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# **Fostering the Role of Clinical Ethics Committees in the Context of Shared Decision-Making in German Hospitals**

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**Dedication**

I dedicate this work to B.E.M. and C.A.G.

Everything I am I owe to you.

## Preface

The copyright of the Master Thesis rests with the author. The author is responsible for its contents. ESHPM is only responsible for the educational coaching and cannot be held reliable for the content.

## Ethical approval

Ethical approval was not required.

## Declaration of competing interests

The author reports no conflict of interests.

## Abstract

While German legislation explicitly implies that healthcare professionals and patients shall follow Shared Decision-Making (SDM) communication rules, SDM does not yet seem to be a national standard in German hospitals. This study investigates whether the involvement of Clinical Ethics Committees (CECs) could encourage its implementation, thereby addressing an identified research gap in linking SDM and CECs specifically. The empirical research is based on eight semi-structured interviews and eight additional questionnaires. Research subjects include physicians who have worked in German hospitals for a minimum of ten years and are members of a CEC for a minimum period of two years. The analysis yielded the following five main findings: (1) SDM is currently not fully achieved in all sections of a routine hospital treatment process. (2) CECs can encourage SDM by fostering ethical awareness among physicians via (a) individual case consultations, (b) ethics and communication workshops, (c) ward visits, and (d) the creation of hospital guidelines. However, (3) not every CEC engages in *all* of the described activities although a need for them was identified due to insufficient patient-physician communication training during medical school. (4) Including CECs in the OPS catalogue in 2021 might act as a positive impetus for creating more CECs. As long as these will be well-staffed, it will enable more physicians to be sensitised for ethical considerations and the importance of reaching consensus with patients, thereby facilitating SDM in the future. Finally, (5) physicians should be further educated about economic dimensions related to hospital treatment so that they can inform patients about economic implications of treatment decisions, as stipulated by German legislation.

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## 1. Introduction

In the modern understanding of contemporary health systems, medical treatment is no longer just a ‘one-way’ service delivered from educated physicians to uninformed patients. In fact, the patient’s legal and ethical role is increasingly recognised as both a person in need and a driving force of the whole treatment process (Deutscher Ethikrat, 2016). Hence, the patient is not just a physician’s workpiece but a well-advised partner who is explicitly encouraged to contribute his individual values and expectations. In this context, Shared Decision-Making (hereinafter referred to as ‘SDM’) is an approach where physicians and patients make decisions together using the best available evidence (Elwyn et al., 2010).

On February 20<sup>th</sup>, 2013, the concept of SDM was embedded in German legislation by way of the Patients’ Rights Act which follows from §§ 630a subseq. of the German Civil Code, otherwise known as ‘Bürgerliches Gesetzbuch’ (hereinafter referred to as ‘BGB’). It did not bring any substantive amendments to the matter itself but only confirmed what had already been worked out in detail by judicial law beforehand (Palandt, 2021). However, the legislator’s idea was to create greater awareness of the topic by shifting this unwritten judicial law to written statutory law. Thus, the normative requirements were given greater attention in terms of legal status (Clausen & Schroeder-Printzen, 2020). The Patients’ Rights Act implies that healthcare professionals shall follow SDM communication rules such as informing patients about all relevant treatment alternatives. Specifically, to ensure the proper elimination of information asymmetry, physicians are legally obliged to provide patients with comprehensive information such as the right to medical consultation, which follows from § 630e I and II and § 630c I and II of the BGB. Additionally, patients are owed financial advice according to § 630c III BGB.

Empirically, however, a discrepancy between the intended and the actual outcome of the legislation was identified. While there is growing consensus that it is a legal necessity, a patients' and citizen's right, and an ethical imperative, SDM does not yet seem to be the national standard in German hospitals (Danner et al., 2020). Some treatment decisions are made even before physicians have spoken to the patient, and sometimes lucrative operations are recommended and executed without a medical need (Bittner & Schmidt-Kaehler, 2018). In this context, Braun & Marstedt (2014) investigate the extent to which German patients are involved in the medical decision-making process. Results from their survey reveal that more than half of the patients had never been involved in decision-making when visiting their physicians. However, as SDM leads to considerable clinical, moral, and economic benefits - and is thus seen as both good in itself and as means to other ends - finding ways to counteract its impediments is relevant on a societal level.

As a starting point, this thesis aims to investigate the gap between the current state and target state of SDM in German hospitals more closely. That is because most research about SDM is being conducted in the USA, Canada, England, and the Netherlands. However, due to the growing need for rationing in the healthcare system as well as the fact that patient satisfaction is of central importance in the context of quality assurance, a trend towards SDM also gradually emerged in Germany (Scheibler, Janßen & Pfaff, 2003). Instead of simply transferring international study findings to the German context, it is of high scientific relevance to study SDM in Germany specifically. This relevance is due to differences in national healthcare systems and medical curricula, culture, and legislative changes that have started to recognise a need for SDM during the last years.

SDM requires ensuring that all information is provided sufficiently by physicians as well as allowing patients to understand the explanation given for any medical treatment (Muscat et al.,

2020). Without the necessary understanding between patient and physician, SDM turns into a major challenge. However, the peculiarity of patients as cooperating partners in a medical workflow is that they may have restricted cognitive abilities. This can occur when patients are treated in a hospital as they may enter a state in which they lose control over their consciousness. Thus, an issue arises of how to ensure the principle of SDM. This thesis proposes the involvement of Clinical Ethics Committees (hereinafter referred to as ‘CECs’) to ensure the above.

CECs’ individual ethical consultations support patients, their surrogates, and physicians, thereby facilitating the SDM process in a situation of conflict. In doing so, they aim to strengthen patient autonomy as well as trust and respect between patients and physicians. Next to individual ethical consultations, CECs can also offer continuing education in questions of clinical ethics and engage in the development of guidelines for recurring areas of ethical problem fields (Akademie für Ethik in der Medizin, 2021). Hence, CECs are not only relevant in critical situations when patients have restricted cognitive abilities, but even in a much wider sense. Despite this, a research gap exists in combining the concept of SDM with the existence of CECs specifically. Therefore, a contribution of the present study lies in explicitly establishing a link between them. Followingly, the research question of this paper reads as follows:

**“To what extent could Clinical Ethics Committees encourage Shared  
Decision-Making in German hospitals?”**

A final impetus for the topic of this study was that the German regulator introduced CECs as a structural feature of billability in the so-called ‘OPS catalogue’ on January 1<sup>st</sup>, 2021. Thereby it was established that hospitals could only be paid for the practice of weaning, that is, the



discontinuing of dependency on assisted ventilation, if they have established a CEC (DIMDI, 2021). In Germany, the ‘ICD-10 catalogue’ is the authoritative diagnosis code for all billings of hospitals, while the OPS catalogue is the associated procedure code. By taking the codes of ICD and OPS together for each patient, a so-called Diagnosis Related Groups-‘Grouper’ (DRG-Grouper) then calculates the exact amount of reimbursement that a hospital can claim for its medical outputs (Deutscher Ethikrat, 2016). By introducing the CEC into a formal OPS description, regulators acknowledge that ethical considerations shall be linked to economic incentives for the first time.

The empirical analysis is based on eight semi-structured interviews and eight additional questionnaires. Research subjects include physicians who have worked in German hospitals for a minimum of ten years and are members of a CEC for a minimum period of two years. The question scheme itself was structurally segmented so that a routine hospital treatment process was broken down into its typical consecutive work steps. This way, it should be made as visible as possible - and comparable between the participants - with which own pre-understanding they view SDM and ethical problem discussions.

The remainder of this study is organised as follows: The following section establishes an understanding of the scope of SDM and describes how it is currently addressed in German health policy and law. Section three provides a literature analysis on SDM, identifies the research gap, and places CECs in this context. Afterwards, section four describes the methodological approach that this research follows in detail. Following this, section five presents the results of the empirical research. Within section six, findings are discussed, limitations are pointed out, and avenues for future research are suggested. Finally, section seven provides concluding remarks.

## 2. Background

This section provides background information on SDM by outlining applicable documents such as empirical research findings and legal acts. According to Mortelmans (2013), the importance of documents is that they can support or confirm information gathered from other sources. Thus, this section provides a solid understanding of the topic to establish a basis for the literature review and empirical study, which will be displayed in the subsequent sections.

### *2.1 SDM defined*

Borysowski et al. (2020) identify three main models of medical decision-making that have evolved: ‘Paternalism’, ‘Informed Decision-Making’ (IDM), and SDM. Paternalism means that a physician’s actions are performed with the intent of promoting the patient’s best interest but without the patient’s consent regarding a particular treatment. The model further developed into IDM, where a physician presents all treatment options to a patient who understands the options and makes his or her own choice. However, IDM is based on an inherently flawed conception of the patient’s autonomy, which assumes that individual values are known and fixed (ibid). Finally, the most recent of the three models is SDM which is a collaborative process that allows patients, or their surrogates, and clinicians to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences (ibid). For the purpose of this thesis, SDM is the focus of research.

Some of the research on SDM focuses on a particular type of care, such as oncology (Frerichs et al., 2016). Other studies have explored the effectiveness of SDM in internal medicine, palliative care, neurology, and psychiatry (Härter et al., 2017). Consequently, SDM is considered appropriate in almost every primary and secondary care situation where a care decision has to be

made. This even applies to some accident and emergency settings (NHS, 2021). That is because there are no fully reliable and side-effect-free treatments, and there are very few clinical situations where there is only one course of action that should be followed in all cases (Coulter & Collins, 2011).

SDM supports individual patients while preserving the stewardship role of the physicians' profession. It may therefore involve negotiation and compromise. However, at its heart lies the recognition that clinicians and patients bring different yet equally important forms of expertise to the decision-making process (ibid). The physician's expertise may centre around certain sections of a treatment process; however, this does not imply patients cannot share their information and decision-making responsibility therein. On the contrary, patients know about the impact of a condition on their daily life, have a personal attitude to risk, as well as their own preferences (ibid). In order to provide an example during a medical workflow, patients' wishes could and should even be considered during discharge management. Instead of informing a patient when it is time to go home, SDM can be achieved by asking the following question: *"On a scale from 0-10, how confident are you to manage things for yourself if you were to go home tomorrow?"*. As care systems increasingly aim to reduce readmissions to hospitals, patients must be discharged only when they feel confident to manage their health at home (ibid).

In addition, Elwyn, Tilburt and Montori (2012) point out that SDM could even correct some of the supply-induced demand that explains practice variation because, more often than not, informed patients make more conservative choices than uninformed patients. Nevertheless, they argue that the widespread and urgent desire to reduce healthcare costs leads to a misinterpretation of the identity of SDM. It risks that the underlying rationale for SDM, including a respectful, empathetic, and patient-focused approach, is being overshadowed. In other words, the efficiency

argument denigrates the intrinsic respect for individual patients and uses them as ‘means’ rather than as ‘ends in themselves’. However, any reduction in utilization should be viewed as a consequence of achieving SDM, not the imperative itself. The imperative for SDM must rest on principles of good clinical practice (ibid).

Finally, next to a risk of misinterpretation, critics of SDM argue that most patients do not want to participate in decision-making. However, there is considerable evidence that patients want more information and greater involvement (Coulter, 1997). In fact, Scheibler et al. (2003) show that SDM leads to higher satisfaction rates and better treatment results according to patients.

## *2.2 SDM in German health policy and law*

In order to comprehend SDM in the German context, this subsection explains how it is currently addressed in German health policy and law. SDM has been part of the German discourse since the late 1990s. The first SDM research programme was funded by the Federal Ministry of Health and was called ‘Patient as a partner in medical decision-making’ (2001-2005). It established the German-language SDM definition ‘Partizipative Entscheidungsfindung’ (participatory decision-making). Since then, according to Härter et al. (2017), the research and implementation of SDM can be split into three levels: micro, meso, and macro levels. These three levels are outlined below.

Firstly, the micro level encompasses changes in communication, involvement of other parties, and a trustful patient-physician relationship (Müller, Hahlweg & Scholl, 2016). Here, universities increasingly integrate SDM as a mandatory class into their medical curricula (Härter et al., 2017). For example, the reform curriculum ‘HeiCuMed’ in Heidelberg offers SDM by way of three mandatory units consisting of seminars and communication training. Similarly, the reform

curriculum ‘iMED’ in Hamburg also integrated specific SDM lectures, seminars, and role plays with simulated patients (ibid). Nonetheless, the survey Health Monitor from 2014 reveals that despite these efforts, only one in four patients reports having experienced SDM once or more often within the last three years, both for primary and secondary care visits. The survey also shows that SDM is more likely to be experienced by patients with higher education, more secondary care visits, or more chronic conditions, such as cancer, chronic back pain, or mental illnesses (Braun & Marstedt, 2014).

Secondly, the meso level is a middle ground between the micro and macro level. It is generally described in abstract terms but can have a concrete impact on individual cases. Here, the Institute for Quality and Efficiency in Health Care (IQWiG) provides evidence-based health information for patients as an independent publisher (Härter et al., 2017). It developed three decision aids for national breast, colon, and cervical cancer screening programmes. It was also commissioned by the Federal Ministry of Health to develop an open portal for quality-assured and evidence-based internet services regarding health information and personal counselling services within the German health care system (ibid). Moreover, in 2006, the first patient university was initiated in Hannover, which aims to offer health education and knowledge regarding healthcare structures for citizens and patients. Studies show that it offers a valuable means of conveying health-related knowledge and participants’ ability to reflect on health information to individuals (Seidel et al., 2017).

Additionally, the Agency for Quality in Medicine (ÄZQ) produces evidence-based health information. It develops specific patient guidelines and support tools for the National Clinical Practice Guidelines Programme (e.g., asthma, chronic obstructive pulmonary disease, coronary heart disease, and diabetes) and oncological guidelines (Härter et al., 2017). What is more, the

scientific association German Network for Evidence-Based Medicine (DNebM) expressively promotes SDM, and the established independent Organisation for Patient Counselling (UPD) informs patients about their rights and prepares patients for medical consultations. Overall, SDM is recommended and advocated as the most valid clinician-patient approach within various National Clinical Practice Guidelines. (ibid).

Lastly, the macro level encompasses structural changes (Müller et al., 2016). Here, the Federal Ministry of Health leads the initiative ‘National Cancer Plan’ to coordinate and improve cancer care since 2008 (Härter et al., 2017). The plan aims to improve the quality of patient information, involve patients actively in making decisions regarding their care, and implement SDM in clinical practice. Thus, German health policy is taking a clear stance against increasing medical treatment rates uncritically - a paradigm shift of fundamental importance (Helou, 2014). Nevertheless, this shift does not only apply to cancer care. As briefly mentioned in the introduction, the Patients’ Rights Act from 2013 implies a general right for comprehensive and understandable patient information as well as informed decisions based on a respectful physician-patient partnership.

A decision of the Federal Court of Justice of May 28<sup>th</sup>, 2019 (File number VI ZR 27/17) is an example of how strict German case law is when a patient is treated without being sufficiently informed about the medical content of the measures beforehand. Text digits 11 subseq. of that decision state:

*“Consent to medical intervention can only be given or refused in its entirety. For this reason, information deficits, irrespective of whether a risk requiring information materialises or not, make the medical intervention as a whole unlawful because of the patient's lack of consent and, if the physician is at fault, lead in principle to liability for all consequences of damage. [...] If [...] only risks have materialised that were not to be explained, the physician's liability may [at most] be omitted if the patient has received at least basic information about the type and severity of the intervention. The basic information is only given if the patient is*

*given an accurate impression of the severity of the intervention and the type of burdens that may be imposed on his or her physical integrity and lifestyle. As a rule, this also includes an indication of the most serious risk associated with the intervention. The basic information gives the patient [at least] a general idea of the severity of the intervention and the direction of the associated burdens on his or her lifestyle. If the basic information is lacking, the physician has deprived the patient of the possibility of deciding against the intervention and avoiding its consequences. The patient's right to self-determination is essentially affected in the same way as if the physician had performed the intervention without asking the patient for consent. He must then also be liable if an extremely rare risk that does not need to be explained has materialised.”*

§ 630c II BGB states that all information and advice must be sufficiently comprehensible for the patient. If problems arise because the patient does not understand the given information sufficiently, a helper must be called in (§ 630d I BGB). A helper in this sense is a private confidant named in a living will (§ 1901a BGB) or a caregiver appointed for the patient (§ 1896 BGB) or the court itself, consulted in more severe cases (§ 1904 BGB). The trusted individual (§ 1901b II BGB) or the caregiver must then be informed instead of the patient (§ 630e IV BGB). The Federal Court of Justice clarified on May 20<sup>th</sup>, 2015, that even an intellectually inferior, forcibly accommodated offender cannot be referred to health protection only by his official guardians. Instead, he or she is entitled to regular protection by a legal caregiver (File number XII ZB 96/15).

Physician and hospital must also provide the patient with a clear picture of his or her situation from an economic point of view. If economic advice is not provided adequately, the physicians are liable to pay damages to the patient. On January 28<sup>th</sup>, 2020, the Federal Court of Justice formulated the following in a revision ruling (File number VI ZR 92/19, Text digit 13):

*“Following § 630c III BGB, the physician must inform the patient in text form about the expected costs of the treatment before the beginning of the treatment if he knows that complete coverage of the treatment costs by a third party is not ensured or if there are sufficient indications for this according to the circumstances. This provision is linked to the duty of economic disclosure developed by the Senate. The duty to provide economic information, codified in § 630c III BGB, is intended to protect the patient from financial surprises and to enable him to have an overview of the economic consequences of his decision.”*

In some circumstances, patients are offered treatment services that do not fall within the broad range of services provided by statutory insurance, but which may nevertheless be individually valuable according to a physician's assessment. In order to ensure that physicians cannot use their information asymmetry to the detriment of patients, the legislator has created the so-called 'IGeL Monitor', where 'IGeL' stands for 'Individuelle Gesundheitsleistungen' (i.e., individual health services). Here, treatments are independently examined for their suitability in general, and patients can find out whether what their physician tells them is true (IGeL Monitor, 2021). In addition, § 27b of the Fifth German Social Legislation Code, otherwise known as the SGB V, has introduced an additional protective mechanism: The 'Second Opinion Procedure'. A second opinion may be obtained at the expense of the health insurance fund for specific interventions whose performance should sensibly not be decided by a single physician. Details are regulated by the Federal Joint Committee (Gemeinsamer Bundesausschuss, 2019).

Concluding, German health policy targets the implementation of SDM in clinical practice on three different levels, and the Court's decisions underline that these developments are not neglected within the German legal system.

### 3. Literature Review

The previous two sections provided background information on the concept of SDM and described how SDM is currently addressed in German health policy and law. Next, a literature review describes which participants are involved in SDM, thereby positioning CECs in the context. This is followed by empirical research findings regarding facilitators and impediments to SDM in clinical practice and a description of the research gap that this study addresses.



### *3.1 Participants involved in SDM: Physicians, patients, and CECs*

First of all, physicians and patients are at the centre of SDM. Hoffmann et al. (2014) specifically focus on the physicians' role by arguing that physicians need to find and appraise research evidence and practice patient-centred communication to support SDM within consultations. However, Muscat et al. (2020) argue that this model is too provider focused. It misses complementary skills that patients need to have to incorporate the evidence and expertise of the clinician, along with their values and preferences, into their decision-making. Simplifying information is necessary but not sufficient to achieve active participation in decision-making (Smith, 2009). It is only a response from healthcare providers to potential shortcomings in patients' ability to understand, engage, and apply information. Hence, patients need cognitive *and* social skills to express personal values, preferences, and experiences and decide which treatment option aligns with these values and preferences (McCaffery et al., 2010). These skills are referred to as 'Patient Health Literacy' (Muscat et al., 2020).

Health literacy is conceptualized as a personal asset. It is a set of personal, transferable skills that can be developed to support greater independence in health decision-making (Nutbeam, 2008). This includes skills to obtain, understand, and use evidence-based information about the natural history of a condition, possible options, as well as benefits and harms of each. It also includes a quantification of these and the ability to deliberate on and articulate their values to construct informed preferences. As a result, different levels of health literacy progressively allow for greater autonomy in decision-making and personal empowerment (Nutbeam, 2000). The 'Health Literacy Pathway' model by Edwards et al. (2012) similarly shows that as patients increase their knowledge and understanding of health conditions, they can actively participate in discussions with healthcare professionals. These findings are particularly relevant for patients with

a long-term condition, as it allows them to become more active in healthcare consultations (ibid). As a middle ground between paternalistic and ‘consumerist’ models of clinical decision-making, acknowledging health literacy skills seeks to recognise the autonomy and responsibility of both health professionals and patients (McCaffery et al., 2010). After all, it takes ‘two to tango’ (Charles et al., 1997).

Dilemmas may emerge when physicians cannot easily assess the degree of mental competence of their patients. Van den Hooff and Buijsen (2014) explore how healthcare professionals deal with patients suffering from Korsakoff’s syndrome who are generally unable to understand relevant information and, consequently, do not wish to give their consent to the care which is offered to them. In these cases, it takes time, energy, and commitment to assess their remaining degrees of competence (Timmerman et al., 2012). Assessing competence also always carries the risk that patients will erroneously not be taken seriously and be classified as incompetent (Van den Hooff & Buijsen, 2014). However, from an ethics of care perspective, a physician’s relationship with a patient has greater value than instrumentally caring for his or her medical needs. Their responsibilities include respect for a patient’s unique otherness as a person (Norverdt et al., 2011).

However, healthcare professionals are seldom qualified to adjudicate ethical or legal matters or even recognise them when they arise (McLean, 2007). Consequently, this conflict has generated much interest in the role of CECs because it is believed that they can change clinical practice both directly via case consultations and indirectly through education and raising awareness of ethical issues (ibid). To understand the objective and structure of CECs and the impact they can have on SDM, Vollmann (2008) distinguishes between case-related and organisational levels in more detail. These two levels are outlined below.

On the case-related level, a focus lies on the treatment and care of an individual patient. Specific decisions and ethical conflicts in these individual cases only take place at the request of those affected. Professional groups always retain their responsibility and their freedom of decision. Therefore, the vote of a CEC is only a deliberative result but never an instruction for action. Once founded, members should reflect the broadest possible spectrum of fields of work and professional groups without understanding themselves as representatives of the interests of individual professional groups (ibid).

In contrast, on the organisational level, an emphasis lies on developing ethical guidelines. Since ethics has often only played a marginal role in the education of health professionals, CECs can address the need for further training by organising regular employee events and workshops. Members of the CEC can act as multipliers for ethical issues in the hospital and thereby increase the level of awareness as well as acceptance and credibility of CECs, thereby making clear that ethics concerns all employees and should not be delegated to a committee only. Such organisational efforts could influence the treatment options for individual patients. The resulting synergy effects can be used, and a lasting change in the culture of a hospital could be achieved (ibid).

### *3.2 Identified facilitators and barriers to SDM*

The last subsection pointed towards the roles of different parties involved in SDM and positioned CECs in this context. In the following, this subsection investigates which factors were identified in the literature to either facilitate or impede the implementation of SDM in practice. Moreover, ways to counteract impediments are examined. It is also important to note that this section transitions from an international perspective to the German context, thereby paving the way for the empirical research.

In an attempt to provide a cogent summation of the evidence base regarding key barriers and facilitators to implementing SDM in Western countries, Alsulamy et al. (2020) conducted an umbrella review of *seven* eligible reviews on SDM. Frequently identified facilitators include providing sufficient information about the patients' condition, treatment options, and possible outcomes. Facilitators also include patients' perception of the acceptability of asking questions, their acknowledgement that the medical encounter involves two experts, that is to say, a physician and a patient, and their acceptance of responsibility for participating in decision-making. Clinicians who listen to and respect patients' opinions, discuss their preferences concerning their involvement in decision-making, and use simple terminology throughout conversations have been shown to facilitate the SDM process greatly. Efforts to encourage and motivate physicians to use SDM and provide them with adequate time for it are also considered essential facilitators for the implementation of SDM. Furthermore, the quality of the relationship between physicians and patients is a key enabler of SDM (ibid).

At the same time, Alsulamy et al. (2020) identify barriers such as patients firmly believing 'the doctor knows best' and that, therefore, only the physician could make an informed decision. Other common barriers include individual patient characteristics, e.g., lack of knowledge or the fear of being described as difficult or troublesome, resulting in poorer quality care or less attention. Patients with more severe or even life-threatening conditions may be less inclined to participate in SDM; hence, the nature of the health condition itself is also a barrier to SDM (ibid). Furthermore, barriers include physicians who do not adequately listen to patients' concerns, have poor interpersonal skills, or believe that patients prefer not to be involved in decision-making. Last but not least, environmental barriers include time constraints and a lack of resources (ibid).

Some of the suggestions to counteract the described impediments include providing ample time in consultations, as longer consultations are more likely to involve elements of SDM (Young et al., 2008). However, the provision of resources, such as time and information, is insufficient if not accompanied by efforts to support and motivate providers to use SDM (Robertson et al., 2011). Physicians need to be motivated, provided with regular training to use SDM, and educated on building a trusting relationship with their patients. They need to listen to patients and elicit preferences and fears, thereby encouraging them to participate in the decision-making process (Alsulamy et al., 2020). At the same time, patients need to acknowledge that they, too, have a role themselves (ibid). The process of SDM starts with the interaction between physicians and patients, and good communication enhances the experience (Ruiz-Moral, 2010).

Complementary decision aids can reduce decisional conflict, improve patient knowledge and patient-clinician communication (Stacey et al., 2017). They are designed to inform patients and help them think about what different options can mean for them, allowing them to reach an informed preference (Coulter & Collins, 2011). Patient decision aids can take a variety of forms, such as one-page information sheets or computer programmes. Although developing them is a labour-intensive task that can take many months, a growing number of patient decision aids are becoming available. That is because if patients are to play a part in the medical decision-making process, they need clear, comprehensible information about the condition and treatment options based on reliable research evidence and comprehensible risks (ibid).

A limitation of the above empirical findings is that they are based on international studies. Ergo, their generalisability to the German context is limited. In order to investigate what factors play a role in the German hospital landscape, it is thus relevant to study SDM in Germany specifically. That is due to differences in national healthcare systems and medical curricula,

culture, and legislative changes that have started to recognise a need for SDM during the last years. While overall research on SDM in Germany is limited, one of the most prominent studies within the German context was conducted by Bittner and Schmidt-Kaehler (2018). Hence, studying SDM in Germany is also relevant because it contributes to the academic literature by further building on their findings. In particular, their qualitative study identified barriers and facilitating factors of SDM in German hospitals and revealed six central findings outlined below.

First, economic pressure impedes SDM because economic interests have a decisive influence on the selection of treatment options. That way, SDM is deliberately incomplete or guided by persuading patients to choose a lucrative therapy for the clinic. Furthermore, since remuneration is independent of the time spent on patient consultations, the corresponding resources are calculated so tightly that SDM as an integral part of everyday hospital life is hardly feasible (ibid). Second, management culture and interprofessional cooperation affect the feasibility of SDM because patient participation is most successful when it is understood as a team effort by all health professionals in the SDM process (ibid). Third, a physician's positive attitude towards SDM is an essential prerequisite for its realisation. While many physicians regularly accept unpaid overtime, others have become insensible in the course of their professional lives (ibid). Fourth, health literacy and the patients' motivation influence the feasibility of SDM. The need for personal motivation for patients to participate in decision-making can be seen in the fact that discussions about treatment options often only come about at the initiative of the patients (ibid). Fifth, physicians wish to receive more support in providing information to patients. There is a need for high-quality material and better orientation aids on the internet to make it easier for patients to select trustworthy information when doing their research. In their study, without exception, physicians rate the use of videos for conveying information positively and expect it to promote

SDM (ibid). Finally, the current education and training in physician-patient communication do not sufficiently consider daily clinical practice. Most physicians report that they had only heard about SDM in theory. Only a few could participate in practical exercises to train relevant techniques with simulated patients (ibid).

As a result, together with experts in the field, Bittner and Schmidt-Kaehler (2018) suggest four concrete fields of action. One of them is a remuneration system that does not stimulate the provision of services but instead gives more weight to patient benefits. However, this is not considered a sufficient approach in itself. Physician-patient communication should not be based primarily on financial incentives but rather on ethical considerations such as respecting a patient's self-determination (ibid). Secondly, training and educational programmes can enable the learning and use of conversation techniques that make physician-patient communication far more effective during medical training, specialist training, and continuous professional life (ibid). Thirdly, successful communication must be established as a central quality standard in hospitals, and work processes should be designed in an interdisciplinary way. Finally, there is a high need for a clear and easily accessible portal for health information and the development of decision aids (ibid).

### *3.3 Research gap*

Based on the outlined literature in this section, the following research gaps can be identified. First, the intersection between SDM and CECs is not sufficiently researched at this point. Additional research is needed to explicitly establish a link between them to enable the described synergy effects outlined by Vollmann (2008). Next, focusing on the German context, several limitations for the study of Bittner and Schmidt-Kaehler (2018) can be identified. These limitations open opportunities for further research, which will be addressed throughout the subsequent sections of this thesis. While the study is placed in the context of German hospitals,

thereby resembling the context of this study more closely, findings are based on focus groups. Therefore, they cannot be used to derive statements that are representative of the population or group of physicians; nor can it be determined with certainty to what extent the described experiences are individual cases or common phenomena (ibid). Furthermore, the role that CECs could play in the context of SDM was not examined. This is striking because the identified concrete fields of action include ethically based respect for the patient's self-determination, training and educational programmes, and interdisciplinary work processes, all of which are closely linked to the activities of CECs. Nevertheless, this confirms the research gap mentioned above. Additionally, their study did not break down a routine hospital treatment process into its typical consecutive work steps. Hence, it was not made visible with which own pre-understanding physicians view SDM in depth. Ergo, these gaps will be addressed in the empirical analysis in the following.

## 4. Methodology

The previous two sections described how SDM is currently addressed in German health policy and law and outlined past research on the topic. They also positioned CECs in the context of SDM and explained the research gap that this study addresses. In order to do so, this section provides a critical overview of the empirical research process concerning study design, the process of data collection, data analysis, and criteria to ensure the quality of the qualitative research.

### *4.1 Study design*

The goals of qualitative research versus quantitative research are description, explanation, and understanding instead of testing hypotheses by calculations (Morse, 1994). It provides information about the 'human' side of an issue, that is, the often-contradictory behaviours, beliefs,



opinions, emotions, and relationships of individuals (Mack, 2005). Given interactive challenges as an overall essence of SDM and the vivid discussions that CECs are involved in, these objectives can be considered pertinent. Interviews with CEC member physicians were selected based on their potential for collecting data on individuals' personal histories, perspectives, and experiences (ibid). Semi-structured and open-ended questions were preferred due to the absence of available research linking CECs with SDM. In order to do justice to the explorative nature of the research question, this study method was particularly well suited for tapping into participants' experiences, attitudes, and needs, as the open-ended nature allows unexpected insights to come to the fore (Mortelsmans, 2013). Questionnaires were also used when physicians were too time-constrained to conduct an interview. Thus, they enabled the researcher to increase the response rate.

Interview questions and the questionnaire deliberately focused on the general topic of SDM instead of targeting physicians from a particular type of care. An essential focus in the selection of all respondents was to ensure their expertise as members of CECs to not only query the participants' own ethical reflections, but principally their personal experiences from practice. This design also allowed to diversify the research setting, as respondents are based in different hospitals across Germany. The question scheme was split into two parts. First, questions regarding SDM were structurally segmented so that a routine hospital treatment process was broken down into its typical consecutive work steps. In this way, it should be made as visible as possible - and comparable between the participants - with which own pre-understanding they view SDM. The assumption was that interviewees might presumably not be aware of how many different work segments of hospital treatment SDM is viable in. This assumption, in turn, was based on the literature review finding that SDM has not yet gained the status that it is normatively intended to have. The second part of the question scheme explicitly aimed to determine which activities CECs

engage in that can ultimately facilitate SDM in clinical practice. It also included a question about the inclusion of CECs in the OPS catalogue, thereby exploring physicians' understanding of the economic dimension related to their treatments (Appendix B, Question 9).

#### *4.2 Data collection*

The process of data collection started in April 2021. In order to answer the research question, as briefly mentioned in the previous subsection, CEC member physicians needed to be assembled. Marshall et al. (2013) showed that there is little rigor in justifying sample size in qualitative research. However, they argue that justifying sample size is evidence that the dataset is sufficient to address research problems. Not providing a justification would be unacceptable in quantitative research and should likewise be unacceptable in qualitative research (ibid). Hence, one of the methods they suggest is to cite sample sizes used in studies with similar research problems and designs. Therefore, acting on the study mentioned above about SDM in German hospitals by Bittner and Schmidt-Kaehler (2018), who used a sample size of 14 participants, a similar number of participants was equivalently targeted. In the end, this target was even slightly surpassed by applying methodological triangulation between the interviews and questionnaires. First, eight CEC member physicians were interviewed. Second, eight more CEC member physicians answered the questions via a questionnaire, given their time constraints, leading to 16 respondents in total. An overview of participants and their fields of expertise can be found in Appendix A. All respondents have worked in German hospitals for a minimum of ten years and are members of a CEC for a minimum period of two years.

Physicians were contacted via multiple channels, including direct messages on LinkedIn and email addresses found on their respective hospital websites. Later, further respondents were contacted with the help of those physicians who had already been interviewed, also referred to as

‘snowball sampling’ (Mack, 2005). This technique helps to find and recruit ‘hidden populations’, that is, groups not easily accessible to researchers through other sampling strategies (ibid). Interviews took place via Zoom and in part via phone in case there were technical difficulties. Before the interviews, participants received a document that included a short introduction to the topic and the aforementioned open-ended questions (see [Appendix B](#)). This way, physicians had the opportunity to think about answers and personal experiences in advance, thereby enabling the researcher to conduct the interviews as efficiently as possible. The average interview length was 45 minutes.

Throughout all interviews, legal and ethical considerations were kept in mind by obtaining the respondents’ informed consent before recording them. Informed consent is one of the most important tools for ensuring ‘respect for persons’ during research (Meck, 2005). If respondents had wished to withdraw from the study, they would have had the opportunity to do so at any point during the research process. Moreover, to guarantee the anonymity of all research subjects, CEC member physicians were offered confidentiality by referring to them as I1-I8 (for interview partners) and Q1-Q8 (for respondents of the questionnaires). All respondents were informed of these facts beforehand. Finally, during the interviews, room was provided for all respondents to openly tell their story and raise any issues they think are important, instead of sticking to predetermined ideas.

#### *4.3 Data analysis*

Given physicians’ informed consent for recording the interviews, it was possible to fully engage in every conversation instead of writing down answers in real-time. Since the research setting was German hospitals and all physicians were German, interviews were also conducted in German. After each interview, recordings were immediately transcribed. Once the transcripts were

finished, an extensive analysis of the quotations began. On the one hand, deductive coding was applied. That is, analytical depth and connection to existing literature were created (ESHPM, 2020). In particular, both the central factors affecting SDM in German hospitals and the concrete fields of action identified by Bittner and Schmidt-Kaehler (2018) were used as sensitizing concepts. At the same time, inductive coding was also adopted to generate new insights that are close to the actual reality of respondents (ESHPM, 2020). Consequently, data was analysed in an abductive manner. Taken together, using Atlas.ti, the process uncovered specific codes, which also required several re-evaluation rounds. Afterwards, it was possible to identify code groups that helped to create a helicopter-view of the codes. According to Saldana (2008), the final number of major themes (i.e., code groups) should be held to a minimum to keep the analysis coherent. Hence, the process resulted in eight codes and three code groups (see [Appendix C](#)).

In the end, a review of the transcripts was done several more times to ensure that the most important findings of the interviews and questionnaires were contained in the code groups. Findings were translated after the interviews were coded to prevent inadequate translations and ensure implied connotations were not neglected (Suh et al., 2009).

#### *4.4 Validity, reliability and generalisability*

There are three criteria to ensure qualitative research quality: Validity, reliability, and generalisability (ESHPM, 2020). Validity means that data interpretations are in line with the data collected. In order to ensure this, each interview protocol was sent to the interviewed physicians to validate the interpretation, also referred to as ‘member check’ (ibid). Transcripts were then either confirmed or corrected by individual physicians. Only afterwards, they were uploaded to Atlas.ti to be used for the analysis. Moreover, disconfirming evidence and deviant cases were explored instead of leaving them out. Given that highly time-constrained physicians were asked to fill out a

questionnaire, methodological triangulation was also applied to increase the validity of overall findings. Reliability means that the data collection and analysis are carefully conducted (ibid). This was ensured by recording and transcribing the interviews and being as self-reflective as possible so that the researcher's opinion and experience did not colour the results. Additionally, raw data such as quotes from interviews are presented in the results section to show the reader what the analysis is based on. Finally, generalisability entails that results can provide meaning outside the specific context in which the research is conducted (ibid). While it cannot be guaranteed that respondents are fully representative of all physicians in German hospitals, by targeting representative physicians in different German hospitals, the scope of non-generalisability was aimed to be reduced. Even if the results were still not entirely representative, they nevertheless shed light on structures, processes, and courses of conduct that apply to many hospitals in Germany (Bittner and Schmidt-Kaehler, 2018).

## 5. Results

In this section, results obtained from interviews and questionnaires are presented. Code groups that are based on identified codes shall serve as subsections. The way identified codes were grouped is visualised in the codebook, which can be found in [Appendix C](#). To begin, challenges regarding a patient-physician relationship in the context of SDM are outlined. Secondly, factors such as interprofessional cooperation and organisational culture are identified to determine the degree of prominence of a CEC within a hospital. Finally, dilemmas that physicians experience regarding financial incentives are displayed. Throughout this section, quotes from the research subjects are presented to provide evidence for the discovery.

### *5.1 Patient-physician relationship challenges*

In the following subsections, challenges regarding the patient-physician relationship are explained. As such, ‘relationship’ refers to the cooperation between physician and patient during a medical treatment process at the hospital. As described in the codebook in more detail, four challenges have been identified in particular: (1) Role expectations in discordance, (2) Concerns regarding patient health literacy, (3) Availability of appropriate premises in the hospital, and (4) Level of physicians’ empathy and reflexivity. These will be discussed in detail in the following.

#### *5.1.1 Role expectations in discordance*

As briefly mentioned in section 4.1, respondents were asked to identify focal points of patient co-determination during the entire medical treatment process. The treatment sections were split up as follows: Anamnesis, diagnosis, therapy counselling, therapy selection, therapy implementation, progress evaluation, determination of post-treatment behaviour, discharge management, and follow-up. As a result, therapy selection was identified as a focal point for most respondents ( $n=13/16$ ). The following quote is representative of the respondents’ answers and offers insights into the underlying reasons for choosing this treatment section:

*“In my opinion, this is where the patient has the greatest say. I am obliged to show the patient alternatives. If I, as an anaesthetist, explain a certain anaesthetic procedure, and this is now a major operation where the anaesthetic also has a significant influence on the success of the operation, then I am obliged, if there are alternative methods, to also explain these to the patient. What hits us at the core, for example, is when we recommend regional anaesthesia, which certainly makes up a very large aspect of the success of the therapy. But we also have to tell every patient that everything would also work without regional procedures. We also have to explain the complications” (I3).*

This quote shows that the focus on co-determination within therapy selection is linked to a perceived obligation and may therefore explain why a majority of respondents identify this stage as a focal point. Upon closer investigation, it turns out that each treatment section is considered a

focal point by at least four respondents. For example, during anamnesis, it was mentioned that every patient can decide here what (not) to tell. In precisely the same way, every physician can then say “*Well, if you do not want to tell me, then I cannot offer you anything on this basis*” (I2). Similarly, regarding the diagnosis, respondents say that, here, the patient already has the right of co-determination because the question is: “*How many diagnostic measures does the patient want to take?*” (I6). Therefore, diagnostics require consent. The patient must be informed, also about alternative procedures and must then consent (I8). Q8 also believes that these two treatment sections are a focal point of patient co-determination, as anamnesis and diagnosis can only work harmoniously with the patient.

However, the fact that four respondents consider anamnesis and diagnosis focal points also means that a remaining number of 12 respondents do not. Even more so, some explicitly say that this treatment section would be out of the patient’s control because, looking at it in black and white, these are simply facts (I3). It was put forward that anamnesis is a technical prerequisite without which medical action is only possible to a limited extent and that diagnosis is just as technical. Therefore, a patient would not be competent to help during these treatment sections (Q4).

A similar overall discordance can be identified regarding the respondents’ perceptions of whether patient involvement is impossible in certain situations. Some respondents mention that SDM would be impossible for patients with limited cognitive abilities, such as severe cases of dementia, because it is very limiting for the diagnosis as well as therapy and later adherence (I1). It also has a prognostic significance due to implementation difficulties in everyday life (ibid). Moreover, physicians express that SDM would be impossible with patients in a coma who cannot be contacted in any way (Q5). However, on the other hand, Q6 and Q8 explain that patient

involvement is never impossible because medical decision-making is ultimately based on an involved patient (Q8). According to I7 and I8, even patients with severe dementia could and should still be asked: “*What do you want to do next?*” or “*What do you have in mind?*”. Several respondents stress that for patients who are in a situation in which they cannot make their own decision, ideally, there is a caregiver, or in the case of minors, a legal guardian. Therefore, they believe that no group is excluded (I1, I2, I3, I8, Q2 & Q4).

In this context, the possibility to learn about the patients’ wishes *before* they enter a state of limited cognitive abilities was mentioned by four respondents (I1, I2, I3 & Q1). I3 describes that when patients are awake and largely oriented in the intensive care unit, they always ask a patient from early on: “*What if...?*” or “*Would you agree to...?*”. As such, Q1 points out the possibility of advanced care planning:

*“In my opinion, patient involvement is only excluded if the patient cannot be reached by communication, that is, if he or she is in a coma [...] and has **not** already taken precautions to make his or her voice heard, for example via an advance directive or by having relatives act as informants in his or her place if the worst comes to the worst” (Q1).*

Finally, respondents mention that they wish for more precise rules on behalf of lawmakers because, in practice, matters are not as black and white as written in legal texts (I2, I3 & I5).

*“What I would like the most [...] is for there to be clearer demarcations. Because we don't have them. So what do I really have to inform the patient about and what not? [...] For example, there are no clear instructions for anaesthetists [...]. And that is extremely difficult for us physicians, because then you tend to explain everything that somehow comes into your head. [U]ltimately, we have to provide information about the most serious complications, regardless of how often they occur. And in case of doubt, the patient is then completely unsettled and not informed about what has happened. So that would be something that one would really like to see from the legislator” (I3).*

The quote exemplifies that legislation is perceived as unclear and that physicians are not always sure what it is that they have to inform the patients about in particular. This is in line with



the previously identified discordances, as perceived ambiguity may translate into heterogeneous role understandings.

### *5.1.2 Concerns regarding patient health literacy*

A further challenge regarding a patient-physician relationship is related to patient health literacy and the concerns thereof. On the one hand, some respondents disclose favouring the patient to be in a somewhat well-informed state, i.e., having some idea of what is going on (I3). That is because the less informed a patient, the worse his or her decision-making competence (Q4). I3 provides an example of a situation where the respondent notices the advantage of informed patients in general:

*“Where we notice it very, very clearly is again in the intensive care unit, namely when it comes to organ donation [...]. Ten years ago, organ donation was something that was almost unheard of, whereas today, people are very well informed, for example, through the press. We benefit a lot from the fact that these people are already pre-informed. They can all relate to the terms ‘organ donation’, ‘brain death’, etc. This is, of course, an extreme example, but it illustrates very clearly that good information for the patient in advance also makes him or her competent to make a decision” (I3).*

Nonetheless, patient health literacy cannot be improved externally via the press only. Hospitals themselves also have many individualised information sheets that are stored in their software systems. Some hospitals even offer educational films that patients can watch on laptops or tablets directly at the bedside or entire films via a YouTube channel (I5). Two respondents (I1 & I3) describe having had an overall positive experience with such information films on standardised procedures that the patients can watch on tablets before talking to the physician. With the help of these tools, patients can comprehend everything quite well:

*“You always have to visualise the patient's subjective impression [...]. You have been there yourself as a patient, leaving the consultation and thinking firstly: “What did the physician actually say again?” and secondly: “I wanted to ask this and that.” You can take these two aspects out of it a little bit because you have*

*already obtained the essential information in a relatively comfortable way beforehand. So I think that such videos would be a very good tool in this regard” (I3).*

However, while they think that these tools could be used more intensively in the future in order to relieve physicians, they also add that one has to be careful about these tools remaining only one component. It should not replace education, and it should not replace information. Instead, it should only be the first orientation. The patient should see all possibilities that exist and be able to recognise alternatives (I3).

Some respondents describe an entirely different experience regarding such tools altogether, for instance, Q4 reveals that they had tried official educational materials and videos, but these were not perceived sufficiently empathetic. On the contrary, they tended to induce a ‘nocebo effect’, meaning that the patients’ negative emotions caused by the videos harmed the entire treatment process.

Furthermore, not only concerning video tools but also regarding online information in general, a certain degree of scepticism was identified. That is because if a patient formed a firm opinion based on incorrect information obtained from the internet and then enters a consultation, it is challenging and time-consuming to break up certain misconceptions (I1, I3 & I4).

*“When I think of the word "internet", I immediately cringe. The experience we all have is that people browse all kinds of sites and get all kinds of information and then come here with a completely false picture. Of course, the internet would be the right channel, but you would really have to have a [...] kind of certified information brochure that is as objective and neutral as possible, so that you do not have to fight against such preconceived opinions in the end” (I3).*

In order to deal with such challenges posed by incorrect internet search results, some respondents recommend specific websites to patients (I7 & I8). At the same time, it is considered necessary not to speak against the patients’ research because one cannot prevent it. In particular,

I8 suggests that trust between patient and physician may vanish when speaking against it because patients then think the physician would not like them to know anything about the topic.

Lastly, a certain degree of scepticism could not only be identified for specific sources and tools but even regarding efforts to increase patient health literacy in general. One respondent, in particular, revealed that it would not help him if a patient were well-informed:

*“After all, we are almost always talking about a very individual treatment situation. The patient will not find his specific treatment situation on the internet or anywhere else. He will not be given an algorithm where he can say: ‘So, I am a patient, 78 years old, with bowel cancer that does not need to be treated. But I have risk factors that are measured by my stroke, blood thinning, and impaired kidney function.’ How is the patient supposed to ask someone about this complexity of his disease beforehand to get adequate information about it? No, that is the physician's job. The patient's ability to inform himself will be very limited. Things like information sheets in the hospital or information sheets for a certain measure are all just impulses with which you can pre-inform patients. However, patients always have very specific questions that concern their very particular case. No sheet or flyer can [...] describe the patient's individual problem. They only describe a disease profile. But this has to be modified individually for each patient. No internet resource can do that. Maybe some artificial intelligence will be able to do that in a few years - I do not want to deny that. But I think it is very unlikely [...]. The patient needs to trust the physician. But, you know, if I go to a lawyer with a legal problem, I also have to trust my lawyer. I have to trust my architect. At the end of the day, I can try to understand it, but ultimately, I have to rely on the experience of a human being” (I6).*

Concluding, while some physicians report a positive experience with increased patient health literacy efforts, other physicians highlight concerns in this regard. On the one hand, that is because if such efforts induce more fears and lead to incorrect preconceived opinions instead of facilitating SDM, challenges between patients and physicians may intensify. On the other hand, treatment situations are described to be so individual and complex that the patients' ability to inform themselves would be limited. Therefore, it was argued that patients would just have to trust their physicians.

### *5.1.3 Availability of appropriate premises*

A third identified challenge for the relationship between physicians and patients relates to the availability of appropriate premises in a hospital. Respondents state that appropriate premises are needed to maintain privacy. While most hospitals have mainly shared dormitories, they are, in fact, entirely unsuitable for private conversations because physicians then either have to get the other patients out of the room or somehow get their patient out of it, which makes the process relatively tricky (I7 & I8). The physicians' mobile phones are also articulated to irritate the patients a lot, making a structured conversation of any form impossible, especially when it comes to difficult decisions (I1 & I4). In response to these distractions, respondents I1, I8, and Q6 bring forward that they wish for the hospital management to provide appropriate premises. *“[They] should set up a room for family or patient discussions. Or that one does not have a long way to go to a quiet corner with a patient without the neighbouring patient overhearing everything”* (I1).

Concluding, both the unavailability of private rooms and distractions caused by mobile phones pose a challenge to the relationship between patients and physicians because they impede personal conversations.

### *5.1.4 Level of physicians' empathy and reflexivity*

A final frequently identified challenge for the relationship between physicians and patients targets the level of physicians' empathy and reflexivity. In terms of empathy, many respondents report talking to the patient in a way that he can understand (I2) and that does not confuse him (Q1). Good communication and good expression facilitate SDM (I3, I5 & Q6), but respondents mention that not all medical colleagues can communicate with the patients at eye level (I1). I6 stresses that

*“[i]f you cannot express yourself in a layman-friendly way, you have failed to communicate as a physician. This is the case with many colleagues, and it is a disaster. You have to meet the patients where they are standing on the basis of their education, understanding, and interest. You must never take your own terminology for granted.”*

One approach towards paying particular attention to patients is to inform them with many numbers to make a good decision. For example, a physician may say: *“We are now proposing a procedure that has a potential risk of complications. We performed this procedure here 2,000 times last year, but we never had a complication”* (I3).

Additionally, the degree of physicians’ reflexivity differs considerably. On the one hand, I3 admits suggesting a patient those treatments that align with the respondent’s personal expertise:

*“I do not want to deprive the patient of his or her rights, but we have all studied for a relatively long time and have a relatively long professional experience and presume to be able to make a very good decision and to be able to assess the consequences of the benefits and risks very accurately. And in these situations, we have to put the patient in the same position to make this decision in a very, very short time. And now we have to be completely honest with ourselves. Every patient I inform about something, I naturally suggest the answer I would like to hear. We all do that. We do not really inform anyone neutrally, but the way we inform always immediately signals the patient: “This is what they think is the better procedure.” [...] Of course, I prefer to do what I am sure I can do well, and I avoid things where I say I have to read up on how it works - to put it quite exaggeratedly.”*

On the other hand, I4 stresses that

*“[one has to admit] that if someone has a rare disease, there is another hospital that has more experience in it. I have a good network and am happy to make appointments. So you also have to be able to hand over patients. Today, you can no longer be a generalist in tumour treatment. There are five to six new drugs every week – you just have to know who the specialists are.”*

In conclusion, the importance of layman-friendly expressions is acknowledged while it is also stressed that not all medical colleagues can speak with their patients in that way. A willingness to hand over patients to other physicians and/or hospitals in case of lacking own expertise could not be identified in all respondents.

## 5.2 Degree of prominence of a CEC

Next, factors that determine the degree of prominence of a CEC are identified. ‘Degree of prominence’ refers to how active and readily accessible a CEC is within a hospital. Factors can be grouped into interprofessional cooperation and organisational culture.

### 5.2.1 Interprofessional cooperation

The degree to which interprofessional cooperation takes place in German hospitals was identified to differ considerably. On the one hand, one respondent admits that their CEC is rarely noticed at all: *“I have sometimes asked myself what we are actually here for. We absolutely have to do something to make ourselves more visible again”* (I7). Yet, other respondents report more engagement. Next to individual ethical consultations that take place in all CECs, albeit with varying frequencies, the CEC of respondent I3 introduces itself during regular information and training events offered by the hospital. There, they underline that everyone can always turn to them in the case of an ethical conflict. Additionally, they offer training sessions for the staff of the intensive care unit. During these sessions, the staff is trained in talking to relatives, focusing on delivering bad news. Finally, there is training for the members of the CEC themselves, such as moderator training, in which the moderation of ethical case discussions in the various critical scenarios is taught. Another respondent mentions a particular training series called ‘Fundamentals of Ethics’, which enables medical and non-medical staff in the hospital to experience a strengthening of competence through basic knowledge of ethical issues. It enables them to reflect ethically and also to argue ethically. *“We thereby bring ethics into people's consciousness. Decision-making is improved at the end of it”* (I1).

An essential factor pointed out by I2 is that people who attend workshops already have an ethical awareness in some way. However, often, some decision-makers are not so clear about many

things. Therefore, the best way to reach them is directly on the wards. Therefore, I2's CEC directly approaches hospital staff:

*"I believe very much in personal encounters. In open discourse without hierarchies. That is why our concept here is that everything is person-specific. The colleagues contact me, and we accompany them on ward rounds. There is no particular case that is pending, but I go along, and then we have a conversation and follow up again. This gives us very good opportunities to clarify a situation in general. And that is usually much more effective than writing something down. People do not read that. They have so many other things on their minds. They need immediate support."*

Q5's CEC also offers ethical ward rounds once a month in the intensive care unit and a weekly palliative care ward round. Ethical questions are discussed and followed by a formulation of recommendations for action. At the same time, it is stressed that CECs should try to do these ward rounds so that they are not perceived as an 'ethics police' but rather as 'normal persons' who want to support decision-making in the hospital (I2). Nonetheless, not all CECs organise these kinds of regular ward rounds:

*"We do not do ward rounds at all. Many years ago, we had this idea to ask the intensive care units once a week: "Is there anything here? Does anyone want to discuss anything?" But we let that go because it never really seemed to occur. We are only acting on request. What we do here regularly is to 'advertise' the CEC and the possibility of an ethical case discussion in the truest sense of the word. You can clearly see that when you always show up and say: "You know we can hold meetings", then there are always inquiries, and in the course of half a year or a year, it fades away again" (I3).*

Similarly, I4 confirms that their CEC does not do anything like ward rounds. Guidelines and workshops are planned, but they have never organised them thus far. As such, while the degree of interprofessional cooperation may differ considerably among CECs, there is a high need for it because patient-physician communication is still not part of medical curricula (I4, I8, Q3 & Q4). The following two quotes illustrate this in more detail.

*"I have been actively keeping track of what students are learning for the last 20 years because all my sons have become physicians. This means that I have always*

*experienced it up to date. It is an absolute rarity that students are prepared for patient consultations during their studies” (I4).*

*“Communication should be a greater part of medical school. I occasionally see, especially among young doctors, that there is a certain avoidance behaviour when it comes to delivering bad news, which is, of course, a fundamental medical activity. [...] We learn a lot of facts at university, but communication is strongly neglected. [...] I have been doing this for 28 years now, and already 30 years ago, when I studied, it was said that [communication] should now be included in the curriculum. And what has happened so far? Nothing. And it will take another 30 years. So I am absolutely frustrated about that. You can only take care of it through your own initiative, for example, with extra communication courses. It is marginal at university and has no value. And I do not think that will change either. All the psychological factors in medicine have often not only been ridiculed but almost fought against for decades. For many doctors, psychology is a competing procedure instead of an accompanying or complementary, or an equivalent one. So there are really many barriers. That is also the reason why it is not really anchored in these curricula. Only general practitioners have to do a course called ‘Basic Psychosomatic Care’. They learn the basics, but of course, it is far from sufficient” (I8).*

Hence, by participating in workshops that compensate for the insufficient level of previous training on communication skills during medical school, physicians may become more aware of the importance of their words, recommendations and communication skills (Q3).

In conclusion, interprofessional cooperation includes activities such as (a) case consultations during an ethical conflict and (b) the organisation of ethics and communication workshops. (c) Ward visits are organised by some CECs but were not reported by many respondents. (d) The creation of general clinical guidelines was acknowledged but described as a future plan instead of being on the agenda currently. Overall, these activities can lead to a sensitisation of ethical issues for all parties involved. It is argued that workshops are essential in light of insufficient patient-physician communication training in medical curricula. However, the analysis shows that CECs do not enact all activities. Therefore, to investigate where this variation comes from, the next sub-subsection analyses organisational culture within a hospital.



### 5.2.2 Organisational culture

A second important factor relating to the prominence of a CEC is organisational culture. For the purpose of this analysis, organisational culture includes both top-down efforts on behalf of the hospital management and bottom-up initiatives taken by CEC member physicians themselves.

Regarding top-down efforts, a respondent stresses that “*the most important is the "spirit" of the hospital management. [...] Is there even a CEC in this clinic?*” (Q3). I5 describes that, at the respondent’s hospital, every physician above a certain rank (senior physician level) is invited to a hotel where they are taught courses on communication skills. Next to that, everyone always has access to courses within the hospital’s education centres, with many offers per year in terms of dementia counselling and more. This even includes courses on mindfulness, problem-solving, psychological resilience-strengthening, and more. The CEC then takes part in them, or CEC members even organise various of these events themselves.

CECs report directly to the management. They are not bound by instructions in their actions, specifically, they are independent and have consultative status. This was emphasised by the vast majority of respondents. A CEC always gives recommendations. It does not decide. Solely one respondent would like CECs to play a more prominent role: “*Unfortunately, [CECs offer] only consultation at the moment. [They do not have] decision-making power*” (I4). The remainder of respondents, on the other hand, seems to favour the independent character. The following quote is representative of the respondents’ justification:

*“Case discussions always have a consultative character. They can only be accepted by all the medical staff if they are advisory. If it were decisive or patronising, then it would be blocked. I can also understand that. For example, if I take care of one of my cancer patients for years, and then a CEC comes and says: “This is the end of the line”, then I would not accept that at all. As always in medicine, there are several opinions. Advice is good but imposing a decision from outside is always bad”* (I8).

The fact that CECs work independently underlines the importance of their self-organisation, that is, bottom-up initiatives taken by motivated CEC members themselves. One such activity can be establishing an ethics letterbox that allows keeping ethics on top of people's minds (I1). Moreover, I5 articulates having developed a flyer for the CEC, which contains a mission statement and an overview of persons of contact. That is because the CEC exists not only for patients but also for staff and relatives. In other words, it is approachable for everyone who is involved in a patient's illness process. According to the respondent, these flyers are available in the intensive care unit, in the mourning areas from the palliative care unit, and in the entrance area, thereby enabling the CEC to inform as many people as possible. I5 stresses that: *"Anyone who has a problem is welcome to approach us."* Additionally, another CEC voluntarily established a therapy update documentation that is stored in the computer system because they perceive advance directives as insufficiently clear in many cases:

*"We try to find out the presumed will of the patient by asking relatives, family doctors, and caregivers: "What would the patient have specifically wanted in this case? This therapy update is not insignificant, especially for recurrent patients" (I1).*

Findings show that engagement depends on the respective objectives decided for by each CEC and its members. They decide whether all possibilities or, for instance, only case discussions, are practised in the hospital (Q3). However, even if a CEC does not engage in all activities that are possible in theory, other bottom-up initiatives taken by individual CEC members can determine the extent to which CECs support SDM in daily clinical practice. For example, while I5's CEC does not do ward rounds, the respondent personally, as a chairperson, goes around as a matter of routine:

*"I then ask: "Are there problems here? Can I do anything to help you?". Then I go to the palliative ward and intensive care unit and neonatal ward, and oncology ward once a week, sometimes only once a month. Especially in oncology or*

*palliative medicine, there are also many staff members who have difficulties coping with the cases, where you have to offer concrete help. That simply has to do with caring and attentiveness towards the staff. That is a matter of personal commitment” (I5).*

Showing personal commitment via ward rounds is in line with Q3’s perception of the role of individual case consultations. In particular, the respondent declares that the question would be what needs to be done, *not* to need individual case consultations with CECs as often as possible because SDM became possible in the dialogue beforehand. Ward rounds may thus be a means to requiring individual case consultations less frequently.

In summation, it was identified that the organisational culture of a hospital influences the degree of prominence of a CEC. Both hospitals who organise communication workshops in a top-down fashion and motivated individual CEC members who aim to facilitate SDM bottom-up can contribute to creating awareness about the importance of reaching consensus with patients.

### *5.3 Dilemmas regarding financial incentives*

Dilemmas can emerge when moral obligations demand, or sometimes only appear to demand, that alternative but incompatible actions are adopted. As a result, it is impossible to perform all ostensibly required actions, although both evaluations seem appropriately grounded in the common morality by way of a set of norms that all morally serious persons share beyond tradition and culture (Beauchamp & Childress, 2013). In the end, a decision ought to be determined by considering all possible and relevant aspects. In other words, the greatest balance of right over wrong must be found (ibid). On the one hand, dilemmas can be caused by DRG system incentives in general. It is essential to analyse them in detail because they are directly associated with the feasibility of SDM efforts. On the other hand, while the opinion concerning CEC-conditional weaning reimbursement is found to be quite heterogeneous among participants, dilemmas can still

be identified. It is necessary to analyse them in the overall context, too, because otherwise, the intended objectives of including CECs in the OPS catalogue may not be reliably achieved.

### *5.3.1 DRG system incentives*

The first dilemma regarding financial incentives relates to time constraints. Within the German DRG reimbursement system for in-patient care, patients are classified according to the largest ‘consuming resource’, meaning that if a patient has several diseases requiring treatment, the remuneration system is oriented towards the treatment of the disease that consumes the most resources. Hence, there is no remuneration for ‘speaking medicine’ (I6). That is, if a physician sits down and talks to patients for an hour, he is paid the same way as if he had spoken to them for a minute (I8). In this context, six respondents highlight that an adaptation of the system would be one sign of appreciation (I8, I6, I5, Q5, Q6 & Q3). Inevitably, a focus on the provision of services rather than patient benefits also translates into time constraints. Physicians have many things to do and many patients to treat. According to I5, not everyone can be informed about every small detail and be ‘covered’ with an ethical discussion. If physicians want to inform their patients in a detailed manner, they have to work extra hours. The following quote explains this in detail:

*“You have to finish [your work] in the evening, that is the way it is. But if you want [...] to do the job for a long time and you do not want to be frustrated in the process, then you have to take the time. It does not mean that a long conversation is good just because it is long. You can also fit everything into a short conversation. That is ultimately the art of good communication. As a physician, you always have a lot of patients at the same time. For example, I have 2,000-3,000 patients a quarter. Then, of course, you have to say: “So, this I can decide quickly and here I have to take more time.” If I notice in the hospital that the conversation is taking longer and I am behind schedule, then I tell the patient that I will come back in the evening. Then we can discuss it again in a calm atmosphere” (I6).*

The respondent also calls attention to the times before the introduction of the DRG system (I6). It changed hospitals in the sense that physicians now work in a very schematised way. A

market was introduced, and benchmarking was made possible. While that was also necessary to a certain extent, it ultimately destroyed medical work, i.e., the way physicians should work, namely putting the patient at the centre of their efforts. *“If I could make a wish, it would be to repeal it”* (ibid). A second dilemma regarding DRG system incentives was made explicit by respondent I4. The experience shared in this context led to the termination of the respondent’s job at a previous hospital:

*“An elderly patient [...] was diagnosed with an intestinal tumour. That is how he ended up with the surgeons [who immediately] said: “I will do the surgery.” But the patient said he did not want that. He was under care, so the caregivers called me, and I told them that I would do the smallest possible operation [...]. Unfortunately, chemotherapy could no longer help this person. The caregiver informed the surgeon, who then said to me: “You have no idea about this. Only I can make the patient healthy.” [...] And then an ethical case discussion was summoned, which also makes sense. But the surgeon said: “Everyone is allowed to participate, except I4.” He put so much pressure on the head of the CEC that the head said: “Yes, well, we will have to do without I4”. And then, this surgeon advertised the surgery so much during the ethical case discussion that the patient actually decided to undergo surgery. And the caregiver called me and said: “I did not have a chance. He will have the surgery now.” [...] When I brought this up [at the hospital], the surgeon went to the management and said: “I4 wants to withhold operations from me. You must not extend his contract”. [The reason the surgeon has been so vehement in pushing this through is that he] has to perform a certain number of surgeries per year. If he does not achieve that, then [the hospital does not] become a bowel centre, for example, or you get your licence to perform bowel operations revoked. But I am pro-patient. I am an enthusiastic therapist. Otherwise I wouldn't be doing this for so long. I always have the right dimension and goal in mind, and, in case of doubt, I always decide for the patient - against costs and hospital guidelines” (I4).*

In short, the fact that conversations between physicians and patients are not linked to financial incentives was described to impede SDM. A focus on the number of patients and operations instead of the quality of treatment for each patient translates into time constraints and even threatened the employment of one physician who disregarded costs and hospital guidelines to offer a patient the best possible treatment.

### 5.3.2 Perception of CEC-conditional reimbursement

A second dilemma regarding financial incentives relates to the recent inclusion of CECs in the OPS catalogue. The following two quotes illustrate that some physicians perceive the inclusion problematic because discussing an ethical question against the backdrop of finances is perceived as inappropriate:

*“The integration of CECs into the OPS is out of place. The CEC should see itself as something that can exist beyond economic interests. To be integrated into an economic context is detrimental to the work of a CEC” (I7).*

*“I believe that all this may certainly have its justification [...]. But I believe that it is not part of the deeper meaning of a CEC. The CEC is the advocate of the patient who cannot speak for himself and these decisions should be independent of all rational and monetary decisions” (I3).*

As such, the following potential negative consequences of the inclusion were identified and serve to explain the perceived inadequacy:

*“[It] leads to the creation of CECs in many places, which will not always be filled with life. I can imagine that there will be many CECs [that are] only formally present. They then do the bare minimum, and that is the disadvantage. I think that, especially in smaller groups, the resources are simply not there to deal with it more. Of course, I very much welcome this because it significantly improves the ethical support of patients. On the other hand, it is always to be feared that many groups will only act half-heartedly” (I5).*

Q3 points out that this is precisely the problem in the USA:

*“As far as I know and as far as can be compared, in the USA, CECs are prescribed from the outset for the accreditation of a hospital. The problem here was [...] that there were suddenly many CECs, but they only existed on paper because it was favourable for some kind of certification.”*

Conversely, many of the same respondents understand why it may also be beneficial to include CECs in the OPS. *“The moment it is relevant for billing, they all do it. [...] And that is also good. The main thing is that they are well-staffed, and the people are well-trained” (I8).* Besides that, a respondent acknowledges the immense costs that arise at a potential final stage of

life, resulting from not having clarified whether the measures offered and carried out are really in the patient's best interest. According to some respondents, it makes sense to look closely at those cases from a cost perspective. Many times, things remain unclear in terms of communication and

*“[in these cases, a CEC then] says: ‘Listen, first of all, it is of no use to the patient, and secondly it is so expensive that these scarce resources should be used for other measures.’ I find that totally legitimate, and it is also ethically important to take it up. It was also anchored in legal documents that doctors are required to take scarce resources into account. Nevertheless, we have grey areas that we have to fill, and it is good if the most competent people possible come together and consider how [individual cases] can be solved” (I2).*

According to I6, it may also occur that a patient who ruled out life-prolonging measures in an advance directive has nevertheless ‘slipped into’ receiving artificial respiration. Then, there are very different opinions among different parties, and a CEC can listen to all of these parties and find consensus on the patient's presumed will.

Other respondents mention that the inclusion is right in a certain way because, in terms of equity, someone else might benefit from the resources that are used (I7). In a hospital, every patient who blocks an intensive care bed could also take it away from someone else. *“[O]ne must not make oneself holier than one is [...]. That is how you have to look at it. It is not only profitable but also increases the quality of care” (I3).*

Besides equity considerations, respondents also recognise other types of benefits. The inclusion underlines that, nowadays, people have become more open to seeing the patient as a whole: *“Ethical aspects were often ridiculed in the past. This is now slowly catching up, also in Germany. As a result, CECs are now being taken more seriously” (I4).*

Contrastingly, some of the respondents express their belief that financial intentions do not play a role in this context and that they cannot imagine why weaning was chosen for the OPS in

the first place (I8). It is believed that a goal may be to bring morality back to the fore rather than pecuniary intentions (I1). The following two quotes exemplify this perception.

*“I do not believe that there are financial interests behind it. Usually, no costs would be saved because the decisions made there are actually independent of any cost-financing models. On the contrary, even more costs are incurred because these meetings often take place outside working hours. So for us, that causes a lot of costs. [Including CECs in the OPS is] more about educational things and establishing the whole thing in everyday hospital life” (I5).*

*“I have not quite figured out yet what the legislator wants to achieve with the mandatory involvement of a [...] CEC for a certain procedure key. I am also not sure whether the weaning OPS code is already armed. It is just that it excludes certain hospitals. You can then specifically control what takes place where. The legislator is very interested in this. They no longer want 2,200 hospitals in Germany to provide the same services at an average level. They want to have a few lighthouses, that is, a few centres of excellence. This is very well established in Denmark, for example. This is how the legislator steers medicine” (I1).*

Consistent with the above, many respondents did not know about the new OPS before the interviews or, equivalently, before receiving the questionnaire. In other words, respondents were not aware that the billability of weaning is linked to a CEC (I7, I6, Q4 & Q8). This finding is coherent with one of the physician’s experiences in economic consulting of hospital organisations:

*“My experience from economic consulting of hospital organisations has shown again and again: Often, the physicians have no (or at least not a very concrete) idea of what economic effects result from their medical and nursing actions. Especially when they are now ‘nudged’ to explore the true will of the patient (in the very difficult decision-making concerning ventilations) with the help of a CEC, this not only serves the patients but ultimately also an efficient use of hospital resources. In addition to the advantages of SDM, this results in positive billing incentives as a useful side effect: The documentation of what was done becomes more detailed and meaningful. At the same time, the existence and work of a CEC, by naming it in the OPS, are also removed from the feeling of ‘only’ doing something ethically good without being economically and technically compelling. The financing of a CEC thus becomes a serious cost calculation component. But once the CEC is installed and established, it can better fulfil its primary function of harmonising treatment decisions definitively with the will of the individual patient. The unwanted is omitted, the intended is achieved precisely. Resources are used precisely. Everyone benefits from this. In order to prevent the provision of a CEC only pro forma and to be able to claim it checked in the billing for maximising*



*revenues without practical improvement of the physician-patient dialogue, the actual question of the use of the CEC should be documented concretely” (Q1).*

Concluding, physicians expressed diverging opinions about the inclusion of CECs in the OPS catalogue. While some respondents perceive this inclusion as inappropriate and identify possible negative consequences, others also acknowledge its rationale. Nevertheless, other respondents cannot understand why CECs were included in the OPS catalogue and were not informed about it altogether in the first place, which is coherent with one of the respondent’s experiences in economic consulting of hospital organisations.

## 6. Discussion

The present study explored how SDM is addressed in German hospitals and how CECs could encourage its implementation. Overall, 16 participants shared their experience with SDM in daily clinical practice and their perspective on the role of CECs in this context. In this section, results presented in the previous section will be discussed and compared to previous literature findings from sections 2 and 3.

To begin, analysing patient-physician relationship challenges in section 5.1 revealed that most respondents choose therapy selection as a focal point for patient co-determination during a medical treatment process. It also showed that this focal point is linked to a sense of obligation. The analysis discovered certain discordances, as some treatment sections that were considered a focal point of co-determination were also explicitly *not* considered a focal point by others. What is more, while some respondents believe that patient co-determination is impossible in some situations, others refer to caregivers, legal guardians, or advance care planning when patients have restricted cognitive abilities. This finding confirms the assumption that some interviewees might presumably not be aware of how many different routine hospital treatment sections SDM is viable

in. As mentioned in [section 4.2](#), this assumption, in turn, was based on the research findings that SDM has not yet gained the status that it is normatively intended to have. Hence, SDM is not sufficiently implemented as specified in German legislation, which was presented in [section 2.2](#).

In [section 5.1.2](#), a contradiction to previous empirical research was identified concerning physicians' views on increasing patient health literacy. While the study by Bittner and Schmidt-Kaehler (2018) disclosed that, without exception, physicians rate the use of videos for conveying information positively and expect it to promote SDM, some of the physicians who took part in the present study were more critical in this regard. This is due to negative experiences, such as a nocebo effect resulting from the use of videos. Next to videos, some respondents were critical towards certain internet sources in general, as they contain incorrect patient information and can lead to wrong preconceived opinions. In this context, no physician mentioned the IGeL Monitor, or the second opinion procedure stipulated by § 27b of the SGB V, described in [section 2.2](#). This may lead to the assumption that these kinds of generalised health policy efforts are not always as effective as they are intended to be. Additionally, one respondent stressed that treatment situations are so individual and complex that the patients' ability to inform themselves is very limited. Therefore, in the end, patients would have to trust their physicians. In any case, believing that patients must only trust their physicians resembles the paternalistic view explained in [section 2.1](#) and, hence, is not in line with collaborative SDM values that take into account a patient's values, goals, and preferences (Borysowski et al., 2020).

Furthermore, the analysis in [section 5.1.3](#) revealed that appropriate premises need to be established in a hospital. Private rooms and fewer distractions are needed to support SDM efforts. In the future, one way to counteract this impediment could be that CECs actively advocate for appropriate premises. By encouraging the preconditions, they would have an effect far beyond

communication itself. In line with this thought, the inclusion of CECs into the OPS catalogue could then also be interpreted as an appeal to the establishment of hospital premises.

In line with the umbrella review findings by Alsulamy et al. (2020), analysing physicians' empathy and reflexivity in section 5.1.4 revealed that the SDM process is facilitated by physicians using simple terminology. However, respondents described that some of their colleagues are not always able to do so. Analysing physicians' reflexivity also disclosed that respondents do not habitually inform patients neutrally but in a way that already implies the answer they want to hear. This unveils a slightly different perspective compared to the findings of the study by Bittner and Schmidt-Kaehler (2018). While in their study, the reason behind recommending specific treatment options is how lucrative these options are for the clinic, respondents in this study referred to their own professional strengths and weaknesses. That is, it was said that they tend to recommend treatments that they do not have to read up on again. Here, CECs could facilitate reflexivity, such that the risk of over- or underestimating oneself is limited. How they can achieve this, in particular, is in line with the following considerations.

Exploring the degree of prominence of a CEC in section 5.2 disclosed that there are many ways in which CECs can facilitate SDM in daily clinical practice. (a) Individual ethical consultations facilitate the SDM process in a conflict situation by assembling everyone involved in the treatment process of a particular patient. (b) CECs can also encourage SDM by organising workshops and continuing education training in questions of clinical ethics. This training targets all medical and non-medical staff in the hospital to experience a strengthening of competence through basic knowledge of ethical issues. Thereby, they sensitise participants to respect patient autonomy in all treatment sections and foster the legal and ethical imperative of reaching consensus. (c) The relevance of ward visits was underlined, as they precisely target the staff that

may not have an ethical awareness in some way beforehand. (d) The creation of hospital guidelines can also facilitate SDM. In sum, the identified activities confirm the possibility for synergy effects described by Vollmann (2008) and link them specifically to the concept of SDM.

Yet, the analysis in [section 5.2.1](#) also showed that there are varying degrees to which CECs engage in such interprofessional activities. As such, a high need for continued education was highlighted, given inadequate training on patient-physician communication during medical school. This finding is partly contradictory to previous literature, given that Härter et al. (2017) argue that universities increasingly succeed in integrating SDM as a mandatory class into their medical curricula. However, in line with the present study, Bittner and Schmidt-Kaehler (2018) also find that the current education and training in patient-physician communication does not sufficiently take into account daily clinical practice. In essence, this confirms the meaningfulness of CECs in bringing ethical considerations into physicians' awareness and thereby ultimately improving patient-physician communication. Results also demonstrated that ward visits and the creation of clinical guidelines are the least frequent activities of the respondents' CECs despite their potential benefits to achieve lasting change in a hospital. Lastly, in [section 5.2.2](#), it was highlighted that CECs need support from both individual CEC members and hospital management to make such efforts visible and easily accessible within the hospital. In other words, the organisational culture needs to be aligned with CECs' objectives.

Investigating dilemmas regarding financial incentives first pointed towards general DRG system incentives in [section 5.3.1](#). Notably, it was frequently highlighted that there is no remuneration for 'speaking medicine' which, in turn, translates into time pressure that physicians experience. While this is not something a CEC can improve per se, this insight is in line with

previous literature by Young et al. (2008) who suggest ample time in consultations to counteract SDM impediments.

The second dilemma regarding financial incentives was analysed in section 5.3.2. It reinforced the need to be aware of potential negative consequences that can result from including CECs in the OPS catalogue, such as creating CECs that only exist pro forma. Nonetheless, it was also stressed that financial incentives might act as a positive impetus for creating CECs that will, on the contrary, be staffed with enthusiastic members. An increasing number of CECs will then enable more physicians to be sensitised for ethical considerations and the importance of respecting patient autonomy as much as possible, thereby facilitating SDM in the future.

In this context, another major finding is that many CEC member physicians did not know about the inclusion of CECs in the OPS catalogue in the first place. This particularly underlines the need for physicians to be educated about economic dimensions related to hospital treatments. As long as physicians are unaware of reimbursement structures related to treatments they recommend and execute, they cannot inform patients about any economic implications of treatment decisions. This is especially important in light of the Federal Court of Justice's ruling from January 28<sup>th</sup>, 2020 (File number VI ZR 92/19) presented in section 2.2. It implies that a physician must also provide patients with a clear picture of their situation from an economic perspective. In fact, if economic advice is not provided adequately, physicians are liable to pay damages to the patient. As treatments become ever more expensive as they approach a patient's possible end of life, it becomes equally ever more critical to assess the adequacy of all procedures.

### *6.1 Limitations and recommendation for future research*

As with the majority of studies, findings have to be seen in the light of some limitations. Firstly, two types of selection bias must be borne in mind. To begin, CEC member physicians who

agreed to participate in this study may be more interested in the outcome of this research than others who did not respond to e-mails and direct messages via LinkedIn in the first place. This limitation was addressed by including questionnaires as part of the data collection process. Questionnaires may attract physicians who are not significantly more interested in the topic than others since it is quicker to fill in than participating in an interview. However, given the nature of this research, this notion cannot be circumvented entirely. In addition, given that all physicians are or have been CEC members, a further selection bias could be that they naturally tend to have rather reflective personalities and bear ethical considerations more in mind in their daily practice than the average physician. However, a physician who is not a CEC member would not have been able to answer the questions about CECs, while non-medical CEC members would not have been able to share their experience with SDM in clinical practice. Therefore, it is assumed that this limitation does not have far-reaching consequences for the value of this research.

A second limitation relates to the absence of available research linking CECs with SDM. This absence acts as a barrier to the availability of a rich theoretical foundation for this research. Hence, there is a high need for further academic research and theory development in this study area. In any case, the findings of this thesis offer a foundation for future researchers who wish to investigate the link between CECs and SDM more closely in the future, as it points towards possible complexities that need to be addressed.

Thirdly, results must be interpreted with caution since the timeframe of this research was limited. Therefore, the number of respondents is relatively small. As a result, certain contrasting views may be missing. This limitation could be addressed in future research by extending the timeframe and including more physicians.

Finally, an interesting future study could slightly adapt the research focus and include non-medical CEC members, such as lawyers and nurses, in the analysis. Insights can then be compared to the derived findings of this study. Thereby, academic researchers may investigate how the professional background of CEC members impacts their perception of the role of CECs in encouraging SDM in hospitals.

## 6.2 Contributions

This thesis contributed to scientific knowledge surrounding the concept of SDM. First, a contribution of this thesis lies in (1) breaking down a routine hospital treatment process to analyse physicians' understanding of the viability of SDM in depth. Additionally, the researcher is not aware of any study that previously assessed to what extent CECs can encourage SDM in hospitals. Therefore, a further contribution lies in (2) creating a link between the SDM model and the existence of CECs in order to enrich the discussion surrounding how to facilitate SDM in clinical practice. A last contribution lies in (3) analysing the impact of including CECs in the OPS catalogue. Studies on this matter have not yet been published since the regulation was just implemented on January 1<sup>st</sup>, 2021.

## 7. Concluding remarks

The following research question was addressed: *“To what extent could Clinical Ethics Committees encourage Shared Decision-Making in German hospitals?”*. Narrowing down all insights of this study yields the following five main findings. (1) Discordances exist in physicians' perception of the viability of SDM during a routine hospital treatment process. Hence, SDM is currently not fully achieved in all sections of a routine hospital treatment process. The analysis also revealed that (2) CECs could encourage SDM by fostering ethical awareness among

physicians via (a) individual case consultations, (b) ethics and communication workshops, (c) ward visits, and (d) the creation of hospital guidelines. However, (3) not every CEC engages in all of the described activities. While individual case consultations were described as the main activity of CECs, ward visits and the creation of hospital guidelines were commonly neglected. In light of insufficient patient-physician communication training during medical school, ethics and communication workshops were identified to be particularly essential. (4) Including CECs in the OPS catalogue might act as a positive impetus for creating more CECs. Insofar as these will be well-staffed, it will enable more physicians to be sensitised for ethical considerations and the importance of reaching consensus with patients, thereby facilitating SDM in the future. Finally, (5) physicians should be further educated about economic dimensions related to hospital treatment. As long as physicians are unaware of reimbursement structures related to treatments they recommend and execute, they cannot inform patients about the economic implications of treatment decisions, as stipulated by German legislation. Future research may thus explore ways to increase physicians' awareness of the economic implications of their decisions as well as all roles and responsibilities related to a CEC, thereby ensuring that their existence enriches the entire treatment process. Doing so, researchers and lawmakers shall not lose sight of the fact that CECs are meant to have a consultative status in ethical questions.



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## 9. Appendices

### Appendix A: Overview of participants ( $n=16$ )

Participant	Method	Physician's area of expertise
I1	Interview	Internal medicine, gastroenterology, and geriatric rehabilitation
I2	Interview	Anaesthesia
I3	Interview	Anaesthesia and intensive care
I4	Interview	Haematology-oncology and additional qualifications in palliative medicine and geriatrics
I5	Interview	Geriatrics and internal medicine
I6	Interview	Internal medicine and additional qualifications in haematology-oncology and palliative medicine
I7	Interview	Internal medicine, geriatrics, palliative medicine, and naturopathy
I8	Interview	Internal medicine with a specialisation in gastroenterology and oncology
Q1	Questionnaire	Urologist
Q2	Questionnaire	General medicine, geriatrics, and palliative medicine
Q3	Questionnaire	Cardiology
Q4	Questionnaire	Anaesthesiology and intensive care
Q5	Questionnaire	Anaesthesiology and palliative medicine
Q6	Questionnaire	Gynaecology and obstetrics, gynaecological, and oncology
Q7	Questionnaire	Surgeon
Q8	Questionnaire	Anaesthesia and intensive care



## **Appendix B: Translation of document sent to participants before the interviews**

### Background

In 2013, the German legislator positively regulated the obligation for shared decision-making between physician and patient in the German Civil Code (BGB), which had previously only applied under customary law: “The treating physician and the patient shall cooperate in carrying out the treatment.” The legal requirement to cooperate does not only apply to the treatment steps themselves but also has an effect in advance: “When informing the patient, alternatives to the treatment must also be pointed out if several medically appropriate standard methods can lead to substantially different burdens, risks or chances of recovery.” The explicit legislative emphasis on the idea of medical cooperation legitimises, after about eight years of practical experience, not only the general legal question of whether and to what extent this right of patients to cooperation is actually implemented in everyday hospital life. Of particular interest is what specific role a Clinical Ethics Committee (CEC) could and should take on - during therapy as well as afterwards in its remuneration.

### Interview Questions Part 1: Shared Decision-Making (SDM)

1. About yourself:
  - a. In which field do you specialise as a physician?
  - b. How many years have you been practising your current profession?
  - c. Since when are you a member of a CEC?
2. Do you personally support the patient's right of co-determination in the selection and implementation of the medical measures you perform?
3. If you divide the course of your work for patients into the nine treatment sections defined below,

- a. Where do you see a focal point for a patient's right of co-determination? During
    - o anamnesis
    - o diagnosis
    - o therapy counselling
    - o therapy selection
    - o therapy implementation
    - o progress evaluation
    - o determination of post-treatment behaviour
    - o discharge management
    - o follow-up
  - b. Why do you put emphasis on the treatment section(s) you choose?
4. Are there groups of cases in which you consider patient involvement in medical decision-making
  - a. impossible?
  - b. indispensable?
5. Which factors
  - a. facilitate,
  - b. impede,that SDM is enabled and implemented in the cases you consider indispensable?
6. According to your personal assessment, how could the impeding factors mentioned be counteracted on behalf of
  - a. physicians?
  - b. patients?

- c. hospital management?
- d. legislators?
- e. others?

Interview Questions Part 2: CECs

- 7. In your opinion and experience, what are the main tasks of a CEC?
- 8. How can CECs effectively facilitate SDM in everyday clinical practice?
- 9. What consequences could the inclusion of CECs in the OPS catalogue have for SDM in hospitals in the future (see OPS 8-718.8 and 8-718.9)?
- 10. Where do you see the limits of CEC involvement in a treatment process as a whole?
- 11. Is there anything else you would like to mention in this context?

Further information

I will ask you for explicit consent to record our interview before it begins. If you wish to withdraw from the study, you will, of course, have the option to do so at any time. I will make sure that your statements cannot be traced back to you personally so that you can express any concerns openly. I will send you the transcript of our conversation soon so that you can confirm that I have accurately recorded your statements. Thank you very much in advance!

**Appendix C: Codebook**

Code Group	Code	Description
Patient-physician relationship challenges	Frictions regarding role expectations	This Code is applied whenever respondents set a different focal point of patient co-determination and whenever frictions are identified regarding respondents' perceptions on whether patient involvement is impossible in certain situations. The Code is also applied when respondents mention that they wish for more precise rules on behalf of lawmakers.
	Concerns regarding patient health literacy	This Code is applied whenever respondents express their views on the importance of patients' medical knowledge and the effectiveness of online information or other tools, such as videos.
	Availability of appropriate premises	This Code is applied whenever respondents mention that their relationship with patients is impeded by the lack of private rooms or other distractions, such as mobile phones.
	Level of physicians' empathy and reflexivity	This Code is applied whenever respondents describe how they use layman-friendly expressions when talking to patients. The Code is also applied when respondents reflect on their professional strengths and weaknesses.
Degree of prominence of a CEC	Interprofessional cooperation	This Code is applied whenever respondents report engagement between their CEC and other employees at the hospitals. It is thereby linked to any hospital-wide activities that the CECs engage in. The Code is also applied whenever respondents point out the relevance of these activities, such as deficiencies in patient-physician communication training during medical school.
	Organisational culture	This Code is applied whenever top-down management initiatives and bottom-up CEC member initiatives are mentioned that support the visibility of CECs within a hospital.
Dilemmas regarding financial incentives	DRG system incentives	This Code is applied whenever respondents mention time constraints and a focus on quantity of care instead of the quality of care.
	Perception of CEC-conditional reimbursement	This Code is applied whenever respondents express their views on the recent inclusion of CECs in the OPS catalogue. This Code also applied whenever respondents are not aware of this recent inclusion in the first place.