In Sweden, only one patient reported that her GP had not received a medical report from the specialist, but then informed himself extensively and the patient did not have to take over the flow of information. A possible explanation for better communication and

exchange of information between different sectors in Sweden and insufficient information flow between GPs and specialists in Germany could be the presence respectively absence of cross-institutional electronic patient records. The “Nationell patientöversikt” (NPÖ), the Swedish EHR has already been introduced in 2009 in Sweden.[4] In Switzerland, health information about patients can be collected in an electronic patient file, called “Elektronisches Patientendossier (EPD)”. The underlying law came into force 2017, the introduction of the Swiss EHR was planned for 2020.[5] As our Swiss interviews took place at the end of 2019, it is not conclusively clear whether the implementation really had a positive impact on the perceived informational continuity. It certainly plays a role that Sweden and Switzerland are two of four countries, playing a pioneering role in the development of national electronic health records (NEHR) in Europe.[8] The same research study that showed this, could also demonstrate that Germany was amongst the worst in the ranking.[8] In Sweden, health care providers of the different sectors can access patient data and relevant diagnostic results through the NPÖ, a national patient overview with the patient’s consent.[7] Shared electronic health records were able to deliver precisely the benefits that were criticized in Germany in our study. A Swedish qualitative study from 2013 on patients’ and caregivers’ experiences with this system revealed the following advantages: Health professionals perceived the interprofessional communication as more guaranteed, because referrals and discharge letters didn’t get lost. They were also of the opinion that patients received more comprehensive care.[6]

Germany seems to be unable to keep up with especially Sweden and possibly also Switzerland in terms of establishing the national electronic health/patient record and thus informational continuity. This has been shown both in our patient surveys and in the literature described above. One German patient of our study literally stated the necessity of digital information exchange systems in present times. Correspondingly, a contemporary possibility to improve communication between institutions and informational continuity in Germany would be the introduction of a NEHR as it’s known from other countries. The infrastructure for a better cooperation and communication between all physicians and health care

workers involved in the patient's care process would be created. Patients could thus benefit from better informational continuity.[78]

Longitudinal / interpersonal continuity

The results of our study give the impression, that longitudinal continuity, also known as interpersonal continuity, which means seeing the same doctor over a longer time can create a feeling of security and trust for patients. In this context, the following circumstances and preferences were described independent of the country of origin of the patients in our study: On the one hand, the described positive effects of established longitudinal continuity can be due to informational continuity which automatically goes hand in hand with longitudinal continuity. On the other hand, the safety created through longitudinal continuity can also be the result of interpersonal factors between doctors, especially GPs and patients. In this context, there was some mention of a family atmosphere. This seems to be an important factor in creating a long-lasting patient-physician-relationship and thus longitudinal continuity. Patients also seem to need some time to get to know their GP and his or her skills in order to build trust. Nine patients from all participating countries described the above-mentioned factors as key-factors. When it comes to joint practices, a minority of two patients from Germany was partly indifferent to which doctor they saw. This was true for one patient, as long as the GP was within the practice. Another patient made sure to have his favourite doctor for important matters. However, the aforementioned differences do not allow any conclusions as to when which situation applies. The only patient, who came from Sweden and reported to be indifferent to a change of GP, stated that this is only true if the GP takes the time to get to know the patient, which creates trust and if there is informational continuity. This was also confirmed by health professionals in an qualitative study from 2022.[79] Two German patients in our study explained that they would give up longitudinal continuity and change their GP if they did not trust and like the GP. It can be deduced that longitudinal continuity is a very important factor for patients but is not enough on its own. Patients are therefore often interested in trust, a familiar atmosphere and sympathy, which often go hand in hand with a long-term relationship but are not necessarily solely dependent on it. We found that a long-term patient-physician-

relationship over years or even decades can create trust, security, and a familiar atmosphere. In cases in Germany where this has been reported, the duration of the relationship lasted between twelve and 40 years. The importance of the same factors has already been described in the past. A systematic literature review found that interpersonal continuity is accompanied by increased patient satisfaction. It has also been confirmed, that over the years of such a relationship, trust, satisfaction, and security can arise and strengthen.[78] Beyond that, Swedish professionals reported in a qualitative study that early and immediate care in emergency situations is more likely to be provided, if the relationship was built over years. In this context it was mentioned that non-verbal communication is essential to ensure adequate care even if the patient can't put into words what he is suffering from.[79] Building a long-lasting relationship is not only about medical issues but also about seeing the patient holistically in his or her private environment and knowing the living circumstances. This was also reported by health professionals in the same study.[79] On the other hand, the wish for interpersonal continuity cannot always be generalized. The review emphasized that different patient groups may favour different features of their care. Some patients might prefer quick access in the sense of less waiting time and may accept seeing different physicians. Other patients in contrast would accept a longer waiting time in order to always see the same doctor. The following patient groups were mentioned, among others, to prefer longitudinal continuity possibly at the expense of a shorter waiting time: critically ill, chronically ill, elderly and patients in emergency situations.[78] This is in line with the results of the group interviewed in our study. The circumstances that have just been described, play a role, particularly in view of the fact that there is a trend from solo practices to joint practices in Germany.[78, 80] Future GPs or practice owners have to deal with the upcoming discord, that patients may prefer having the same physician, which may not always be possible in joint practices or PVZs. In this context, it is also important to call to mind, that as so often, every patient is different and so are the needs. In order to accomplish patient-centred care, patients have to be asked, what their priorities are.

In summary, especially chronically and seriously ill patients and elderly value **interpersonal** but also **informational continuity**. Regarding this, our study and the literature are in agreement.[78] Both informational and interpersonal continuity can be associated with higher patient satisfaction, the feeling of security and trust and better care.[78] Measures should be taken in the future in order to achieve informational and interpersonal continuity, especially for this particular patient group.

In Germany, the introduction of a **digital patient file** could contribute to the improvement of informational continuity[6], which was described as deficient by patients in our study.

Measures to build **trust** and **security** by preserving **interpersonal continuity**[78, 79] for this particular group[78] should be in focus, even if the trend is towards joint practices and primary health care centers.[80] This could be for example the allocation of patients to a main contact person within the practice or center. Depending on the severity of the situation, this or an alternative person could then be contacted, which was also reported by patients in our study.[78]

4.1.3 Organization, management, and guidance: essentials of good care

Good care coordination is especially essential for chronically ill or multimorbid patients.[46, 81] This also emerged from our study. While interviewing patients, two main issues arose in the thematic complex of coordination. On the one hand, care coordination is about organisation and management of care. On the other hand, it is about guidance and advisory functions. In Germany, the advisory functions were primarily described to be concerned with planning of rehabilitation, following programs such as heart sport groups and specialist appointments. The difference between organization and guidance and advisory functions in the context of coordination can be explained well using the topic of rehabilitation. Often, the organisation of a rehabilitation program in Germany worked well, as it was organized by the hospital. Nevertheless, patients in Germany reported that the advice regarding rehabilitation, i.e. which facility would be suitable for the patient, was inadequate or non-existent. The same was the case with heart sport groups.

Patients in Germany felt lost when they had to organize them by themselves. The need for more guidance was also described in chapter 4.2.1.

The fact, that this part of coordination, namely guidance and advice seem to be partially inadequate, is coherent with the existing literature. The need for better coordination in form of guidance through the health care system was also stated by the BMC (Federal Association Managed Care) in Germany.[45] In this context, the health kiosks and health pilots currently under political discussion appear to offer a reasonable option. In these, patients can receive the information they need about existing offers. The BMC states in its position paper, that health pilots are mainly needed where complex health care situations occur. This is the case for geriatric, oncological, cardiological and psychiatric-neurological patients.[45] As the patients from our study also belong to this group, it can be stated once again, that patients can describe their care situation very well. The BMC has also looked at how health pilots can be further established: the founding of a BMC “health pilots” workgroup in 2020[45] was a first step towards linking existing pilot projects. This led to an evaluation of 38 existing projects in Germany, which resulted in the elaboration of the framework conditions and key points for the further establishment of these health pilots. The areas of responsibility of the pilots have been defined: they should provide information about existing offers, coordinate measures, link different health care providers, create individual health care plans, and regularly monitor the implementation of these.[45] This should be realized independently of other health care institutions and should be localized to the patient’s place of residence.[45] Furthermore, the BMC suggests a prescription of the health pilot service through GPs, specialists, and hospitals. Nonetheless, health insurance companies should be enabled to identify patients with complex care conditions and recommend health pilot services.[45] Regarding the education for health pilots, the BMC has already developed a qualification schedule based on the existing curricula for case and care management.[45] Stegmeier et. al.[77] described the required competences for practicing the pilotage profession as follows: social and organizational skills are just as important as a comprehensive knowledge of disciplines and sectors and the competence to grasp and solve complicated, cross-sector situations. To secure the required competencies to

meet the needs of each patient, Stegmeier et. al.[77] suggest, that these pilots should be specialized in the particular requirements of a patient group. This specialization can be understood as building on the respective basic training. Candidates for the pilot profession can come from a wide range of professions: Therapists, nurses, doctors, social pedagogues or social workers can become pilots through additional training.[77] In summary, the suggested plan for the regular introduction of health pilots across Germany[45, 77], and not just as part of pilot projects, fits perfectly with the needs of the patients in our study.

Care coordination between different levels of care seems to be a problem in several OECD countries. This was also outlined in a 2020 OECD report.[75] Surveys of patients in this study have shown that coordination between GPs, specialists and hospitals are deficient. It is remarkable, that this was reported by only 29% of the German patients, while the share was way higher in UK, Switzerland and Sweden (38%, 43%, 51%).[75] Apparently, a large part of this poor coordination is due to bad communication between GPs and specialists[75], which was also described in chapter 4.2.2 of our study. Patients from Germany and Sweden mentioned that their GP didn't receive records from specialists or hospitals. In Jersey, patients described this interprofessional communication as sufficient. A Swedish patient explained that the situation is difficult when different doctors make different statements. As poor care coordination may lead to lower care quality[81], it is of great interest to improve this. The approach to improve informational continuity through digitalized patient files was described in chapter 4.2.2. However, this should not be the only approach to improve coordination. In addition, coordination should be enhanced by the establishment or strengthening of core coordinators.

Patients expect their GP to act as a core coordinator.

The interface between the two areas of the coordination topic described above appears to be the role of the core coordinator. When it came to a core coordinator in Germany, the patients' statements varied. Some patients stated that their GP takes on the role of a core coordinator. It was mentioned that the GP is the first one to ask for help, takes care of the big picture, helps to organize matters such as nursing home care and recommends specialists. In summary, it was described

as positive, when the GP took on the role of a core coordinator. On the other hand, some German patients reported, not having someone who guides them through the system or recommends specialists. Patients' experiences therefore differed significantly. The results cannot be linked to special structural characteristics. This could be subject of future research. In Sweden and Jersey, similar reports were obtained. A Swedish patient felt lost and indicated that it would be positive to be able to rely on someone who leads, has new ideas for further treatment possibilities and suggests what the next steps are. Another Swedish patient talked about the positive experience, when he grew the feeling that the GP had an eye on him and arranged check-ups at regular intervals. In Jersey, none of the patients had someone to rely on for coordination and guidance. All patients in Jersey described that they and their partner are responsible for finding their way through the health care system. The existence, respectively the absence of a core coordinator seems to have a good, respectively bad influence on patients, regardless of the country of origin. This is coherent to the existing literature. An Australian patient-reported outcome study examined how pancreatic cancer patients' experiences and outcomes were influenced by the degree of coordination of care. This study could demonstrate that better coordination, more precisely better communication, and navigation were affiliated with improved quality of life and better outcomes in physical, emotional, and functional well-being. Furthermore, patients with better evaluation of communication and navigation were less likely to be anxious or depressed.[82]
The need for achieving better coordination by strengthening the role of a core coordinator can be derived from the partially poor coordination outcomes reported both in our study and in the OECD report.[75] The patients' expectation of the GP as a core coordinator can be deduced from various reported factors and observations. Apparently, trust in the GP's competence and diagnostic skills are very important for patients. The enormous confidence placed in GPs can be deduced from the fact that patients in Germany repeatedly reported that trust in relation to the GP plays an important role for them. For example, they described that all medical matters are handled by the GP or that the same is chosen carefully and due to confidence in the GPs' skills. In addition, some patients

described the GP as the person who guides them through the system. Furthermore, the results showed that most of the interviewed patients consulted their GP even in an emergency, like myocardial infarction and stroke, instead of presenting themselves in an emergency department. This once again illustrates the enormous trust placed in the family doctor and the patients' desire to be coordinated by the GP. For these reasons, the GP may be a suitable person to act as a core coordinator. To offer patients a point of contact and the feeling of well-coordinated and guided care, strengthening the GP as a core coordinator seems to be important, especially for chronically ill, seriously ill or multimorbid patients.

This background raises the question of whether it is easier for GPs to act as core coordinators if a gatekeeping system is in place. An interesting finding of our study was that the presence of gatekeeping in healthcare systems does not necessarily lead to better guidance or coordination through the healthcare system. Patients from different countries expressed a need for more guidance and coordination, regardless of the presence or absence of gatekeeping. Patients from Jersey with a gatekeeping system[5] as well as patients from Germany, Sweden and Switzerland, as partly non-gatekeeping countries[5, 83] expressed the feeling of being lost and desiring a core coordinator. In Switzerland and Germany there is partial gatekeeping, as patients can enter into so-called family doctor contracts.[5, 83] As the participation in such contracts was not surveyed in this study, patients' experiences cannot be linked to this structural characteristic. The impression, that the existence of gatekeeping has no influence on patients' experience of desiring a core coordinator is strengthened by the existing literature. A literature review of the universities of Hamburg and Göttingen examined the question, if GPs central qualities including good coordination of care and patients' experiences, are influenced by the presence respectively absence of gatekeeping.[83] The review found out that the degree of established coordination in the sense of a GP acting as a core coordinator is not dependant on the existence of a gatekeeping system.[83] Training in the area of coordination of care would presumably improve the function of GPs as core coordinators, which was also stated by some GPs themselves. Nevertheless it could be shown,

that both GPs and patients, who came from Germany, among other countries favour a gatekeeping system, in order to improve coordination.[83]

In the previous section, both the introduction of health pilots and the strengthening of GPs as core coordinators were discussed. This must not be seen as contradictory. Both roles are meaningful and differ to a certain extent. While GPs as core coordinators know their patients over several years and thus enjoy the trust placed in them[78, 83], health pilots may know more about several, in some circumstances complicated and ramified supply structures and offers, GPs may not even know.[45] In a nutshell, the GP can assume a control function, while the health pilot is more a source of information.[45, 83]

Summary: The overall impression is that patients mainly need help in the form of **advice** and often not in the form of organization of care itself. **Health kiosks** could provide a remedy, especially regarding counselling towards rehabilitation e.g. sport groups and providing a point of easy contact.[45] Nevertheless, a **core coordinator** for example the GP, who knows the patient and can guide him or her through the system can have a positive impact on the patients' experience.[82, 83]

Pilots would primarily have an advisory, informative, and consultative function.[45, 77] In contrast, GPs as core coordinators and trusted persons would act as a pivotal point, taking care of the big picture, dealing with medical issues, functioning as a first point of contact, and having both medical as well as private background information. In this context, interpersonal continuity also plays a significant role.[78, 83]

4.1.4 Factors that appear to influence access to health services

Access to cardiac groups – central point of concern in Germany

It was not only counselling and information about further care offers that patients described as deficient. Patients, especially from Germany, also miss concrete offers. They mentioned rehabilitation offers and cardiac (sport) groups in particular. One patient from Germany reported that she was disappointed, because no one from social service came to see her in hospital, although it was announced beforehand. She was then told that rehabilitation after hospital won't

work. Two other German patients described the search for a heart sport group as difficult and unsatisfactory. Surprisingly, this was the case in rural and urban areas in Germany. First of all, these reports are consistent with the existing literature. For example, the position paper on outpatient cardiac groups of the German Society of Cardiology (DGK) reports that there is a manifest lack of such groups in Germany.[84] This is a considerable problem, as cardiac groups should be an integral part of phase III (WHO) treatment after cardiovascular events. According to this phase classification, which was described by the World Health Organization in 1993, the measures should be lifelong and close to home.[85] There is also a "should" recommendation for the participation in cardiac groups in the German national care guideline for chronic CHD (coronary heart disease) from 2022 for outpatient cardiac groups.[86] The recommendations thus clearly contradict the prevailing reality in Germany, which was also reported by German patients in our study. This is why there is a need for action. The lack of cardiac groups in Germany is probably mainly due to the current valid obligation to have cardiac sports groups supervised by a doctor. However, since there is a shortage of doctors in this field, fewer cardiac sports groups could be offered so far.[84] Both the DGK[84] and the German Society for Prevention and Rehabilitation of Cardiovascular Diseases (DGPR)[87] are in favor of changing this regulation. They advocate the division of patients into risk groups in the future. Depending on the risk of the respective group, a doctor would then no longer have to be on site to look after the cardiac sports group if the risk is low. Low-risk groups would then only be supervised by a trained group leader.[84, 87] The lack of cardiac sports groups, which are so important and also strongly recommended by experts[85], could thus be counteracted. In this area, the solution approach of non-physician staff, which has already been described elsewhere, comes into play. It is thus also shown in this example that non-physician staff can relieve physicians in certain areas.

Moreover, the international comparison could show, that the supply by heart groups was a problem in Germany in particular. The impression gained from our study that Germany has a major problem in the provision of rehabilitation programs such as cardiac sport groups can be confirmed by the literature. A

cross-sectional study from 2019 showed that Germany's unmet need for cardiac rehabilitation services was significantly higher than the one in Switzerland and Sweden. The same study revealed that the unmet need in Germany was among the highest of the European countries surveyed.[88]

Geographical aspects

Patients from Germany and Jersey reported that having a short access route to health care offers is a relief. Most of the patients in Germany and one patient from Jersey stated, that an access route of under ten to 15 minutes is acceptable to them. Only one patient from Germany stated that an access route of 30 minutes was a burden, whereby the GP offered home visits as a facilitation. The cut-off point seems to be 30 minutes for journeys to health care offers, both GP and other services such as sport groups. Although nothing was reported in Sweden and Switzerland in this regard, the acceptable times to access healthcare services appear to be equal regardless of the patient's country of origin. This assumption can be made as neither negative nor positive experiences were reported in Sweden and Switzerland.

In Germany, the access route to the GP does not seem to be a problem in most cases. This was also shown in the "Deutschlandatlas" from 2019, which dealt with living conditions in Germany. It could be shown, that 87% of the German population could reach a GP within five minutes, 11% within five to ten minutes by car.[89] Satisfactory distance to a health care service does not apply to access to sport groups or similar. There were several reports of travel times of over 30 or even 60 minutes in Germany, which was considered as too long for patients. This was the case no matter if the patient lived in an urban or rural area of Germany. The problem of cardiac group availability described above is mirrored in the long distances that have to be traveled to reach one. This should also ease a bit in the future with the solution approach described above.[84, 87] Above that, health care centers, so called "Primärversorgungszentren" (PVZ) could at least save journeys by having several providers under one roof. In contrast to MVZs, it is characteristic for PVZs to combine not only physician health services but also services from other providers under one roof.[90] This cross-professional health care could also include heart sport groups or other rehabilitation offers.

Appointments with physicians – Waiting times affect patients enormously

Regarding waiting times for appointments with physicians, a distinction is made between GP and specialist appointments in the following.

In all participating countries, waiting times for appointments with GPs were not an issue most of the time. In particular, the majority of German patients in our study reported, being satisfied with waiting times for GP appointments, which ranged between zero to three days. Although waiting times for GP appointments did not pose a problem in Germany, one patient narrated waiting times for a GP appointment of two to three weeks. As a result, he thought about changing the GP, as he felt affected by it. This was an exception and was only mentioned here to symbolize that longitudinal continuity can come at the expense of waiting times. Excessively long waiting times therefore appear to play an important role. It can be concluded, that waiting times for GPs in Germany are in general not a big problem, which matches the existing literature. The OECD report on waiting times in an European comparison from 2020 described, that the risk of not getting a reply from the GP on the same day was particularly low in Germany.[91] But when the waiting time really does get longer, patients seem to feel badly affected and may, as in the case of patient GER5, be at the expense of longitudinal continuity. Waiting times can furthermore play an important role when it comes to unmet health care needs. The OECD has also investigated this and found that waiting times are the main reason for unmet health care needs in European countries and also in Germany. The proportion of unmet care needs due to waiting times was significantly higher in Sweden and the UK, at over 90% each, but the proportion was also almost 50% in Germany.[91] To bring this back to the point, it can be said that although waiting times for GP appointments are not too much of a problem in Germany, this should never be left out of sight due to its enormous impact on access to health care services.

While the influence of waiting times on access applies across countries, the following was reported exclusively in Sweden. Three out of seven Swedish patients stated they had difficulties in reaching their health care center and thus had worse access to their physician. That in turn is in perfect agreement with the existing literature. The 2020 OECD study demonstrated that the probability of

receiving an answer from the medical practice within the same day was way lower in Sweden than in Germany or Switzerland. More precisely 24% of Swedish patients claimed sometimes, rarely, or never receiving a same day reply from their medical practice. That was twice as high as in Switzerland and almost twice as high as in Germany (12% and 13%).[91]

Especially in Sweden and Jersey, waiting times for specialist appointments were reported to be a problem. It was reported that a waiting time of up to six months for a specialist appointment was experienced. In Jersey, it was reported that the Emergency Room was a valid alternative to long waiting times to see a specialist. The situation described in Sweden and Jersey matches the report of the OECD. In this, it is described, that waiting times for specialist care even deteriorated in the United Kingdom and Sweden between 2010 and 2016.[91] Although waiting times for specialists appointments in Germany are often subject of political debate and criticism, the patients of our study from Germany and Switzerland have not mentioned long waiting times for specialists, which again corresponds with the literature. With 75% of the German respondents receiving a specialist appointment within one month and even 97% receiving such an appointment within two months, Germany occupies one of the top places in the OECD comparison from 2020.[91] Our results are beyond that consistent with the results of surveys conducted by the commonwealth fund in 2016.[92] In this, 19% of respondents from Sweden and the UK claimed to have to wait at least two months for an appointment with a specialist. In Switzerland, on the other hand, the figure was only nine and in Germany just three percent.[92]

The reports of patients from all participating countries on waiting times for GP and specialist appointments, which match the literature, show once again, that patients are very capable to observe and adequately report on their care structures and international comparisons should play a role in finding out more about the supply situation and learning from other countries.

Immediate care in case of emergency

Patients from almost all countries stated, that the quick, adequate, and attentive reaction of the GP, sending the patient directly to the emergency room when needed, was perceived as positive. Factors relating to the GP that were perceived

as beneficial by German patients in emergency situations were as follows. It was received as positive in several German cases if the family practice was reachable by phone immediately or the flow of information was maintained by the practice staff, so that the GP could react appropriately a few minutes later. Another patient raved that the GP came straight to his home in an emergency, while another one was taken to hospital personally by the GP. It was received as facilitating, when patients with stroke or myocardial infarction were registered in advance in the emergency room by the GP. As far as the GP is concerned, no negative examples were mentioned in connection with the reaction in an emergency. This was the case in Jersey, Sweden, and Germany. It transpires that GPs play an influential role in the emergency care of their patients and have a tremendous impact on the patients' experience. Although no negative examples were reported, critical attention should nevertheless be given once again to the patients' pathway that was surveyed in Germany. This showed that more than half of the German patients contacted their GP first when experiencing symptoms of a stroke or myocardial infarction. In Sweden, where the pathway was not surveyed, at least one patient also chose the GP as his/her first point of contact and was then sent to the ER immediately. In view of the fact that studies could show that the GP has a delaying effect as the first point of contact for myocardial infarctions[93] as well as strokes[94], this must be considered as potentially dangerous. The same studies were able to prove the banal fact that direct contact with the ambulance could reduce the time to diagnosis and thus treatment.[94] In fact, this was the only factor that could shorten the time.[93, 94] And this is precisely where a further issue arises in this context. Only one third of the Germans, surveyed in an Austrian study from 2013 would have called an ambulance in the case of a stroke. This is probably due to the fact that only one third of stroke symptoms and half of myocardial infarction symptoms were recognized by the German participants of the aforementioned study.[95]

Thus, educating the population about the following is necessary and can make adequate treatment of the menacing diseases of stroke and heart attack more probable if necessary.[93-95]

The population must be informed about the alarm and cardinal symptoms of both stroke and myocardial infarction. Particular attention should be paid to the diversity and variety of symptoms of both conditions.[95] Furthermore, education is needed on when it is important or "bad enough" to contact the ambulance directly rather than the GP, as this appears to be the most relevant delay factor.[93, 95]

Summary: Although **waiting times** for GP and specialists appointments were usually not a problem in Germany[92], waiting times should never be left out of sight due to its **enormous impact on access to health care services**.[91] In case of increasing waiting times, patients seem to feel heavily affected, as reported by Jersey and Swedish patients in our study. Waiting times play an important role in relation to access to health care and unmet health care needs. They are the main reason for unmet health care needs in European countries and also in Germany.[91] Therefore they should always be monitored, although they were satisfactory in Germany in our study.

In Germany, unsatisfactory **density** of **health promoting offers** and thus **long distances** were reported. In general, short access routes to health care offers are a relief, long ones are a burden.

One example for the lack of health promoting offers are cardiac sport groups. Long access routes to these in Germany could be partially eliminated by relying on non-physician staff.[84, 87] Furthermore, primary health care centers with several providers under one roof could be a possible alleviation by saving journeys.[90]

The **GPs' behavior in case of emergency** can influence patients' perception of **emergency care**: a quick and attentive reaction, the availability by phone, direct help by coming to the patients' home or taking him to the hospital and the prior registration at the hospital were perceived as positive by patients. Nevertheless, GPs as a first point of access can be a delaying factor in emergency situations.[93, 94] The education of the population about alarm symptoms of stroke and myocardial infarction and on when to call an ambulance thus appears to be a reasonable measure.[93-95]

4.2 Strengths and weaknesses

4.2.1 Recruitment process

Selection of participating countries

The aim was to select countries for participation in the study that differ in some structural characteristics. These were described in chapter 1.1. Based on the different or common structural characteristics, conclusions could be drawn in some cases.

A weakness in the selection of the participating countries could be, that all four countries, that participated in the study are OECD countries. This means, that all health care systems of the participating countries have an upscale standard.[2] As a result, the findings might not be transferable on countries or health care systems, that are not members of the OECD and might have a poorer educated or simply different health care system. However, it is also a great strength that the international comparison took place at all. Various conclusions could not have been drawn without the international comparison. We found out, that patients are well capable to describe their experiences about the health care system regarding structural characteristics and that an international comparison can help to compare different structural conditions.

Selection of the inclusion criteria

In our study, a homogenous set of samples with similar cases was selected for different countries. By determining the inclusion criteria described in chapter 2.3.2, we aimed to find this homogenous sample.[54]

In Germany significantly more patients with heart attack than patients with stroke participated. Since our aim was to interview patients who frequently encounter various health care institutions, which is the case for both myocardial infarction and heart failure and stroke, this imbalance does not pose a methodological problem. Beyond that, the overall distribution of diagnoses was balanced, when all countries are included in the calculation: six patients who had suffered stroke, nine patients who had experienced a myocardial infarction and seven with heart failure participated.

Sample size

As qualitative studies don't intend to achieve statistically representative results, sample sizes in these studies can be considerably smaller than those of quantitative studies.[54] While the size of a sample is calculated beforehand when researching in a quantitative way, this isn't the case for qualitative studies. In these, the sample size can be considered sufficient, when no new topics are arising.[54] When we realized that this was the case, we stopped recruiting interview partners.

Effects of the Covid pandemic

Unfortunately, the Covid pandemic took place in the middle of our project schedule. This led to different difficulties in the execution of the project plan. It was difficult to recruit general practitioners who were willing to take part in the project and search for patients. In Germany five GPs didn't report back although they had initially indicated that they would participate. Two other German GPs stated to have no capacities to participate in the study by recruiting matching patients. As we nevertheless reached the aimed sample size, this was not a real methodological weakness but merely a delaying factor for the progress of our project.

4.2.2 Conducting the interviews

In general, semi structured interviews are suitable to capture the patients' experiences and thoughts. It is particularly noteworthy that patients can raise own topics, which might be the greatest advantage in contrast to closed methods.[51] We aimed to carry out the interviews face-to-face to capture also subtle information conveyed through eye contact, facial expressions and gestures.[54]

All interviews in Sweden, Switzerland and Jersey were conducted in person. Because of the covid pandemic, only two German interviews were carried out in person. The remaining German interviews took place by phone. A distortion effect can therefore not be excluded, as mimicry and gestures as well as eye contact can influence the course of an interview.[54]

Due to the different native languages of the patients, different interviewers conducted the interviews. By using a common interview guideline, we sought to achieve best comparability and standardisation.[54]

However, a possible bias could be the fact that the interviews were conducted by different professions: the German interviews were conducted by a medical student, the Swiss, the Jersey, and the Swedish interviews were carried out by physicians. German patients conveyed the feeling that they were more likely to open and make honest statements towards a student. In addition, they gave the feeling of giving the offspring a tip along the way. The circumstance that the Jersey patients were even interviewed by their treating physician stands in direct contrast. It was not mentioned by the patients in Jersey, but it could still be possible that they were not expressing their true thoughts or criticisms especially towards the GP, as the circumstances and characteristics of the interviewer, especially different power dynamics can influence the course of an interview and an interviewee's responses.[54] Interviews could be conducted by the same professional group in the future.

4.2.3 Analysis

International comparison

The international comparison can be considered as a strength, as many insights could be gained through this. In order to achieve a high degree of comparability and a standardized analysis, we created the described category system and code book on the one hand. On the other hand, we initially planned site visits during which the material would have been analysed jointly. However, due to financial constraints and the Covid pandemic, the plans had to be adjusted. We stuck to our code system but summarised and merged the contents using online providers, which cannot live up to our own quality standards of discussing and analysing content together.

Due to financial constraints, the Swedish interviews were not translated in their entirety. Only relevant patients' statements were translated after merging contents and statements. Therefore, the main researchers, carrying out relevant parts of the project, were unable to access the transcripts from Sweden due to language barriers. For future projects, translations of all interviews would be desirable.

4.2.4 The fulfilment of the quality criteria

Reliability and objectivity

In qualitative researches, objectivity can be realized, if coding and interpretation are independent on the researcher performing the coding and analysis.[52, 53] By coding content in a team of at least two researches, this was achieved in our study. By introducing a code book, containing clear and precise code definitions, intracoder reliability (meaning that the coding is consistent at various points in time) was strived for.[51-53] The code book can be found in the appendix.

Validity

A method is described as valid if it is capable of answering the research questions.[51-53] We were able to gather the needed data for answering our research questions with the chosen method.[51-53]

Firstly, we were able to find out, that patients' perceptions of their care provision can provide information about the quality of their care. Secondly, we were able to put the gathered information in the context of specific structural components of the care pathway, related to access, coordination and continuity. An attempt was therefore made to minimise the validity gap.

Plausibility verification

As described above, we aimed to realise the highest degree of validity, reliability, and objectivity and thus the plausibility verification of our results. By this, reasonableness and accuracy of results in qualitative content analysis can be aimed.[51-53]

4.3 Ethical considerations

As the study is a non-invasive methodology and we only conducted interviews, no adverse effects for the patient can be detected.

In addition, the informed consent of all participants was obtained in advance. Each patient received an information sheet about the project procedure in advance. Although Pope et. al. described the difficulty for qualitative researchers to describe data gathering and utilization exactly at the beginning of the study[54], we were able to stick to it in the course of the project.

Confidentiality was reached by anonymizing all statements that could provide personal information about the interviewee.[54] This included the anonymization of the cities of origin, patients' names and names of all health care workers that were mentioned.

4.4 Conclusions and outlook

Considering the fact that patients in our study were able to make several valid statements about the structural characteristics of their care that often corresponded to the literature, patients' experiences should play a defined role in health policy planning. This is particularly relevant in view of the fact that patients' experiences were among the least frequently examined parameters in the evaluation of healthcare systems in the past.[49] Furthermore, international comparison can add to understand patient preferences in relation to healthcare organization and recommendations could be addressed to inform health policy and decision-makers.

The following practical implications could be derived in this study:

1. The **flow of information** between patients and physicians should be maintained by considering the following conclusions: Using **lay-friendly explanations** and keeping patients as well as their relatives **informed** about preventive measures and upcoming therapeutical and diagnostic steps can increase the degree of patient-centeredness and satisfaction. This was reported both in our study and in the underlying literature.[65, 67] As it has been shown that physicians' communication skills and the degree of patient centeredness can be enhanced through communication training, obligatory **skills training** of physicians could be a possible solution.[67]

   As GPs as a first point of contact can be a delaying factor in emergency situations[93, 94], the education of patients regarding cardinal symptoms of stroke and myocardial infarction is important. Informing citizens about when to consult an ambulance or the emergency room is important to keep time-to-treatment short.[93-95]

2. The **flow of information** between different health care providers should be maintained in order to **enhance informational continuity**: Especially vulnerable patient groups, such as chronically and seriously ill patients value

informational continuity. Both our study and previous studies have shown that satisfactory informational continuity is associated with higher patient satisfaction and the feeling of trust and security.[78] Thus, the enhancement of informational continuity seems to be an important goal. The introduction of an **electronic health record (EHR)** could help to prevent fragmented informational continuity with the aim of cross-institutional communication and exchange of information.[6, 78]

3. The strengthening of **non-physician staff (APNs and health guides)** should be pursued: Non-physician staff are shown to be a relief for GPs and thus could counteract the shortage of GPs.[68, 69, 71, 72] Moreover, non-physician staff can function as a low threshold contact point for patients who often place a lot of trust in non-physician staff, which was reported in our study. Some patients would rather talk to non-physician staff about private problems than to physicians.[71-74] Non-physician staff can relief the need for more guidance within the health care system[45] and can play a role in view of the increasing GP shortage.[68, 69, 75]

   Consequently, needed (new) professions would be:

   - **APNs** within GP practices could serve as an easy, highly trusted contact person.[71-74]
   - **Health pilots**, acting independent of GP practices, could be suitable to assist the patient with advice, guidance, and information.[45, 77] According to the BMC[45], health pilots should be found within larger organizations, such as primary health care centers.[45]

   Furthermore, the density of health promoting offers could be increased by relying on non-physician staff. For example, the **offering of cardiac (sport) groups** could be extended by a change of current regulations. Physicians should no longer be mandatory for low-risk groups. These could be supervised by non-physician staff instead.[84, 87, 88]

4. In contrast to individual practices, **primary health care centers** could offer various advantages: Against the background of the (new) professions described above, it seems to make sense to educate teams as a whole. In this context, the role of **core coordinators** arises alongside the professions

described above. Having a core coordinator, who knows the patient and can guide him or her through the system, can have a positive impact on patients' experiences.[82, 83] Especially chronically and seriously ill patients, corresponding to the patients in our study, favor interpersonal continuity. With the GP as a core coordinator and thus a main contact person, interpersonal continuity could be strengthened, which in turn can create trust and security.[78, 79] The team in a primary health care center could consequently consist of GPs as core coordinators, APNs and health pilots. Interfaces could thus be better defined.

As short access routes to health care offers were reported to be a relief and long ones a burden, primary health care centers could improve patient satisfaction by saving patients travel time due to the unification of several providers at one location.[90]

5. Waiting times should never be left out of sight due to its **enormous impact on access to health care services.** Waiting times for GP and specialist appointments were rather satisfactory in our study in Germany, while Jersey and Swedish patients felt highly affected from long waiting times. As waiting times are also the main reason for unmet health care needs in Germany and thus play an important role in accessing health care[91], they should always be observed.

5 Summary

5.1 Abstract

Introduction

Different health care systems across the world are confronted with three main challenges: an increasing burden of multimorbidity combined with an aging society and an unmet need for GPs (general practitioners).[14-16, 19] By being first point of contact, providing a comprehensive range of health care services and having a coordinating function, PC (Primary care) can be a central part of the answer.[34] Patient satisfaction, especially in a qualitative manner, was studied least often, when the quality of PC was examined.[49] By comparing patient satisfaction in different international health systems in an open-ended, qualitative manner, we aimed to derive insights about health care structures and answer the question, whether patients can describe their requirements and whether there is a link to structural conditions.

Patients and methods

From December 2019 to April 2021, we contacted GPs from different areas and asked them to recruit potential interview partners. Because of their pathway through various institutions of the health care system, stroke or myocardial infarction (MI) during the past year or heart failure were inclusion criteria. We excluded patients with a psychiatric disease.[30, 31, 62] 22 Patients from Germany, Sweden, Switzerland, and Jersey were interviewed, using a semi-structured guideline. There was one drop-out in Germany. The overall male to female ratio was relatively balanced with thirteen men and nine women with an average age of 74 years. Significantly more patients with MI than patients with stroke participated. Data saturation was achieved through structured interviews.[63] For analysing the transcribed interviews, a code system was developed in a mixed deductive inductive way, consisting of eight main categories and 85 subcategories.[53]

Results

As far as our research question is concerned, it can be answered as follows: Patients' perceptions of their care process in and after acute incidents such as

MI and stroke can provide information about the quality of their care process and can also be partially related to structural characteristics of a health care system. Health care processes in general were considered as positive if a flow of information was accomplished in a lay-friendly and family involving way. Non-physician staff can create reassurance and provide the patient with the feeling of having an available contact person in the background. Longitudinal continuity in the context of trust, a sense of security, and a long-lasting doctor-patient relationship was perceived as positive. A shortage of continuative offers following acute treatment such as heart sport groups, self-help groups and physiotherapy, as well as the provision of information and education about it was criticized by patients. It was conspicuous, that especially in Germany poorer communication between PC physicians and specialists as well as worse informational continuity was bemoaned.

Discussion and conclusions

Since patients' experience can provide important information but has been underrepresented to date[49], it will be extremely important to strengthen this research in the future. This does not only apply to the care processes after MI and stroke but may very well be transferred to other areas of health care. Furthermore, international comparison can expand information about patients' preferences in relation to healthcare organization. Recommendations could be addressed to health policy and decision-makers. Besides that, the following conclusions were derived.

The flow of information between patients and physicians should be maintained by the use of lay-friendly explanations and the provision of information about all steps towards patients as well as their relatives.[65, 67] This can be improved through communication training of physicians.[67] As GPs as a first point of contact can be a delaying factor in emergency situations[93, 94], the education of patients regarding emergency symptoms is important.[93-95] The flow of information between different health care providers should be maintained in order to enhance informational continuity. Especially vulnerable patient groups value informational continuity, which can lead to higher patient satisfaction, trust and security.[78] Thus, the introduction of an electronic health record in Germany seems to be a

reasonable step.[6, 78] Non-physician staff can function as a low threshold and trusted contact point for patients[71-74], can relief the need for more guidance within the health care system[45] and can play a role in view of the increasing GP shortage.[68, 69, 75] Needed professions would be APNs within GP practices serving as an easy, highly trusted contact person[71-74], as well as health pilots, acting independent of GP practices and assisting the patient with advice, guidance, and information.[45, 77] Above that, the density of health promoting offers, for example cardiac (sport) groups could be increased by relying on non-physician staff.[84, 87, 88] Primary health care centers can offer various advantages. It seems to make sense to educate teams as a whole. In this context, the role of core coordinators arises. Having a core coordinator, who knows the patient and can guide him or her through the system, can have a positive impact on patients' experiences.[82, 83] With the GP as a core coordinator, interpersonal continuity could be strengthened, which in turn can create trust and security and is favored especially by chronically and seriously ill patients.[78, 79]

As short access routes to health care offers were reported to be a relief and long ones a burden, primary health care centers could improve patient satisfaction by saving patients travel time due to the unification of several providers at one location.[90]

Waiting times for GP and specialist appointments were rather satisfactory in our study in Germany, while Jersey and Swedish patients felt highly affected from long waiting times. As waiting times are also the main reason for unmet health care needs in Germany and thus play an important role in accessing health care[91], they should always be observed.

5.2 Deutsche Zusammenfassung

Einleitung

Verschiedene Gesundheitssysteme auf der ganzen Welt sehen sich mit drei großen Herausforderungen konfrontiert: einer zunehmenden Belastung durch Multimorbidität in Verbindung mit einer alternden Gesellschaft und einem ungedeckten Bedarf an Allgemeinmedizinern.[14-16, 19] Indem sie die erste Anlaufstelle für viele Patienten ist, ein umfassendes Angebot an Gesundheitsdienstleistungen bereitstellt und eine koordinierende Funktion hat,

kann die Allgemeinmedizin ein zentraler Teil der Antwort auf diese Herausforderungen sein.[34] Die Patientenzufriedenheit, insbesondere in qualitativer Hinsicht, wurde am wenigsten untersucht, wenn es um die Qualität der PC ging.[49] Durch den ergebnisoffenen, qualitativen Vergleich der Patientenzufriedenheit in verschiedenen internationalen Gesundheitssystemen wollten wir Erkenntnisse über die Strukturen der Gesundheitsversorgung gewinnen und die Frage beantworten, ob Patienten ihre Bedürfnisse beschreiben können und ob es einen Zusammenhang dieser mit strukturellen Bedingungen gibt.

Patienten und Methoden

Von Dezember 2019 bis April 2021 haben wir Hausärzte aus verschiedenen Regionen kontaktiert und sie gebeten, potenzielle Interviewpartner zu rekrutieren. Aufgrund ihres Weges durch verschiedene Einrichtungen des Gesundheitssystems war ein Einschlusskriterium ein Schlaganfall, ein Myokardinfarkt (MI) im letzten Jahr oder das Leiden an einer Herzinsuffizienz. Patienten mit einer psychiatrischen Erkrankung wurden ausgeschlossen.[30, 31, 62] 22 Patienten aus Deutschland, Schweden, der Schweiz und Jersey wurden anhand eines halbstrukturierten Leitfadens interviewt. Es gab insgesamt einen Drop-out. Das Verhältnis zwischen Männern und Frauen war mit dreizehn Männern und neun Frauen und einem Durchschnittsalter von 74 Jahren relativ ausgewogen. Es nahmen deutlich mehr Patienten mit MI als Patienten mit Schlaganfall teil. Die Datensättigung wurde durch strukturierte Interviews erreicht.[63] Für die Analyse der transkribierten Interviews wurde in einem gemischt deduktiv-induktiven Verfahren ein Codesystem entwickelt, das aus acht Hauptkategorien und 85 Unterkategorien besteht.[53]

Ergebnisse

Unsere Forschungsfrage kann wie folgt beantwortet werden: Die Wahrnehmung des Versorgungsprozesses durch die Patienten bei und nach akuten Ereignissen wie MI und Schlaganfall kann Aufschluss über die Qualität des Versorgungsprozesses geben und teilweise auch mit strukturellen Merkmalen eines Gesundheitssystems in Verbindung gebracht werden. Gesundheitsprozesse im Allgemeinen wurden als positiv bewertet, wenn der

Informationsfluss in einer laienfreundlichen und die Familie einbeziehenden Weise durchgeführt wurde. Nichtärztliches Personal kann Patienten beruhigen und ihnen das Gefühl geben, einen verfügbaren Ansprechpartner im Hintergrund zu haben. Langfristige Kontinuität im Kontext von Vertrauen, Geborgenheit und einer dauerhaften Arzt-Patienten-Beziehung wurde als positiv empfunden. Ein Mangel an weiterführenden Angeboten im Anschluss an die Akutbehandlung wie Herzsportgruppen, Selbsthilfegruppen und Physiotherapie sowie die Bereitstellung von Informationen und Aufklärung über diese wurde von den Patienten bemängelt. Auffallend war, dass vor allem in Deutschland eine schlechtere Kommunikation zwischen Hausärzten und Spezialisten und somit eine schlechtere Informationskontinuität beklagt wurde.

Diskussion und Schlussfolgerungen

Da Patientenerfahrungen wichtige Informationen liefern können, aber bisher unterrepräsentiert sind[49], wird es äußerst wichtig sein, diese Forschung in Zukunft zu verstärken. Dies gilt nicht nur für die Versorgungsprozesse nach Herzinfarkt und Schlaganfall, sondern kann auch auf andere Bereiche der Gesundheitsversorgung übertragen werden. Darüber hinaus kann ein internationaler Vergleich die Informationen über die Präferenzen der Patienten in Bezug auf die Organisation der Gesundheitsversorgung erweitern. Empfehlungen könnten somit an die Gesundheitspolitik und Entscheidungsträger gerichtet werden. Darüber hinaus wurden die folgenden Schlussfolgerungen abgeleitet.

Der Informationsfluss zwischen Patienten und Ärzten sollte durch laienfreundliche Erklärungen und die Bereitstellung von Informationen über alle Schritte gegenüber Patienten sowie deren Angehörigen aufrechterhalten werden.[65, 67] Dies kann durch Kommunikationstrainings bei Ärzten verbessert werden.[67] Da Hausärzte als erste Anlaufstelle in Notfallsituationen ein verzögernder Faktor sein können[93, 94], ist die Aufklärung von Patienten über Notfallsymptome wichtig.[93-95] Der Informationsfluss zwischen verschiedenen Gesundheitsdienstleistern sollte aufrechterhalten werden, um die Informationskontinuität zu verbessern. Gerade vulnerable Patientengruppen wissen Informationskontinuität zu schätzen, welche zu höherer

Patientenzufriedenheit, Vertrauen und Sicherheit führen kann.[78] Die Einführung einer elektronischen Gesundheitsakte in Deutschland scheint daher ein sinnvoller Schritt zu sein.[6, 78] Nichtärztliches Personal kann als niedrigschwellige Anlaufstelle, der Vertrauen entgegengebracht wird, fungieren[71-74], kann den Bedarf an mehr Beratung innerhalb des Gesundheitssystems entlasten[45] und kann angesichts des zunehmenden Hausärztemangels eine Rolle spielen.[68, 69, 75] Nötig wären APNs als niedrigschwellige Ansprechpartner in Hausarztpraxen[71-74], sowie Gesundheitslotsen, die unabhängig von Hausarztpraxen agieren und den Patienten mit Rat, Anleitung und Informationen zur Seite stehen können.[45, 77] Darüber hinaus könnte die Dichte an gesundheitsfördernden Angeboten, z.B. Herzsportgruppen, durch den Einsatz von nicht-ärztlichem Personal erhöht werden.[84, 87, 88] Primärversorgungszentren können verschiedene Vorteile bieten. Es scheint sinnvoll zu sein, Teams als Ganzes zu schulen. In diesem Zusammenhang ergibt sich die Rolle von core coordinators. Ein zentraler Koordinator, der den Patienten kennt und ihn durch das System führen kann, kann sich positiv auf die Patientenerfahrungen auswirken.[82, 83] Mit dem Hausarzt als zentralem Koordinator könnte die longitudinale Kontinuität gestärkt werden, was wiederum Vertrauen und Sicherheit schaffen kann und besonders von chronisch und schwer kranken Patienten wertgeschätzt wird.[78, 79]

Da kurze Anfahrtszeiten zu Gesundheitsangeboten als Erleichterung und lange als Belastung empfunden wurden, könnten Zentren der PVZs die Patientenzufriedenheit verbessern, indem sie den Patienten durch die Zusammenführung mehrerer Anbieter an einem Ort Anfahrtszeit ersparen.[90]

Die Wartezeiten für Hausarzt- und Facharzttermine waren in unserer Studie in Deutschland meist zufriedenstellend, während sich die Patienten in Jersey und Schweden durch lange Wartezeiten stark beeinträchtigt fühlten. Da Wartezeiten auch in Deutschland der Hauptgrund für unerfüllte Gesundheitsbedürfnisse sind und somit eine wichtige Rolle beim Zugang zur Gesundheitsversorgung spielen[91], sollten sie stets beachtet werden.

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7 Declaration of own contribution

The dissertation work was carried out at the Institute for General Medicine and Interprofessional Care (Institut für Allgemeinmedizin und Interprofessionelle Versorgung) of the University Hospital Tübingen.

The study was designed in collaboration with **PD Dr. Dr. med Heidrun Sturm**, **Antonia Bauer** (*Institute for General Medicine and Interprofessional Care, Tübingen*) **and Prof. Fabiano Tonaco Borges** (*Health Planning Department Niterói/Rio de Janeiro, Federal Fluminense University (UFF) Niteroi/Rio de Janeiro*). Furthermore, we were in close cooperation with **Christina Andrea**, **Maria Liljeroos**, **Carina Wennerholm** (*Department of Health, Medicine, and Caring Sciences (HMV), Linkoping University*), **Dr. Andrew Dickinson** (*Co-operative Medical Care Bath Street, St. Helier, Jersey*), **Dr. Beat Sottas** (*Sottas formative works, Fribourg*) and **Prof. Dr. Stefanie Joos** (*Institute for General Medicine and Interprofessional Care, Tübingen*).

I undertook the complete recruitment of participating GP practices in Germany, through which I was subsequently able to recruit the participating German patients. Patients from the other countries were recruited through the respective collaborating research team.

After training by PD Dr. Dr. med Heidrun Sturm, I carried out the German interviews and transcription of the German and Swiss interviews. Together with Antonia Bauer I created the underlying code system and carried out the qualitative content analysis of the transcribed interviews of Jersey, Germany, and Switzerland as well as the fusion of the contents of all participating countries.

Furthermore, I evaluated the content of the quotes from all participating countries (Germany, Jersey, Sweden, Switzerland) and interpreted the results.

I confirm that I wrote the manuscript myself under the supervision of PD Dr. Dr. med. Heidrun Sturm and that any additional sources of information have been duly cited.

Signed by Julia Weber _____

on _____ in Munich.

An erster Stelle möchte ich mich bei meinen Eltern für die immaterielle und finanzielle Unterstützung während meines Studiums bedanken!
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8 Appendix

8.1 Interview guideline

1 Introductory question
Please tell me, what happened? Can you tell me about the journey through the health care system you took from the onset of symptoms?
2 Positive experience in the health care process
Can you remember an incident of your care after you had a stroke/heart attack which felt especially positive for you? Why was it positive for you?
2.1 Description of the relevant details
Who was involved? What did those involved do and from what did they refrain? Which actions where especially effective? What was missing? What was your own roll?
2.2 Analysis of the happening
Why was the action effective? - In what way was it especially positive? - By which details could you and other involved persons recognize that the incident was a prime example for good care? - What part of the incident was a positive experience? - Why exactly was that helpful? What was the result? - Which specific consequences followed? What did you and the involved learn from this incident? - What parts would you wish for more often? - In what way is that typical/normal or unusual/an exception?
2.3 Possible additional questions
How can you explain that? How did you feel during the happenings?

3 Negative experience in the health care process

Please remember an especially negative incident during your care process. Please tell me, what happened and why it was negative for you?

3.1 Description of the relevant details

Who was involved?

What did those involved do and from what did they refrain? Which actions where especially effective?

What was missing?

What was your own roll?

3.2 Analysis of the happening

Why was the action effective?

- In what way was it especially positive?
- By which details could you and other involved persons recognize that the incident was a prime example for good care?
- What part of the incident was a positive experience?
- Why exactly was that helpful?

What was the result?

- Which specific consequences followed?

What did you and the involved learn from this incident?

- What parts would you wish for more often?

In what way is that typical/normal or unusual/an exception?

3.3 Possible additional questions

What parts would you wish to be avoided?

How did you feel during the happenings?

4 How do you judge the other contacts / providers of your care: what could be improved, what was especially positive / important.

5 Category-based questions *In order to make sure that patients perception and judgment of the relevant elements of this study (access, continuity, coordination) will be covered, make sure that the interview can answer the following questions. If not, ask the patient the following questions directly.*

5.1 Access (General & Gatekeeping)

Are you satisfied with how your GP can be reached?

- Is it easy to get an appointment? Do you find the opening hours appropriate?
- How many days do you normally wait for an appointment?
- Is it a long journey to get to your GP from your living place?

What do you do to see a specialist?

- Do you directly contact a specialist (for example a cardiologist) or do you first make an appointment with your GP and ask him for a referral?
- Is it difficult to get a referral to a medical specialist from your GP? Does your GP help you with the referral and does he recommend you a specialist, when you need one?
- Does this work for you? / How do you perceive this (problems, solutions)?

Which role plays your GP

- How does this affect you?

Who guides/supports you with therapy throughout the entire system?

- Does this work for you?

5.2 Continuity of care / gatekeeping / coordination of care

Do you see the same professional regularly or do you see different ones?

- Within the practice and in general. Why?
- Do you have your own doctor (for example a GP), whom you normally contact first, when you have a health problem?
- Do your family members also have the same GP?
- How often do you see your doctor? How often in the last 6 months?
- Since when, do you visit this doctor? (1/10/20 years? maybe since you were a child?)
- Do you feel your providers are well informed about you / your condition?

Who is responsible to follow your care? How is your care coordinated? (When and) who do you ask for help in case you struggle to organize your care?

- Does your GP informs the medical specialist about your illness when you are referred?

- Do you think your condition is taken good care of / embedded / supported?

How do the different persons involved in your care communicate and collaborate?

- Do you think, the doctor knows important information about your medical background? Did your doctor has medical records at hand?
- Do you also go to other health care providers (for example other specialists, physiotherapist, psychotherapist, psychologist)?
- If yes, do you have the feeling, that your doctor knows the results from the other health care providers (for example psychologist)? Does your GP know about the medications described by your other doctors or health care providers?
- Does your doctor know about your living situation?
- Does your doctor also deal with non-medical problems, like personal problems or worries?
- Do you think they are doing a good job?

Have you missed an appointment? Give an example and explain why!

- Where there reasons like costs or long ways why you missed an appointment?

8.2 Interview transcripts

Interview transcripts of Germany and Switzerland are only available in German. Relevant text passages were then translated into English as required. Interview transcripts from Jersey are available in the patients' mother language English. The interview transcripts of Sweden were not translated due to financial constraints. The transcripts are not printed as part of this dissertation but can be accessed digitally if required.

8.3 Code book

CODE	CODE DEFINITION	APPLICATION FOR	EXAMPLES / QUOTES
1 Case description	general information about each instance	information about the history and circumstances of the case and the patient himself	
1.1 further process & outcome	information about the results following the incident and its treatment		
1.1.1 health situation/outcome	describes, which health status the person has by now, after the whole incident; describes if he/she is completely free of complaints or if he/she has health remains of the incident		GER3: "Well, in any case, they have restored me quite well. [...] The only thing I say is: that's the terrible thing, I'm so tired in the evening. I'm fine during the day, but in the evening, I can't say out loud how tired I am." *(L. 81)*
1.1.2 impact on private life	describes influence of the incident and the following procedure on private life	including f. ex. relationsship, mental health, social contacts, leisure activities	Interviewer: "So you have [...] picked yourself up well." GER4: "Except for playing tennis and jogging. [...] I don't dare do that yet. Going out and running around the mountain. *(Ll. 421-424)*
1.1.3 impact on working life	describes influence of the stroke/heart attack on the patient's job	f.ex. If patient talks about inability to work after the incident but also about retraining/re-education; when patient had to change the job	CHE1: "And now, since the heart attack, my employer has given me the opportunity to change departments. And disability insurance is now supporting me and has given me certain courses and retraining opportunities. [...] The hard work of hand forming, i.e. bending by hand, is pretty tough. I tried at the beginning, but I couldn't do it anymore." *(L. 3)*
2 Interview setting	Circumstances under which the interview took place	f. ex. survey time, if the interview was conducted by phone or in person etc.	GER3: "Where are you?" Interviewer: "I'm on the phone. [...] At home." GER3: "And you're coming now?" Interviewer: "No, no, we wanted to do this over the phone." GER3: "Oh, yes, that's right." *(Ll. 1-7)*
3 Patient centeredness	Patient centeredness is one of the six characteristics defined by the Institute of medicine (IOM), that qualitative health care should be able to provide; accordingly, patient centered care should be driven by the decisions and needs of the patient or the patient relatives, which are individual to each patient; since not every patient has the same needs, clinical decisions have to be guided by individual needs and aims; (Committee on Quality of Health Care in America, I. o. M. (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C.: National Academies Press.)		

3.1 Perceived needs	because patient centered care is guided by the patients' needs, this code is used, when he/she expresses his/her requirements to the health care system		Interviewer: "So the GP gets involved if he thinks it's necessary. And otherwise, did you see another GP in between or did you always see Dr. G. [GP]?" GER7: "Wait a minute, when was that? When we used to live in CityXY, I don't think we had a GP at all, I was younger then, I didn't miss anything. There was one in town if you needed any medication. I had a check-up once a year, but apart from that. I didn't need a family doctor who came directly." *(Ll. 197-198)*
3.2 Frequency of patient contact	describes how and how often regular contacts with the health care system (f.ex. PC) take place	f. ex. When the patient has regular appointments with the GP once a month	Interviewer: "In the whole process since the heart attack, has there been any situation or behavior by certain people that you liked or that you noticed positively?" GER2: "Well, I have to say that N. [practice assistant] calls me regularly to see how I'm doing and whether everything is OK with my tablets and to take blood samples. So she often calls quickly." Interviewer: "But is that once a month or twice a year or something like that?" GER2: "Phew. How often does she call, maybe once every two months to find out?" *(Ll. 81-82, 85-86)*
3.3 Responsiveness to patient needs	Patient needs were acted uponed and resolved		Interviewer: "Do you have any wishes or would you have had any wishes?" GER2: "Yes, definitely from the rehab. That they would have been more responsive to the person. It was just like a bunch of chickens. Thrown together and then do it." Interviewer: "Always played the standard system a bit." GER2: "Exactly, always the same. Which didn't suit me at all in the end." *(Ll. 99-102)*
3.4 Human element	in the sense of interpersonal components	for example, when a patient builds a relationsship of trust with an employee of the health care system	CHE1: "But yes, the closest, really the closest was always Mrs. W. [APN], who talked openly with me about it. And she actually took away my fear of everything. And yes, she really helped me and still helps me now, I come here about once a month." *(L. 7)*
3.5 Patient information / relatives	category describes the status of knowledge of the patient and his/her relatives; very important for patient centered care, since the patient should be informed to participate in shared-decision making		GER1: "I wanted the stent to be put in here, but they didn't do that, I don't know why." *(L. 48)*
4 Pathway	purpose of the category is to show where and when the patient entered the health care system, got the first care of the stroke/heart attack and how the care continued		
4.1 First point of access	indicates first instituion that the patient chose to contact in the acute situation		Interviewer: "[...] in the situation where you had the pain and then told your children about it, they sent you to the doctor, didn't they?" GER3: "They then sent me there. They didn't let go and one of them went with me. She just registered me. And then I went to Dr. O. [GP]." *(Ll. 170-171)*

4.2 Process / Pathway of care	aim of this category is to arrange the different stations of the healthcare system, through which the patient has passed, in the right and chronological order; use the following individual categories if patient mentions, that he/she has gone through one of them	passages should be attached to the subcategories of this category	Interviewer: "Ok. You came to the hospital by ambulance?" GER7: "Yes." Interviewer: "So if you can summarize it, it was actually the emergency doctor, the family doctor, your husband of course.." GER7: "That was all there." Interviewer: < "and the hospital was involved." GER7: "Yes." *(Ll. 69-74)*
4.2.1 0 / Rescue team	/		
4.2.2 1 / PC	/		GER5: "[...] I suspected that it was in the heart. So I had a feeling for it myself. Then I called my GP and said I needed an ECG because it's hard to get an appointment with a GP. And these young ladies like to do the ECG without a doctor and then I got an appointment straight away." *(Ll. 38)*
4.2.3 2 / specialist	specialists that work in the outpatient care and not in the hospital		GER9: "Then I asked her [the doctor in the rehabilitation] if she knew a good cardiologist. And she recommended one, Dr. H. in CityXY, and I also asked Dr. S. [GP] if he knew Dr. H., who assured me that I was in the very best of hands. And yes. I basically went to him as well." *(L. 130)*
4.2.4 3 / hospital	/		GER1: "And then I reported here [to the GP] and they told me to come straight away and N. [practice assistant] told her colleague to write an ECG as soon as I arrived. They did that straight away and [the GP] told me to go straight to the hospital in CityXY. And there they said [...] something about a heart attack. *(L. 4)*
4.2.5 5 / rehab	/		CHE1: "And then I went to rehab." *(L.1)*
4.2.6 6 / follow-up	/		GER5: "In other words, I went home, made an appointment with my GP to discuss it, and two days later I saw my GP there and we discussed the whole incident. Then they wrote me a prescription for six different medications and said that I would have to go back to hospital a month later for a myocardial scintigram." *(L. 66)*
5 Access	includes everything, that happens before the actual contact to the primary care setting, means facilitations or obstacles that influence if or how the patient reaches the care he or she needs; this covers for example appointment booking systems, geographical or financial hurdles but also the physician density or inequality due to social characteristics. (Kringos, D. S., Boerma, W. G. W., Hutchinson, A., van der Zee, J. & Groenewegen, P. P. (2010). The breadth of primary care: a systematic literature review of its core dimensions. BMC Health Services Research, 10(1), 6. https://doi.org/10.1186/1472-6963-10-65)		
5.1 available services	Services that appeared in interviews, does not mean that this structure was available to patient		

5.1.1 support structures	which structures were available to patients, who are no longer that independet and need support	this can be support structures for everyday life but also in coordinating patients' healthcare	GER3: "[...] He's definitely confident with medication and stuff, you know. We can get it straight away, [...] if we get a prescription [...]. Then [my home help] will get it. [...]. We have her in the morning from a quarter past nine until seven at night. So she comes three times a day, always for three hours. *(LI. 503 - 506)*
5.1.2 information and counselling	which services were available to patients, to inform them about possible other structures	this can be for example informational offers or information courses, offered by health insurances	Interviewer: "So what would you miss most now? You said fitness. Can you think of anything else that would be helpful?" GER2: "Counseling centers, actually. Where you can go and say, I have this problem, what can we do. That's actually all missing." *(LI. 156 - 157)*
5.1.2.1 informal third party services	non-offical services regarding information and counselling		Interviewer: "Good. Do you have any questions or suggestions?" GER2: "Sure, that's just the topic, [...] weather heart patients could also meet and exchange ideas outside of doctors." *(LI. 162 - 163)*
5.1.3 prevention	which services were offered to patients with the aim of prevention disease and improving health	this can be for instance prevention in the form of sport courses or nutrition courses	Interviewer: "[...] Well, there is always scientific discussion here that there should be someone in the villages who knows all the offers in the region and who you can ask what is offered by which health insurance company and what offers there are for advice on nutrition, quitting smoking etc.. Is there such a thing here and if there were, would you find it important?" GER2: "Important, actually. I mean, I'm not the only one who suffers like that. My work colleague is too. He also had a serious heart attack and he's also looking for something. But there's nothing really here." *(LI. 115 - 116)*
5.1.3.1 formal services	includes official services, that provide help for the patient		Interviewer: "And do you have any support? So could you come here now and say, can you help me find something or will you do it yourself?" GER2: "I often go to the AOK and ask if there's anything nearby, but they always say no. You have to drive further away. That's kind of a shame." *(LI. 117 - 118)*
5.1.3.2 informal third party services	non-official services regarding prevention		GER4: "Yes, yes. Nobody told me anything. Dr. O. [GP] said: Yes, then have a look on the Internet under cardiac sports group. I said: Yes. I mumbled to myself: I've already done that. It's all difficult for me to get to, isn't it? Firstly because of the distance, and then most of them were already too busy." *(LI. 116 - 118)*
5.2 Appropriateness of services	specifies if patient thinks that the available services were suitable for his or her needs	use the category if patient explains why he/she didn't make use of special services or offers	GER1: "And then I have a bit of osteoarthritis above it. He [the GP] told me to go to the doctor in a quarter of a year and I was a bit of a shit because I said I didn't want to go to the doctor every quarter of a year because of it and then I am in for two minutes. He prescribed me insoles, that's all ok." *(L. 110)*

5.3 (no) barriers in seeking care	did there occure any obstacles, due to which the patient couldn't find access to the desired care offer; this category can be coded both when barriers appeared and when none appeared		Interviewer: "Have you ever missed an appointment with your family doctor?" GER6: "No." Interviewer: Okay. And have there ever been any obstacles that could have prevented you from making your appointment or anything like that? GER6: No. *(Ll. 168 - 171)*
5.3.1 opening hours practice	describes if opening hours of the practice are appropriate or not respectively if their occured problems because of the opening hours of the practice		Interviewer: "And do you find the opening hours of your GP appropriate?" GER8: "Yes, you know, I'm not [so pleased about that], I know that I can go to the doctor from 8-12 or in the afternoon from 3 p.m., but I've been very lucky so far that nothing major has happened, so when I go to my doctor now, I just pick up a prescription for my medication." *(Ll. 128-129)*
5.3.2 access route	describes the procedure that must be followed, before an appointment can be taken, including appointment booking and the "journey" to the practice or other structures		
5.3.2.1 Appointment booking	use this category when patient has problems in seeking care because of the way of booking an appointment		Interviewer: "And that is always looked at. ok. And the appointment is then automatically made?" GER2: "It's automatic then, yes, I have to go again in February." (Ll. 145-146)
5.3.2.2 no problem although "long" journey	patient has to drive a "long" way to see the doctor, but is okay with that or there are other solutions		Interviewer: "And when you have the appointment, is his practice far away from your home?" GER6: "Yes, it's about 8 stops on the streetcar." Interviewer: "Ok. So probably about half an hour?" GER6: "Yes, roughly." Interviewer: "Ok. Is that ok for you or is it too long?" GER6: "Yes, it is. [...] And he's often come to my house when I've been so unwell that I couldn't go." *(Ll. 89, 104 - 109)*
5.3.2.3 no problem (short access route)	patient doesn't have to drive a long way; in his opinion, the approach is not too long		Interviewer: "O.K. And how far is it from your home to the GP?" GER4: "Oh, two stops on the subway. So no problem." *(Ll. 359 - 360)*
5.3.2.4 long journey is a barrier for seeking care	patient has to drive a "long" way to see the doctor, and sees this as a problem, that worsens his/her access	this may occur for example in rural regions, where the physician density is not that high	Interviewer: "Do you think it [further offers like heart sport groups] would be great?" GER2: "Yes, but if I have to drive half an hour. That's just too far for me." *(Ll. 113 - 114)*
5.3.3 financial aspects of seeking care	what impact does money have on access to care services?		Interviewer: "And do costs play a role? The expense?" JER1: "Yes." Interviewer: "Just tell us why. [...]" JER1: "Well, every time you go to the doctor [...], which is on average 40 quid. Just to see the GP. And if I got to go three times in a month..." Interviewer: "That's 120 pounds, that's a lot of money. [...] you don't have to pay when you see a doctor in the hospital, do you?" JER1: "No." *(Ll. 119-124)*

5.3.3.1 barriers to request care	money as a barrier for seeking care		
5.3.3.2 (no) financial barrier aspects	patient sees money not as a barrier to seek treatment		Interviewer: "And we have now learned that in Switzerland you always have to pay extra when you go to the doctor or for medical care. Are there any situations in which you consider not going because of the money?" CHE1: "No, not because of the money. Health is more important. Especially when you're at a point like I was, life or death, you don't look so much at the money. You're willing to pay a bit more, but you're willing to live a few more years." *(ll. 35 - 36)*
5.3.3.3 incentives to follow structured pathway	sometimes, health insurances create incentives (f.ex. bonuses in the form of non-cash rewards or discounts for the next doctor's visit)		
5.3.4 waiting time	does waiting time delays access to care structures?		
5.3.4.1 timely care	/		GER7: "Yes, first you were disinfected due to corona [in the hospital] and then it went on quickly. So I wasn't standing around somewhere and didn't know what was going on." *(L.44)*
5.3.4.2 waiting time until appointment	/		Interviewer: "And how long does it normally take to get an appointment?" CHE1: "If it's something serious, immediately. If it's something where you can wait, you should allow about a week. [...]. So I always make sure that after work, because I've already missed quite a lot of work, then I always check after work and so far it's always been tip top. And if it doesn't work with the normal times, they also have evening hours. I've also been able to use them before. *(ll. 31 - 32)*
5.3.4.3 waiting time in waiting room	/		Interviewer: "Waiting times and that sort of thing." CHE1: "I actually have quite few. So you're taken after 5-10 minutes [at the GP]." *(ll. 21 - 22)*
5.4 workforce shortage	use this category if patient couldn't find good access to care because of a lack of health care personnel		Interviewer: "Yes, we had heard that the doctors from the region always came, on a daily basis, and that these ... you didn't like that, I assume?" CHE3: "Yes, it ... we felt safer with the family doctor. The question was always yes, is this person really sufficiently trained when decisions are made regarding medication. There was a certain amount of uncertainty." Interviewer: "And what did you then do to feel more secure?" CHE3: "Yes (laughs). Nothing." Interviewer: "There was no alternative. There was no other option." *(ll. 52 - 57)*
5.5 technology in healthcare		f. ex. Video consultation instead of consultation in person	

5.5.1 remote communication	indicates how the GP handles communication with his/her patients	Interviewer: "Yes, if we come back to the GP now. How satisfied are you with the way you can reach your GP?" GER6: "Yes, by telephone. And so when I say whether he can call me, he calls me back." Interviewer: "Ah, that's good." GER6: "Yes, because he's usually in consultation and it's hard to disturb him. But he's always called back so far." *(Ll. 86 - 89)*
5.5.2 routinely written requests	are there report or referral letters, that are sent automatically to the patient	
6 Continuity	includes three different aspects; contains longitudinal continuity, which means as much as medical contact between patient and provider over a longer time, which is based on a patient-centred and not disease-centred approach; should not only be long-lasting but also match the patients' requirements; every provider involved in the patients' care should always have admission to the patients' history and medical findings, especially if the provider did not collect the information himself, which ensures informational continuity (Kringos, D. S., Boerma, W. G. W., Hutchinson, A., van der Zee, J. & Groenewegen, P. P. (2010b). The breadth of primary care: a systematic literature review of its core dimensions. BMC Health Services Research, 10(1), 6–7. https://doi.org/10.1186/1472-6963-10-65)	
6.1 Monitoring of course of disease	indicates, who is responsible for keeping an overview of the disease and tracking the course of the disease	
6.1.1 specialist	/	Interviewer: "Do you have a cardiologist?" GER2: "Yes, in Sigmaringen. At the hospital." Interviewer: "Is it attached to the hospital or is it separate?" GER2: "Well, I have contact with him if anything happens." Interviewer: "When something happens. But regularly?" GER2: "No, I just have to come once a year." Interviewer: "You see a cardiologist once a year." *(Ll. 63-69)*
6.1.2 GP	/	Interviewer: "And how often do you usually see your GP per month or per year?" GER2: "Very little actually. If I need my tablets, then yes, and my blood tests, which I do regularly, also because of my thyroid I have to have regular blood tests." *(Ll. 69-70)*
6.2 informational continuity	see definition of continuity	Interviewer: "And how often do you usually see your GP per month or per year?" GER2: "Not often, actually. If I need my tablets, then yes, and my blood tests, which I do regularly, also because of my thyroid I have to have regular blood tests." *(Ll. 123-124)*
6.4 effects of (not) changing health professionals or practices	passages, showing the perceived effect of guaranteed longitudinal continuity or deficiency of longitudinal continuity are classified with this code or rather it's subcategories	

6.4.1 benefit / continuity creates security	/	Interviewer: "So it's also important to you that you stay with the same company for as long as possible?" GER5: "Yes, that's actually the most important thing, because he's had my data for 40 years. If you look in the archive, he has all my data in there. So you can read from it and I think that's actually important." Interviewer: "Yes, so you also have the feeling that he always knows everything [...]" GER5: "Yes. Exactly." *(Ll. 143-146)*
6.4.2 perceived lack of continuity	/	Interviewer: "[...] You said that the home visits were no longer made by Dr. H. [GP], but by XY. And was that worse for you in terms of care when someone else came?" CHE3: "Yes, I wouldn't say worse. [...] It's bad in that sense. You didn't always get anywhere straight away. I was an emergency case once, then finally had to see Dr. W. [another doctor] with breathing problems, heart and so on and [...] then he probably took me to do an ECG. Afterwards he said he couldn't take anyone else for further treatment. That's just terrible, of course." *(Ll. 3-5)*
6.5 compliance to treatment plan	indicates if the patient sticks to the treatment plan	
6.5.1 show up to appointment		
6.5.2 self-monitoring		
7 Coordination	means coordination within the care structure as well as cooperation with other health care providers; includes how the primary care team is structured, whether there are any other non-physician staff and how the distribution of tasks in the team is organised; cooperation with other health care providers including specialists and other public health employees; Coordination contains also the gatekeeping function as well as the competence to outsource care to specialists if necessary. **(Kringos DS, Boerma WG, Hutchinson A, van der Zee J, Groenewegen PP. The breadth of primary care: a systematic literature review of its core dimensions. BMC Health Serv Res. Mar 13 2010;10:65. doi:10.1186/1472-6963-10-65)** **(Macinko, J., Starfield, B. & Shi, L. (2003). The Contribution of Primary Care Systems to Health Outcomes within Organization for Economic Cooperation and Development (OECD) Countries, 1970-1998. HSR: Health Services Research, 38(3), 839. https://doi.org/10.1111/1475-6773.00149)**	
7.1 organisation of acc. To specialists = org. of appointment allocation	who is responsible for organizing the access to specialist doctors as the other levels of health care	Interviewer: "Yes. But if you had another problem, I don't know, somehow ... any other specialist, would you go there directly or would you ask Dr. O. [GP] about it first?" GER4: "I once had a colonoscopy, that was, oh, two or three years ago, I had the idea: Wow, I could have a colonoscopy. And then Dr. O. [GP] chose a doctor near me." *(Ll. 243-244)*

7.1.1 perceived effects of distribution of responsibilities	indicates which perception the distribution of responsibility in coordination of care causes	f. ex. When the patient organsises the access to specialist himself but whishes for more support or feels left alone or if patient is fine with organising care himself	Interviewer: "Ok. And did you make the appointment with the lung specialist yourself or does he do that?" GER6: "No, I do that myself." Interviewer: "You do that yourself ok. But are you happy with that?" GER6: "Yes, I am." Interviewer: "Ok. So that works well for you, that he recommends someone and you make the call yourself?" GER6: "Yes, exactly." *(Ll. 114-119)*
7.1.1.1 patient organizes specialist appointment by themselves	/	use this category for the evaluation of the fact, that the patient organises the access to specalists himself/herself	Interviewer: "So when you make an appointment with a cardiologist, do you do that yourself?" GER8: "I do that myself, of course." *(Ll. 144-145)*
7.1.1.2 GP organizes specialist appointments	/	use this category for the evaluation of the fact, that the GP organises the access to specalist for the patient	GER6: "Dr. O. [GP] has also called the hospital a few times, where I usually stay, and he also makes the appointments in case I need a colonoscopy." Interviewer: "Ah, in that case he makes the appointment, not you?" GER6: "Yes, in this case he does." Interviewer: "And how do you feel about that? Is it good for you that he does it for you or would you rather do it yourself?" GER6: No, that's fine. Because they're colleagues, they can do it better together." *(Ll. 184-189)*
7.2 overall coordination responsibility	which of the people involved takes on a coordinative role?		
7.2.1 patient initiative	to what extent organises the patient his/her own care?		Interviewer: "Ok. And yes, this is again this coordinating and communicating between the two doctors, they will probably both prescribe medication. How is that communicated or how does that work?" GER9: "I can tell you how it went from the rehabilitation clinic. I basically thought it through myself and took the stuff I got at the rehabilitation clinic, the medication plan, kept it, photographed it and presented it to my GP. And he checked it, approved it and said we'd continue with it." *(Ll. 271-272)*
7.2.2 core coordinator	who of the persons mentioned below (assistent nurse, patient navigator, social worker, GP) takes on the core coordination? Core coordinator = the person, who has an overview over the patients' entire care process, including all components and stations of care; a core coordinator can act as a contact person in case of queries		Interviewer: "And are there any further discussions or do you somehow have someone who simply makes a complete plan for how you should look after yourself now that you've had a heart attack?" GER2: "No, I don't have one." *(Ll. 61-62)*
7.2.2.1 assistent nurse	/		CHE1: "And she took away my inner fear a little and talked to me. What I could change in my life, what I need to pay attention to, what I'm allowed to do. She's always watching my back." *(L. 1)*
7.2.2.2 patient navigator	/		

7.2.2.3 social worker	/		Interviewer: "So it was a social worker who arranged it [the rehabilitation]?" GER2: "She came into my room and asked me straight away if I wanted to go on a rehabilitation. I was like, yes, of course I can imagine 3-4 weeks and then I'll go straight to Ü.. But it wasn't particularly good." *(Ll. 11-12)*
7.2.2.4 GP	/		Interviewer: "And would you also talk to the GP about non-medical things? So any private matters, if you need help or something? [...] So he [the GP] also helps with organizational things when needed?" GER7: "Yes, definitely." *(Ll. 135-136, 139-140)*
7.3 organisation of further care (f. ex. Rehab..)	*similar to category 7.1;* who is responsible for organizing the access to further care steps as the other levels of health care		Interviewer: "Who organized the rehabilitaton?" GER2: "Oh, that was the pension insurance company. They organized it right away, a week later, I went straight to Überlingen." *(Ll. 9-11)*
7.3.1 organisation of follow up			Interviewer: "And who organizes that you go to the check-up?" GER7: "I do that myself. During treatment they say "we'll see you again in six months" and then I just call and yes." *(Ll. 177-178)*
7.4 organisation of admission to hospital	*similar to category 7.1;* who is responsible for organizing the access to hospitals as the other levels of health care		GER8: "I was [...] sitting on the sofa and wanted to get up and then I felt dizzy. And then I wanted to move my right hand and there was no strength left in it at all. And then I told my wife and she came and then we called my family doctor. And he said I should come down immediately [...] and he took blood and did a few tests and then said it would be better for him if I went to hospital. So he got me a wheelchair and drove me to the hospital emergency room himself." *(Ll. 17)*
7.5 interprofessional cooperation			
7.5.1 collaboration between PC and others (inpatient, ...)	to what extent do the employees of the primary care practice work together/communicate with other levels of the health care system	use this category if patient talks about the collaboration between the PC practice and other health care structures f.ex. rehab, specialists, hospital, physiotherapists, psychotherapists	Interviewer: "[...] Did the GP also have all the information about your hospital stay?" GER3: "Yes, I got all that. I was given a note, a letter, where everything was ..." Interviewer: "Who gets the letters then? Does the GP get them directly from the hospital?" GER3: "I got them when I went home, I got the papers and our assistant took them back to Dr. O. [GP]." Interviewer: "Ah, okay." *(Ll. 550-556)*

7.5.1.1 unsure how/if information is communicated between inpatient care & P			Interviewer: "How does the exchange of information work, do you know that? Between the specialist and the GP?" GER8: "Uh, I don't know how it works between the doctors." Interviewer: "But do you feel comfortable with that?" GER8: "[...] I keep saying that you have to be lucky enough to get into the right hands, that's a big plus. The relationship between the patient and the doctor has to be right. Otherwise, everything else is useless." *(Ll. 196-199)*
7.5.1.2 informational continuity between professions			Interviewer: "And the results from the [university hospital], do they also go to Dr. O. [GP]?" GER4: "They go to Dr. O. [GP]. They go to, how do you say it? They go to the address of my family doctor." *(Ll. 195-196)*
7.5.2 collaboration within same PC structure	to what extent are the employees of different professional affiliations within a primary care practice communicating and collaborating	f.ex. If the patient has the feeling, that the care within the PC practice is uncoordinated or the practice nurse is not communicating with the practice physician	Interviewer: "In Germany, we don't have this division between [APN] and Dr. S. [GP] yet, i.e. the division between doctors and nursing staff. And that's why it's always interesting for us to see what one does and what the other does. Or what would you say? For example, adjusting medication: would you say that [the APN] can do that too?" CHE1: "Yes, she does that too. She has already prescribed it for me. Just for stress relief when I had palpitations at work. Or I couldn't fall asleep, she's also prescribed that for me. But everything was plant-based. So she also looks at the medication." *(Ll. 41-42)*
7.5.2.1 distribution of responsibilities			
8 perceived quality of care	subjective assessment of the quality of care experienced by the patient		
8.1 consequences of perceived quality of care			
8.2 patient involvement / centeredness	see definition of patient centeredness (main category); category is applied, when patient talks about the distribution of responsbilities, in concerns of organizing care		GER6: "Yes, it is." Interviewer: "So it's good as it is?" GER6: "Yes." Interviewer: "So you wouldn't like to be more involved in decision-making and so on?" GER6: "No, no." *(Ll. 192-197)*
8.2.1 patient is fine with organizing his/her own care	patient feels independent and can organize care by him/herself		Interviewer: "So the GP is not involved?" GER7: "If it has to be somehow, yes, but what I can do myself, I do myself." Interviewer: "So then through connections, do you look at who you know?" GER7: "Yes. Exactly." *(Ll. 107-110)*

8.2.2 patient wishes for more coordinative support	when patient feels left alone in the organization of care	GER4: "That's not so funny. The predecessor, Dr. S. [GP], was already different." Interviewer: "Why? [...] What did he do better?" GER4: "He did examinations straight away, he also checked this and that. So he did a lot on his own initiative, right?" Interviewer: "Ah, okay. So he also told you: Here, Mr. K., we have to do this and that again." GER4: "[...] Dr. O. [GP] doesn't do that." Interviewer: "Ah yes, okay." *(Ll. 330-338)*
8.3 workforce	describes the personnel, that was/is involved in the care of the patient	
8.3.1 competence	does the patient have the feeling that the involved personnel was competent/incompetent?	Interviewer: "And [...] you weren't satisfied with the rehabilitation." GER4: "Well, the whole situation there in Bad F.. What kind of people they were. Mamma mia. No." Interviewer: "Tell me why. What kind of guys were they? " GER4: "Well, the cardiologist, he always listened to the front and back and said: Well, that's OK, and then he gave me these orders, these prescriptions about what I had to do for exercise." Interviewer: "And then you somehow felt a bit overwhelmed in that state, didn't you?" GER4: "Yes, it was just too much. I also told him that he should reduce the effort a bit, and yes, he wasn't interested in that at all. So bad man. Very bad." *(Ll. 65-70)*
8.3.2 availability	does the patient have the feeling, that there was not enough personnel involved due to a lack of personnel?	Interviewer: Okay. Was there anything in the whole process that you were not at all satisfied with?" GER6: "No, not really. The only thing that always bothers me is that the doctors don't talk to the patients." Interviewer: "That the doctors don't talk to the patients?" GER6: "Yes. I was discharged from hospital. Nobody said anything about what I should or shouldn't do or what I shouldn't do. And the doctors just don't have any time at all, that's the problem." *(Ll. 62-65)*
8.4 overall satisfaction	sums up, how the patient felt about the care he got	GER4: "Well, the emergency room in S. [Municipal hospital in the state capital] was enormous. There were three or four people lying next to each other and they were very well looked after. So there every little detail was taken care of." Interviewer: "So it's important for you that they take care of you." GER4: "Yes, that was very good. Yes." *(Ll. 152-154)*
8.4.1 evaluation of GP care	sums up, how the patient felt about the care he got, especially the care of the primary care practice	Interviewer: "And why didn't you go to another practice?" CHE1: "Why? Because it's good." *(Ll. 14 - 15)*

8.5 improvement suggestions and wishes	this category summs up everything the patient mentions, that could amend the quality of the health care system	GER9: "I have to say, in IT times, it could be done differently than the patient carrying the note from A to B. Data protection issues would also have to be regulated and managed. And that this information is stored somewhere in the database or somehow reaches the other party electronically and is available there. I've also been between the clinic and the GP and so on, so it seems to be an insane disaster here in Germany." *(L. 250)*
8.5.1 further care and support	summarizes suggestions for improvement and wishes regarding the further care and support (after the incident)	Interviewer: "Do you have any wishes or would you have had any wishes?" GER2: "Yes, definitely from the rehab. That they would have been more responsive to the person. It was just like a bunch of chickens. Thrown together and then do it." Interviewer: "Always played the standard system a bit." GER2: "Exactly, always the same. Which didn't suit me at all in the end." *(Ll. 99-102)*