PATIENT INVOLVEMENT IN MEDICAL DECISION-MAKING: EXPLORING PATIENTS' PERSPECTIVES

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Thomas Miller
Hamburg, June 2025

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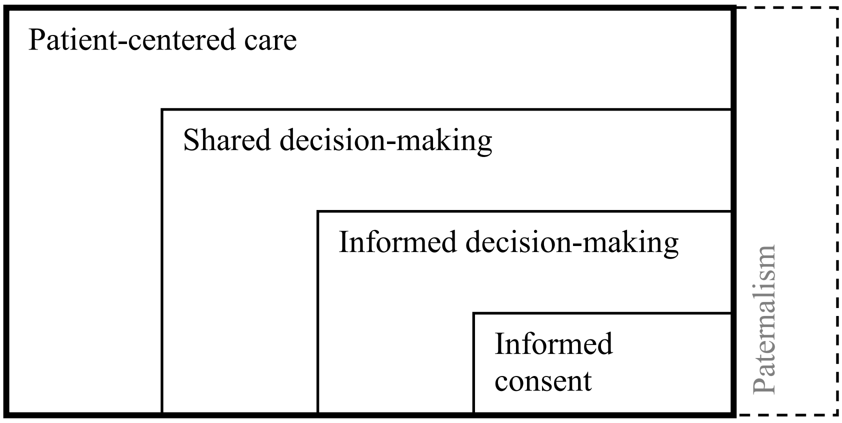
1.1.1 Conceptual Overview of Patient Involvement

Involving patients in medical decisions has evolved into a dynamic domain of study. Originating in the 1980s, this field was primarily driven by ethical and legal considerations from a regulatory perspective (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1982). International regulators intended to establish healthcare systems grounded on two fundamental ethical principles: personal welfare and autonomy (Frosch and Kaplan 1999). To date, the scientific literature uses different terminologies for patient involvement, notably patient autonomy, informed consent, shared or informed decision making and patient-centered care (Altin and Stock 2016; Bensing 2000; Bravo et al. 2015; Constand et al. 2014; Rubinelli et al. 2009; Cribb and Entwistle 2011). These patient involvement concepts aim to systematically incorporate patient needs, perspectives, preferences, and values into medical decision-making processes. The aim is to enhance or restore patients' autonomy, encompassing associated rights, responsibilities, and opportunities (Bravo et al. 2015).

Various patient involvement concepts attempt to achieve this objective. Following Opel (2015), Figure 1.1 contextualizes these different concepts.

Figure 1.1. Patient Involvement Concepts.



They share varying degrees of divergence from the principle of *paternalism* (depicted outside the perimeter in Figure 1.1), which deliberately disregards patients' preferences and values. In a paternalistic approach, clinicians independently make decisions on behalf of the patient, typically based on a professional evaluation of what constitutes the patient's best interest (Tonelli and Sullivan 2019). At most, the patient has the right to refuse the medical decision. In contrast, *informed consent* upholds individual autonomy by providing a choice between treatment options. The essence of informed consent is the patient's explicit agreement, essentially giving them the right to veto a short list of potential interventions proposed by a physician (Faden 1986). *Informed decision making* goes beyond this, describing a process where patients gather relevant health information from their clinician as well as other clinical and nonclinical sources, and make decisions based on this information and their individual values (Sheridan et al. 2004). In both informed consent and informed decision-making, clinicians primarily function as educators, providing patients with information to make autonomous decisions. This approach minimizes the influence of personal or professional judgment from the clinician. While the clinician's role may still include implementing treatments, such as prescribing medication, they remain largely uninvolved in the decision-making process regarding the course of care. In simple terms, in paternalistic models, the physician makes the decisions, whereas in informed models, the patient makes the decisions. *Shared decision making*, on the other hand, describes a collaborative decision-making process between physician and patient. Healthcare professionals and patients jointly make decisions about tests, medical diagnoses, treatment alternatives, and therapies. These decisions are ideally based on the most reliable evidence, as well as patient preferences and values (Coulter 2018; Bae 2017; Epstein and Street 2011). This ideal clearly goes beyond selecting between alternative interventions proposed by a clinician. Tonelli and Sullivan (2019) describe shared decision making as a process that starts even before a diagnosis, when clinician and patient collaboratively decide which symptoms to investigate, which processes require explanation, and what value is derived from making a diagnosis. Subsequently, patients actively participate in the diagnostic process by determining how the disease affects their overall health and life, thereby personalizing the diagnosis. This patient participation enhances the physician's diagnosis but does not replace it. In this way, both parties jointly contribute to the decisions made. Finally, the concept of *patient-centered* *care* extends beyond shared decision-making by aiming to understand and integrate patients' values, needs, and desires into healthcare decisions (Constand et al. 2014). As the broadest involvement concept, it may encompass all the aforementioned concepts, including the more simplistic informed consent model, if this aligns best with the patient's values, needs, and desires (Opel 2015).

From this brief contextualization of the various concepts of patient involvement, questions arise about what factors may undermine the effectiveness and intended value of this approach to healthcare. On the patient side, for instance, the issue of consumerism may emerge, as highlighted by the professional literature (Freidson 2001). The critical point is that consumerism undermines professionalism in medical decision-making by overemphasizing patient choice and autonomy at the potential expense of physicians’ medical expertise and responsibility. This shift prioritizes the idea of healthcare as a market transaction rather than a professional, trust-based relationship. Another factor is that patient involvement often assumes all patients desire equal involvement, overlooking those who prefer to delegate decisions to experts. Issues on the side of physicians, for instance, arise in situations that may require that decision authority rest with clinicians, as patients, such as in cases of severe accidents or acute illnesses, have no real choice if they seek positive health outcomes. Additionally, physicians may justifiably find it beneficial to help patients in critically evaluating their values and preferences. In this view, the professional's role may involve persuading patients to make better medical decisions while simultaneously respecting and fostering their autonomy.

These considerations indicate that there can be no single, universally applicable approach to patient involvement. The diversity of situations in which patients and physicians may encounter each other suggests that both parties must find the appropriate approach and level of patient involvement for each consultation. This expectation presents a significant challenge for physicians. Patient involvement thus becomes part of the broader question of how to develop and deliver richer, potentially more collaborative models of healthcare (Cribb and Entwistle 2011). How can (or should) physicians involve specific patients in specific situations? Addressing this question requires adaptable approaches for individual consultations, grounded in theory and practically implementable. This involves creating robust theoretical frameworks to guide patient involvement and ensuring these frameworks can be effectively applied to diverse healthcare settings.

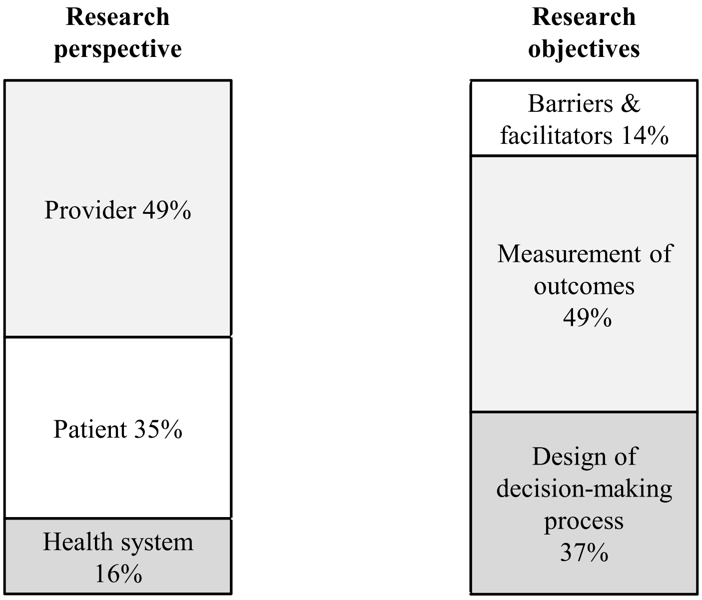
The lack of theoretical frameworks for adapting patient involvement to specific clinical contexts and individual patient needs constitutes a key barrier to its broader integration into mainstream medical practice (Coulter 2017, 2018). Numerous research findings reveal a contradiction between the desire of most practitioners and patients for patient involvement and its insufficient implementation in healthcare practice (Longtin et al. 2010; Dahl Steffensen et al. 2017; Frosch and Kaplan 1999; van der Weijden et al. 2017; Légaré and Witteman 2013; Dimopoulos-Bick et al. 2019). This implementation deficit seems less surprising when considering the demands that patient involvement places on physicians. Ultimately, patient involvement expects health professionals to facilitate patient decision buy-in, ensuring that patients feel comfortable with a medical decision (Cribb and Entwistle 2011). Whether this is achieved through paternalistic approaches, informed consent, or shared decision-making is primarily at the physician's discretion. It is an ambitious expectation for physicians to consistently identify, in each context, the most suitable approach that optimizes patient involvement. This expectation is further intensified by the requirement that physicians, when necessary, assist patients in evaluating and critically appraising their own preferences (Cribb and Entwistle 2011). Patient involvement, in this case, means that providers may attempt to persuade the patient of the benefits of some health-related values relevant to the decisions at hand, especially if patient preferences demonstrate a lack of understanding about relevant health issues or possible interventions. In such cases, it is not sufficient for a physician to simply elicit patients' preferences and unreflectively incorporate them into the decision-making process (Cribb and Entwistle 2011).

One possible way to address these patient involvement challenges is to systematically investigate patient perspectives in a theoretical manner. The underlying idea is to enable physicians to quickly and accurately understand what is particularly important to patients in specific decision-making situations. This understanding can help to gain a patient's acceptance or to identify where (and how) persuasion may be necessary to prevent harm to the patient. The aim of this dissertation is therefore to combine different forms of patient perspective analysis and determine how physicians can more effectively tailor patient involvement to specific individuals and situations. To this end, I first delineate the research landscape's focal points and potential gaps or biases that may arise.

1.1.2 Patient Involvement Research Perspectives and Objectives

Research on patient involvement examines three different levels: the health system, the healthcare provider, and the patients (Bravo et al. 2015). Based on my systematic literature review of 99 articles on patient involvement (Chapter 2 of this dissertation, published by the journal PEC in 2023), studies predominantly adopt the provider's perspective. Figure 1.2 summarizes the three foci and the research objectives of the examined studies. The percentages indicate the proportion of publications that represent the stated research perspective or research objective.

Figure 1.2. Patient Involvement Research Focus and Objectives.



The figure illustrates that healthcare providers are the primary subject of investigation within the scope of patient involvement research, followed by patients and the health system. Examining outcomes of patient involvement outweighed other research objectives of the studies. Another important research area was the design of the shared decision making process between doctor and patient, along with involvement-specific interventions and strategies. Many of these studies focus on specific use cases, which limits their generalizability. This is exemplified by titles such as "Implementing shared decision making in the NHS: lessons from the MAGIC programme" (Joseph-Williams et al. 2017), "Challenges and Strategies of Implementing Shared Decision Making in Individualized Oncology" (Haltaufderheide et al. 2019), or "Supporting stroke patients' autonomy during rehabilitation " (Proot et al. 2007).

This overview of the current research on patient involvement provides an impetus for further problematization and also highlights underexplored areas. Firstly, the field is characterized by various research perspectives that highlight specific interventions, outcomes, a wide array of diseases, healthcare settings, and patient scenarios. This has led to a fragmentation of existing research findings and, in many cases, to conflicting results lacking overarching theoretical explanations. Secondly, the emphasis of current research on outcomes and process design may have led to the underlying phenomena influencing these outcomes and processes remaining opaque.

A review of key research findings on patient involvement illustrates this lack of focus on underlying phenomena, such as the perspective of patients. A significant portion of the research has concentrated on developing interventions and approaches. An example of this are patient decision aids that describe decision options and their consequences for specific medical conditions (Danner et al. 2020; Longtin et al. 2010; Elwyn et al. 2012). Such information material was found to support structured patient involvement interventions, for instance the Three Questions approach, which encourages patients to inquire about options, benefits, harms, and their likelihood (Shepherd et al. 2016; Shepherd et al. 2011; van Veenendaal et al. 2018). Another approach targeted at practitioners is the Three Talk Model designed to allow physicians and patients to cooperate, discuss alternatives, and make preference-based decisions (Elwyn et al. 2017). Still, contemporary studies present inconsistent results regarding the success of patient involvement, even when incorporating the described interventions. Some research has identified positive correlations between patient involvement and health, health literacy, and the accuracy of risk perception (Driever et al. 2020; Altin and Stock 2016; Bensing 2000; Bravo et al. 2015; Constand et al. 2014; Fortune et al. 2016; Epstein and Street 2011; Rubinelli et al. 2009). Other studies have primarily discovered negative outcomes in the implementation of shared decision making (Coulter 2018; Hughes et al. 2018). Furthermore, the utilization of patient decision aids has not met its anticipated expectations. Research indicates that merely distributing these aids to patients is insufficient for their involvement (Constand et al. 2014; Joseph-Williams et al. 2017; Hargraves et al. 2016). Patient decision aids fail to cater to the health literacy needs of a large portion of the population, and the majority of patients do not utilize them (Tracy et al. 2022). Given this context, it is surprising that Bae et al. (2015) propose overcoming the limited success of patient involvement by providing even more patient decision aids with even more detailed information (Bae 2015). This conclusion highlights that patient involvement research partly remains focused on optimizing existing processes rather than prioritizing the investigation of previously unexplored phenomena that may influence these processes.

Nevertheless, current research acknowledges that patients' individual perspectives and preferences regarding involvement in medical decisions represent a significant, yet insufficiently explored area (Coulter 2018; Joosten et al. 2008). This lack of a systematic understanding is a critical factor preventing the success of patient involvement (Timmermans 2020; Khunkhun et al. 2022). For instance, not fully understanding patients' preferences may lead to clinicians misinterpreting them, which has been identified as a significant barrier to successful patient involvement (Légaré et al. 2008). Although interventions like the Three Talk Model explicitly inquire about these preferences, it is likely that patients will not – or cannot – fully disclose them during the unique context of a consultation (Haltaufderheide et al. 2019; Pham et al. 2020). This is especially true when the preferences relate to uncomfortable topics such as mistrust or feeling overwhelmed. Therefore, I suggest to enhance patient involvement and buy-in by systematically investigating patient perspectives outside of consultations. This approach allows for the development of a general systematic understanding of patients' views on involvement in medical decision-making. The theories and frameworks developed from such investigations can in turn inform situation-specific physician-patient conversations.

1.1.3 Research on Patient Perspectives

Before reviewing the existing research on patient perspectives, I will briefly summarize the current problems of patient involvement identified in the previous sections. Depending on the stakeholders and situations involved, patient involvement can be conceptually very multi-faceted, ranging from simple informed consent to holistic patient-centered care. Some of these situations may not be suitable for shared decision making, as they may, for instance, involve medical emergencies that leave little room for alternative options. Furthermore, it may not be sufficient to consider the preferences of certain patients without criticism, as this could potentially be harmful to their health. Given this context, the research field is too fragmented to provide overall guidance for collaborative care. It is likely that significant explanations for the success or failure of patient involvement have remained unexplored. Interventions and involvement tools show mixed results and sometimes fail to fully involve patients. Many of the issues mentioned here seem to arise from a lack of knowledge about patients' perspectives on involvement. This deficit increases the likelihood of misunderstandings and situations where patients and doctors talk past each other, with patients superficially agreeing but not genuinely supporting the decisions. It also makes it more challenging for physicians to assist patients in critically evaluating their perspective, if they feel this is required. In such cases, understanding the patient's mindset becomes even more crucial to prevent poor health decisions. This is particularly relevant in situations where a perceived lack of understanding about relevant health issues or possible interventions is more an emotional problem (such as lack of trust) than a cognitive one.

Investigations into patient mindsets in the literature on patient involvement are only partially suitable for understanding the backgrounds and prerequisites of successful involvement. On the one hand, they predominantly examine preferences in the context of individual medical conditions (Miller and Reihlen 2023). On the other hand, they largely ignore specific decision logics and primarily investigate whether patients prefer involvement or not, without providing explanations for either preference (Arora and McHorney 2000). The literature describes various theories regarding doctor-patient relations (Childress and Siegler 1984; Emanuel and Emanuel 1992; Roter 2000). These theoretical frameworks, however, have not yet been empirically confirmed and have therefore scarcely been incorporated into the literature on patient involvement.

Other research fields, such as Sensemaking Theory or research on mental models, explore and confirm the significant influence of preferences on decision-making behavior. Consequently, knowledge alone does not drive decisions (Tuomi 1999). Instead, they are contingent upon different preferences, interpretive frameworks, and knowledge structures (Ringberg and Reihlen 2008).

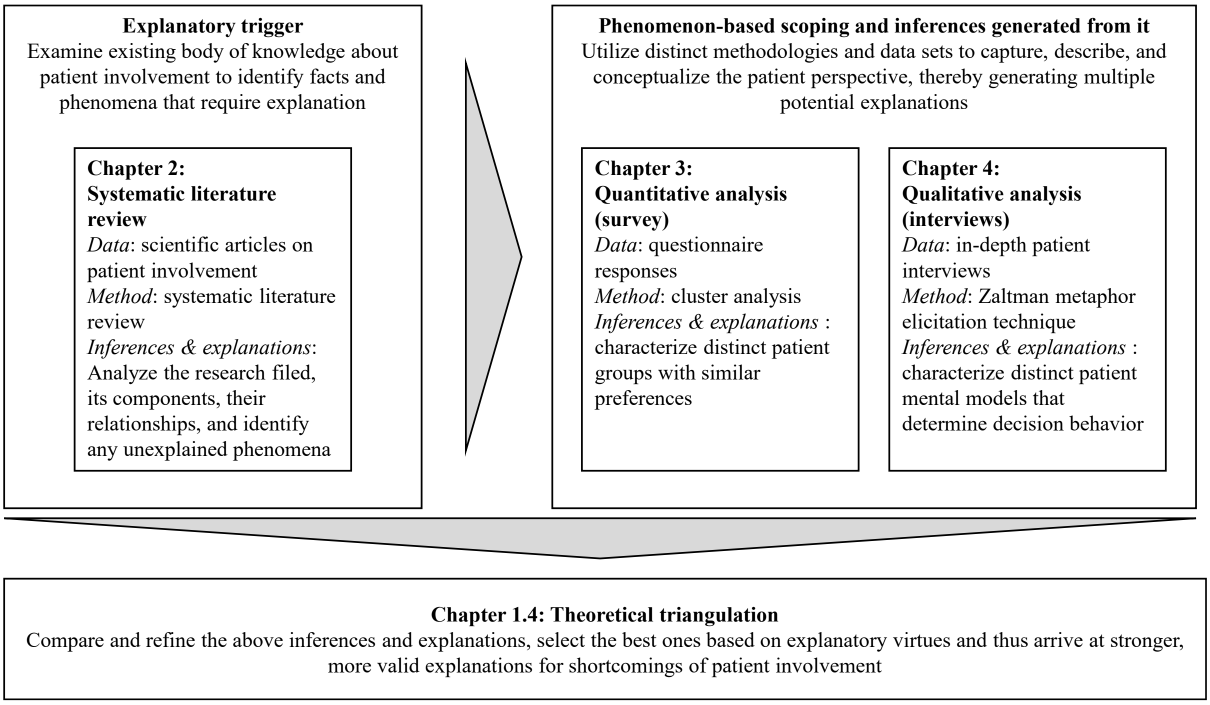
Overall, patient perspectives continue to be insufficiently explored, despite the potential insights that could be gained from other scientific domains to enhance our understanding of them. This lack of a theoretical foundation to understanding patient preferences is likely to make it difficult to firmly establish patient involvement in medical practice.

1.2 ADVANCING PATIENT INVOLVEMENT

To derive robust theories regarding the role of patient perspectives in patient involvement, this dissertation follows Cornelissen's (2023) proposal for theoretical triangulation. The fundamental idea is that we can achieve a more comprehensive understanding of a theme by utilizing diverse data, theorizing styles, and methodologies (Cornelissen 2023). This method aims to provide a more nuanced and comprehensive understanding of phenomena, which is particularly useful in a field characterized by the richness and complexity of human experience (Turner et al. 2017). It can also highlight associations that may have been overlooked in previous research approaches and methods (Cornelissen 2023). Moreover, employing alternative research methods and theoretical perspectives mitigates the specific inferential biases and threats to validity that come with the reliance on any single approach (Cornelissen 2023). This is particularly true when, as in the present case, both qualitative and quantitative approaches are used for triangulation (Denzin 2012). Overall, I expect this combination of methodological practices, data, and perspectives to enhance the richness and depth of the inquiry into patient involvement, providing more comprehensive explanations overall.

Figure 1.3 illustrates how I apply Cornelissen's theoretical triangulation and how this dissertation navigates it.

Figure 1.3. Theoretical Triangulation in this Dissertation Based on Cornelissen (2023).



Explanatory trigger
Examine existing body of knowledge about patient involvement to identify facts and phenomena that require explanation

Chapter 2:
Systematic literature review
Data: scientific articles on patient involvement
Method: systematic literature review
Inferences & explanations: Analyze the research filed, its components, their relationships, and identify any unexplained phenomena

Phenomenon-based scoping and inferences generated from it
Utilize distinct methodologies and data sets to capture, describe, and conceptualize the patient perspective, thereby generating multiple potential explanations

Chapter 3:
Quantitative analysis (survey)
Data: questionnaire responses
Method: cluster analysis
Inferences & explanations : characterize distinct patient groups with similar preferences

Chapter 4:
Qualitative analysis (interviews)
Data: in-depth patient interviews
Method: Zaltman metaphor elicitation technique
Inferences & explanations : characterize distinct patient mental models that determine decision behavior

Chapter 1.4: Theoretical triangulation
Compare and refine the above inferences and explanations, select the best ones based on explanatory virtues and thus arrive at stronger, more valid explanations for shortcomings of patient involvement

Explanatory trigger: In Cornelissen's work, an “explanatory trigger” refers to evidence, observations, or anomalies that prompt researchers to seek explanations. These can be unexpected or puzzling phenomena that drive the need for deeper investigation and theoretical development. Starting from this vantage point, they can ask basic questions about facts but without yet doing any further inferential work on such facts (Cornelissen 2023). In the context of patient involvement, I was able to draw on a large body of research and identify the most significant evidence and inferential patterns that have been established (Dellsén 2021). The second chapter consolidates these research findings with a conceptual model encompassing three levels: health system, provider, and patients. Thereby, it specifies mechanisms across all three levels that drive the patient involvement processes and outcomes. At the same time, a review of prior research allowed me to observe discrepancies in the context of patient involvement that acted as an explanatory trigger. For instance, the findings presented in Chapter 2 illustrate that patients involved with identical medical decision-making strategies exhibited markedly diverse patient-reported outcomes regarding involvement success. As described, the literature primarily attributes this anomaly to an incomplete understanding of patient preferences and characteristics, which subsequently complicates patient involvement in real-world healthcare settings (Miller and Reihlen 2023). Consistent with this, Chapter 2 shows that the existing literature rarely uses research designs and theories that address patients' preferences, thoughts and feelings in general and outside of consultations. Instead, current research approaches focus on processes and interventions designed to make physicians better “patient involvers” without explicitly considering and differentiating individual patient involvement preferences and expectations. This lack of attention to the patient voice is the explanatory trigger (Cornelissen 2023) of this work. It sets the stage for phenomenon-based scoping.

Phenomenon-based scoping: This step, as understood by Cornelissen, involves the collection and analysis of diverse data to explore and understand a phenomenon from multiple perspectives. This idea emphasizes the importance of gathering varied types of data to facilitate comprehensive inferencing and theory development. Building on this approach, Chapter 3 and 4 of this dissertation apply two distinct methodologies and data sets to capture, describe, and conceptualize the patient perspective, thereby generating multiple potential explanations. Chapter 3 surveys patients and Chapter 4 conducts in-depth patient interviews. Both intend to simultaneously expand and more deeply explore the phenomenon of patient involvement. In the sense of theoretical triangulation, they approach the topic from different angles: Chapter 3 conducts a quantitative analysis by examining clusters of patient preferences through statistical techniques and survey data. Essentially, it reveals how specific characteristics within patient groups correlate with varying levels of desire for involvement and the specific content related to that involvement. Conversely, Chapter 4 uses qualitative analysis to explore how patients’ mental models drive their sensemaking. In Cornelissen’s terms, this method adopts a “configurational grammar”, which theorizes based on distinguishing features and their outcomes by examining in structures of prominence and centrality. Thereby, Chapter 4 shows how four distinct mental models guide patients’ sensemaking and involvement expectations in medical decision-making.

Theoretical triangulation, represented by the concluding section of this Chapter, summarizes the findings from Chapter 2 and 3 to gain a more complete understanding of patient involvement. By comparing inferences from these two chapters I identify where observations and results converge and reinforce each other. Furthermore, triangulation reveals where results diverge or parallel each other, thereby pointing to areas for further research.

Overall, triangulating the results of Chapter 2-4 confirms that patients have different perspectives that significantly influence their decision-making behavior. They identify what drives these perspectives and how doctors can better consider and address them. It thus establishes a theoretical foundation to effectively enhance patients' active involvement in medical decision-making.

1.3 LAYOUT OF THIS WORK

In line with the contributions presented above, this dissertation comprises three manuscripts, each presented in a different chapter. In the second chapter of my dissertation, *Assessing the Impact of Patient Involvement Healthcare Strategies on Patients, Providers, and the Healthcare System: A Systematic Review*, I synthesize a fragmented research field with a systematic review, integrating findings from 99 articles into a theoretical framework. Integrating three levels – the health system, providers, and patients – in one conceptual model allows to identify novel associations between patient involvement conditions, interventions, and outcomes. Additionally, this analysis delineates where patient involvement ideas and approaches overlap or conflict.

This holistic picture of patient involvement shows how an approach integrating health systems, healthcare providers, and patients can make patient involvement more effective than isolated interventions. It also substantiates that patient involvement benefits individual patients and the health system as a whole. In addition to showing the benefits of patient involvement, my analysis highlights various problems and shortcomings. These issues primarily lie within the sphere of interaction between healthcare providers and patients. For instance, I found that patient involvement approaches have not yet led to a significant uptake of patient involvement in the medical practice. Furthermore, my review consistently reveals that patients underutilize available information tools. Despite their desire for independent and reliable information, current offerings often fail to meet their needs. This is one facet of an overall limited understanding of the effective consideration of patient preferences that my review identifies. Taking into account patient preferences remains challenging without a systematic approach to the topic and considering barriers at the provider level, such as time constraints and limited availability of staff training. In summary, this chapter will help scholars and practitioners navigate a fragmented and interdisciplinary knowledge landscape and focus their attention on areas of research that promise significant leverage to promote patient involvement.

In the third chapter of this dissertation, *Patient Preferences for Involvement in Medical Decisions: A Cluster Analysis*, my co-author Laura Venz and I address some of the challenges identified in the second chapter and provide a comprehensive analysis of patient preferences for involvement. A novel aspect of our study lies in the utilization of a survey to explore a wide range of potential preferences arising from barriers and facilitators documented in the literature. This approach allows us to address preferences that might remain unexplored during a typical consultation. Through cluster analysis, we identify three distinct patient groups with similar preferences. These groups exhibit statistically significant differences based on their motivation to assume responsibility for their health, their information-seeking behavior, their trust in the healthcare system, and their utilization of digital tools. Notably, these differences are independent of gender or age. Specifically, we categorized the three identified groups as follows. “Autonomists” are driven to actively manage their own health. “Networkers” trust the health system and prefer healthcare providers that are well connected and digitally skilled. “Consultees” have confidence in healthcare providers but are less inclined to seek self-education about their medical condition. This confirms, on the one hand, that patients indeed have distinct preferences, and these preferences can significantly impact their decision-making behavior and preferences for specific treatment alternatives. On the other hand, knowing about these preference groups, physicians can more accurately determine what level and nature of involvement in medical decisions a particular patient prefers.

To triangulate diverse patient preferences from an alternative perspective and further illuminate the reasons and consequences of these preferences, the fourth chapter of this dissertation, *Understanding Patient Perspectives: Four Mental Models to Guide Patient Involvement in Medical Decision-Making*, theorizes how patients make sense of medical decisions. Designed as a qualitative analysis, this study presents an explanatory scheme (as proposed by Cornelissen, 2023). This explanatory scheme profiles patient preference phenomena, attributing a set of distinguishing features to their manifestations and outcomes. Based on 24 in-depth patient interviews, my co-author Markus Reihlen and I use the Zaltman Metaphor Elicitation Technique to outline four distinct mental models that significantly influence the sensemaking of medical decisions from the patient’s perspective. These models exhibit partial similarities with the preference groups discussed in the third chapter. We refer to them as “the proactive patient”, guided by the desire to maintain control (similar to “autonomists” in Chapter 3), “the collaborative patient” preferring to share control (similar to “networkers” in Chapter 3), “the reliant patient”, preferring a paternalistic doctor-patient relationship (similar to “consultees” in Chapter 3), and “the belief-centered patient”, primarily driven by strong beliefs (not reflected in our cluster analysis in Chapter 3). Each mental model represents a distinct logic that drives a patient’s sensemaking and that is substantiated by historical antecedents from the literature. The four mental models and their sensemaking dynamics provide orientation as to how physicians can approach patient-specific involvement in medical decisions and how to introduce medical information such as patient decision aids. While the third chapter surveys the characteristics of different groups of patient preferences, metaphorically speaking, Chapter 4 looks into the machinery of medical decision-making to establish how patient sensemaking is influenced by distinct logics, i.e., *how* preferences develop. Physicians can incorporate these logics during conversations, thereby increasing the likelihood of effectively communicating with patients to achieve the desired involvement outcomes.

Table 1.1 lists the three articles of this dissertation by title, co-author, target journal, and publication status.

Table 1.1. Article Overview.

Article	Title	Co-authors	Target journal	Status
1	Assessing the Impact of Patient Involvement Healthcare Strategies on Patients, Providers, and the Healthcare System: A Systematic Review	None[1]	Patient Education and Counseling	Published in 2023
2	Patient Preferences for Involvement in Medical Decisions: A Cluster Analysis	Laura Venz	Journal of Patient Experience	In preparation for submission

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[1] The journal *Patient Education and Counseling* published a heavily abridged version of this article. Markus Reihlen, having contributed to the shortened version, is listed as a co-author. However, the version presented in this dissertation (Chapter 2) is a significantly revised and expanded version for which I am the sole author.

3	Understanding Patient Perspectives: Four Mental Models to Guide Patient Involvement in Medical Decision-Making	Markus Reihlen	Journal of Professions and Organization	In preparation for submission

1.4 CONCLUDING REMARKS

Insufficient understanding of patients' perspectives for involvement remains a significant barrier to widespread adoption of patient involvement in clinical practice (Miller and Reihlen 2023; Khunkhun et al. 2022). Without research into the effective understanding and integration of their perspectives, patient involvement and its positive outcomes will likely remain short of their potential. Thus, recognizing patient perspectives is crucial for advancing patient involvement in healthcare decision-making processes.

This dissertation aims to address this challenge in patient involvement research by presenting three interconnected chapters, each analyzing theoretical aspects from distinct perspectives and with different theoretical "grammars" (Cornelissen 2023). Taken together, the chapters richly explore groups of patient preferences and provide a theoretical triangulation that helps to understand and explain their role in patient involvement. This theoretical foundation enables physicians to more accurately determine what level and nature of involvement in medical decisions a particular patient prefers. Thereby, its findings help to promote patient involvement and, subsequently, patient trust, satisfaction, and adherence to treatment.

When considering the stock of explanatory considerations provided by Chapter 2-4 and the inferences generated by their different methods and data, a set of overlapping, and thus converging, interconnections emerges (Cornelissen 2023; Turner et al. 2017). Both Chapter 3, which involves a survey measuring agreement to involvement barriers and facilitators developed using a conceptual framework from existing literature, and Chapter 4, which conducts a "deep" investigation of patient mental models through interviews based on metaphors, reveal one crucial finding: *There are patient groups with significantly different perspectives, while patients within each group share common characteristics.*

This finding offers a theoretical basis for improving current patient involvement by systematically considering patients' expectations, preferences and capabilities. It enables physicians to formulate precise questions and increases the likelihood of truly understanding patient involvement perspectives. It will also prevent physicians from categorizing patients, often unconsciously and automatically, based on biased cognitive reference points (Lakoff 1987). Such intuitive categorization can be superficial or even harmful (Lakoff 1987). By establishing a solid theoretical basis for categories of patient perspectives, this work helps to question practitioners' existing categorizations and, if necessary, to calibrate them more appropriately to the individual patient.

The finding that distinct patient groups exist is also relevant in the context of measuring the success of patient involvement. As described in the section "Current Research on Involvement Interventions," patient-reported outcomes related to involvement are often inconsistent and fall short of overall expectations. These discrepancies can be explained by the existence of distinct patient groups. When two patients with vastly different expectations undergo a similar involvement process, there is a high likelihood that they will assess it differently in terms of quality and outcomes. Differentiating among patient groups would allow for better explanations of patient-reported outcomes and targeted improvements based on specific patient segments.

Both Chapter 3 and 4 found similar patient groups: (1) "autonomists" and "the proactive patient", motivated to take charge of their own health and guided by the desire to maintain control, (2) "networkers" and "the collaborative patient", trusting the health system, preferring to share control, and favoring healthcare providers that are well connected and willing to deliberate, and (3) "consultees" and "the reliant patient", having confidence in healthcare providers, being less motivated to educate themselves, and preferring a paternalistic doctor-patient relationship. In terms of the third step of triangulation, these similarities between the findings of different methods and data indicate that the results support each other. Overall, they underline that different preference groups exist regarding patient involvement, and that patients within a group tend to think, feel, and decide similarly.

Furthermore, the triangulation of Chapters 3 and 4 reveals divergent results. This does not necessarily indicate a contradiction; rather, it can contribute to a better holistic understanding of the field when combined with convergent findings (Turner et al. 2017). The ZMET study in Chapter 4 identified a patient group that we did not find in the quantitative study in Chapter 3: "the belief-centered patient", who is driven by strong beliefs. The survey-based Chapter 3 did not adequately inquire about this specific type. This occurred because we designed the survey using existing literature, which in turn does not commonly emphasize beliefs when examining patient involvement. In contrast, the survey identified features of preference groups that were not as prominent in Chapter 4's interviews. This is particularly true regarding the role that digitization and wearables play in patient preferences. Chapter 3 found significant differences between patient groups in this regard (unlike Chapter 4). Two of the three groups identified in Chapter 3, "autonomists" and "networkers", consider it important to collect and share individual health data during consultation. "Autonomists" are motivated to take charge of their own health, but in their experience, doctors and health insurances do not help them achieve this goal. As a result, they tend to rely more on digital tools, data and personal responsibility. "Networkers" are also digitally savvy and prefer to manage their own health. For example, they expect physicians to use their collected health data in diagnosis and therapy during doctor visits and were willing to share their health data. As a result, they tended to favor healthcare providers who showed a similar preference for digital tools and data collection. For patients in the "consultees" group, the use of digital tools and the collection of health data were significantly less important. We also found that if patients used "wearables", i.e., digital tools that collect health data, their preferences were more likely associated with the "autonomists" and "networkers" groups. This significance of digitalization in the healthcare sector was missing in the qualitative study from Chapter 4, which for its part established the differences between patient groups based on mental models. It identifies central constructs that are important for patients' sensemaking, but are associated more with deeply ingrained values and character traits than with digital usage behavior.

In addition, the results of the quantitative analysis provide indications of the percentage distribution of the individual patient groups within the population. However, due to the small sample size of 24 interviews in Chapter 4, statistically significant statements about the distribution of the identified mental models are hardly feasible.

The observed commonalities and distinctions across the chapters provide deeper insights and a better understanding of patient involvement, serving as a stepping stone for future research (Turner et al. 2017). Further triangulation, employing additional research methods, would enhance the differentiation of characteristics and underlying logics within the identified three to four patient groups. Moreover, it is crucial to comprehend how knowledge of the features and decision-making logics of ideal types genuinely impacts patient involvement outcomes. Understanding how clinicians in clinical practice can effectively and efficiently identify and involve specific patient groups will be relevant for establishing best involvement practices. Lastly, investigating the role of digitization and emerging technologies in shaping patient preferences and possibilities for involvement presents an intriguing research avenue.

This dissertation shows that it is worthwhile to better understand the patient perspective on patient involvement, including patient preferences, mental models and sensemaking. The physician-patient encounter is unique, often involving decisions with significant consequences. While successful consultations can foster trust and motivate patients toward problem-solving, this ideal scenario is not always realized. Patients may leave consultations feeling misunderstood, confused, and unmotivated. The overarching goal of the studies presented in this dissertation is to increase the probability that medical consultations will effectively involve patients to achieve the optimal medical decisions for their health. Its findings contribute to enhancing doctor-patient encounters by improving doctors' understanding of patients. Physicians can therefore not only help their patients medically, i.e. with their professional competence, but also personally with their human competence. In order to leverage this potential, this dissertation offers a better understanding of the perspectives and mental models that patients bring with them when they visit a physician. It helps to recognize the resources patients utilize in their specific situations and identify any constraints that might hinder problem-solving. Anchoring this understanding even more deeply in medical practice can make healthcare systems more sustainable. Ultimately, physicians' increased knowledge about patient preferences, mental models, and sensemaking will enable them to help patients become more self-effective and successful in regaining and maintaining their health.

Hopefully, future research will find the implications of this dissertation useful for the practice of patient involvement and advancing the theoretical and methodological considerations that I put forward.

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ASSESSING THE IMPACT OF PATIENT INVOLVEMENT HEALTHCARE STRATEGIES ON PATIENTS, PROVIDERS, AND THE HEALTHCARE SYSTEM: A SYSTEMATIC REVIEW

2.1 ABSTRACT

Background: Patient involvement has become an important and lively field of research, yet existing findings are fragmented and often contested. Without a synthesis of the research field, these findings are of limited use to scholars, healthcare providers, or policymakers.

Objective: Examine the body of knowledge on patient involvement to determine what is known, contested, and unknown about benefits, risks, and effective implementation strategies.

Methods: Systematic literature review of 99 journal articles using a conceptual model integrating three levels: health systems, health providers, and patients. This study extracts individual research findings and organizes them into a model structure to provide a holistic picture of patient involvement.

Results: The review highlights overlaps and conflicts between various patient involvement approaches. Its results show benefits for individual patients and the health system as a whole. At the provider level, however, it identifies clear barriers to patient involvement.

Discussion: Patient involvement requires collaboration among health systems, healthcare providers, and patients. This review shows that increasing patient responsibility and health literacy requires policymaker interventions. This includes incentives for patient education by providers, adapting medical education curricula, and building a database of reliable health information and decision support for patients. Furthermore, policies supporting a common infrastructure for digital health data and managed patient data exchange will foster provider collaboration.

Practical Value: This review shows how an approach integrating health systems, healthcare providers, and patients can make patient involvement more effective than isolated interventions. Such systematic patient involvement is likely to improve population health literacy and healthcare quality.

Funding: This study did not receive any external funding.

Keywords: Patient autonomy, patient involvement, patient-centered care, shared decision making, healthcare strategy

JEL classification: I12 (health behavior), I11 (analysis of healthcare markets)

2.2 INTRODUCTION

Involving patients in healthcare decisions is a fundamental concern for health regulators, insurers, and patient representatives (Stiggelbout et al. 2015). With this approach, these stakeholders aim to realize two fundamental ethical principles, personal welfare and autonomy (Frosch and Kaplan 1999). Research on patient involvement dates back to the 1980s (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1982). To date, however, few professional healthcare organizations practice systematic patient involvement (Coulter 2018). Clinics tend to prioritize maintaining the quality of care and profitability over introducing new approaches whose impacts on these two core issues are not yet fully understood (Elwyn et al. 2016). Consequently, they change only incrementally (Scott 2000) and the meaningful and consistent implementation of patient involvement has been slow (Danner et al. 2020; Coulter 2018).

A large body of research on "patient involvement" or similar concepts such as "shared decision making", "patient autonomy", and "patient-centered care" has emerged. To date, research has identified a range of barriers and facilitators (Friedberg et al. 2013; Gravel et al. 2006; Joseph-Williams et al. 2014; Légaré and Witteman 2013), conflicting outcomes (Bae 2017; Longtin et al. 2010; Stiggelbout et al. 2012), and patient preferences (Haltaufderheide et al. 2019; Herlitz et al. 2016; Pham et al. 2020), as well as a wide spectrum of specific situations (Coulter 2018). On the other hand, research shows that involving patients, e.g., via co-design and co-production of healthcare services, can improve patient experiences (Marshall et al. 2019) and make health studies more effective (Slattery et al. 2020). Overall, the field is characterized by different research perspectives that emphasize specific interventions, numerous diseases, healthcare providers, and patient types. This has led to fragmentation of existing research findings. The limited focus and lack of consensus on the conceptualization of patient involvement hinder healthcare decision-makers from effectively allocating resources and capital, as they lack a comprehensive overview of realistic opportunities and risks (Elwyn et al. 2016). Consequently, without a synthesis of the research field, the current patient involvement findings are of limited utility to scholars, healthcare providers, and policymakers.

I thus conducted an integrated literature review and synthesized a body of primary studies on patient involvement. This review locates and discusses representative studies on patient involvement and integrates their findings into a theoretical framework. In this way, I was able to achieve the first research objective: to outline where patient involvement ideas and approaches overlap or conflict. Second, the model allows to identify novel associations between patient involvement conditions, interventions, and outcomes. Most studies take one of three perspectives: the individual patient, the healthcare provider (e.g., physicians, medical groups, hospitals, specialized providers, etc.), or the health system (country-specific characteristics concerning health financing, service provision, and governance (Wendt et al. 2009)). Instead, I aim to integrate evidence from all three levels and show how health systems, health providers, and patients can collaborate to facilitate patient involvement. I believe this integrative view provides a more comprehensive picture of how – and under which conditions – patient involvement interventions can improve healthcare. Third, this study helps to identify managerial implications. Providers can use the synthesized findings to guide strategy development by building on conclusive evidence about the opportunities and risks of patient involvement.

2.3 METHODS

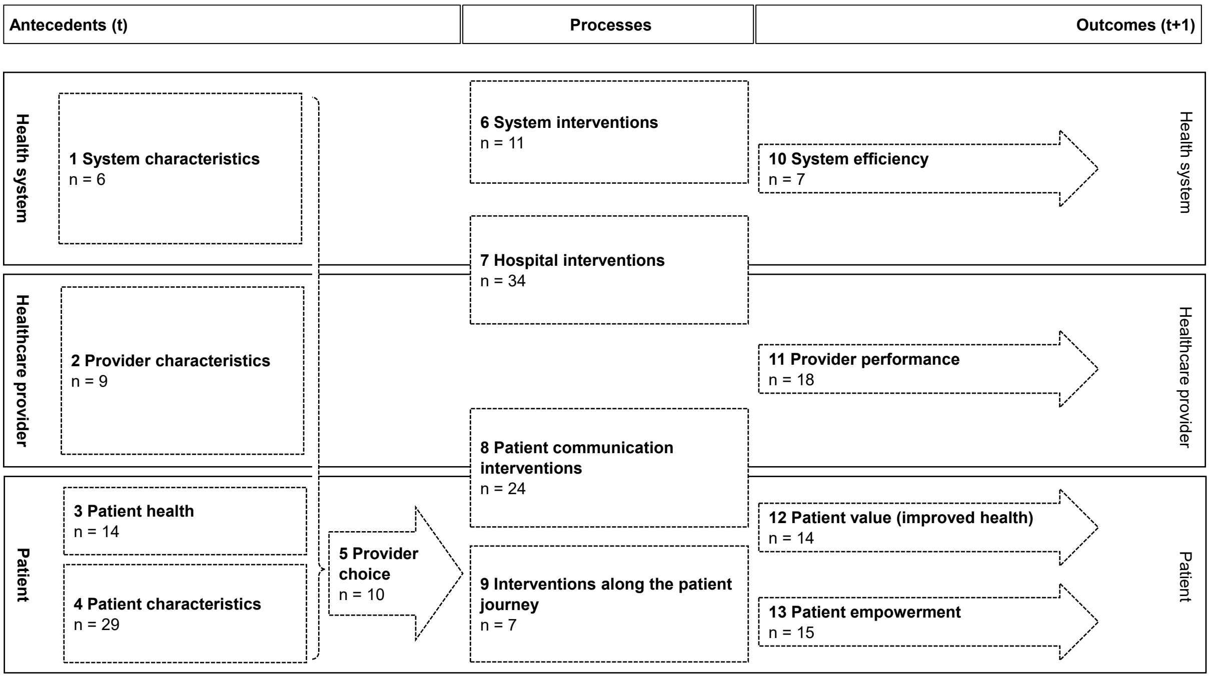
At its core, patient engagement has been guided by the idea of patient self-determination (Aujoulat et al. 2007). The current " Declaration of Geneva" echoes this notion by requesting physicians to respect their patients' autonomy (Word Medical Association 2017). Thus, I started with the term "patient autonomy" to identify key concepts related to patient involvement. Following Bravo et al. (Bravo et al. 2015), patient autonomy can be divided into "patient-centered interventions" and "shared decision making". Following these considerations, I chose "patient autonomy", "shared decision making", and "patient-centered care" as the common review focus. I selected "patient-centered care" instead of "patient-centered interventions" because the former term has been used much more frequently in the literature.

“Patient autonomy” encompasses rights, responsibilities, and opportunities fostering patients' self-determination (Bravo et al. 2015). Generally, autonomy means deciding without any external control or influence (Fortune et al. 2016). “Shared decision making” is closely related to patient autonomy as it aims to restore or promote patients’ autonomy (Bae 2017; Epstein and Street 2011; Epstein 2000) by incorporating patients’ values and preferences. Clinicians and patients work together to decide on tests, treatment options, and therapies based on the best available evidence and patient preferences (Coulter 2018). “Patient-centered care” is defined as care consistent with patients’ values, needs, and desires by involving them in healthcare decisions (Constand et al. 2014).

An analytical framework is required to evaluate a research field systematically (Epstein and Street 2011; Donabedian 1988). I developed a framework that (i) is detailed enough to map research findings on current status, interventions, and outcomes and that (ii) can show associations of research results across several levels. To achieve this, I used the three levels of analysis suggested by Bravo et al. (Bravo et al. 2015): patient, healthcare provider, and the healthcare system. In addition, I followed Donabedian’s (Donabedian 1988) three components approach and chose antecedents, processes, and outcomes as the second dimension of the framework. “Antecedents” describe conditions prior to the intervention, such as patient health or treatment preferences. “Processes” encompass various interventions to involve patients, e.g., staff training. “Outcomes” summarize the review’s findings on the results of interventions. A table with these two dimensions as headings yields nine boxes which I labeled individually (for example “system characteristics” for the health system preconditions). After reviewing the literature, I added four more fields for clarity: (i) two sublevels for patients to distinguish between health status and individual characteristics, (ii) patient communication between patients and providers, and (iii) patients’ provider choice based on both patient characteristics and health.

The analytical framework and its research domains are displayed in Figure 2.1. I use this framework to map individual findings from the literature to the model’s 13 boxes, from “system characteristics” to “patient empowerment”.

Figure 2.1. Integrative Framework.



Articles published in academic journals form the basis for my research as they represent validated knowledge (Podsakoff et al. 2005). I used the meta-database Web of Science Core Collection to identify relevant articles. My search strategy, summarized in Figure 2.2, follows the PRISMA guidelines. First, I searched the Web of Science Core Collection meta-database for titles from 1985 to January 2021, using the keywords “patient autonomy”, “patient-centered care”, and “shared decision making”, yielding a total of 1,242 entries (113, 337, and 792 individual results)[2].

I narrowed down the results by searching for articles with an implementation theme (TS=(implement* OR outcome)). This yielded a total of 875 records (19, 174, and 682 results individually). I read the abstracts of these records, applied the selection criteria, and conducted follow-up searches to identify additional references.

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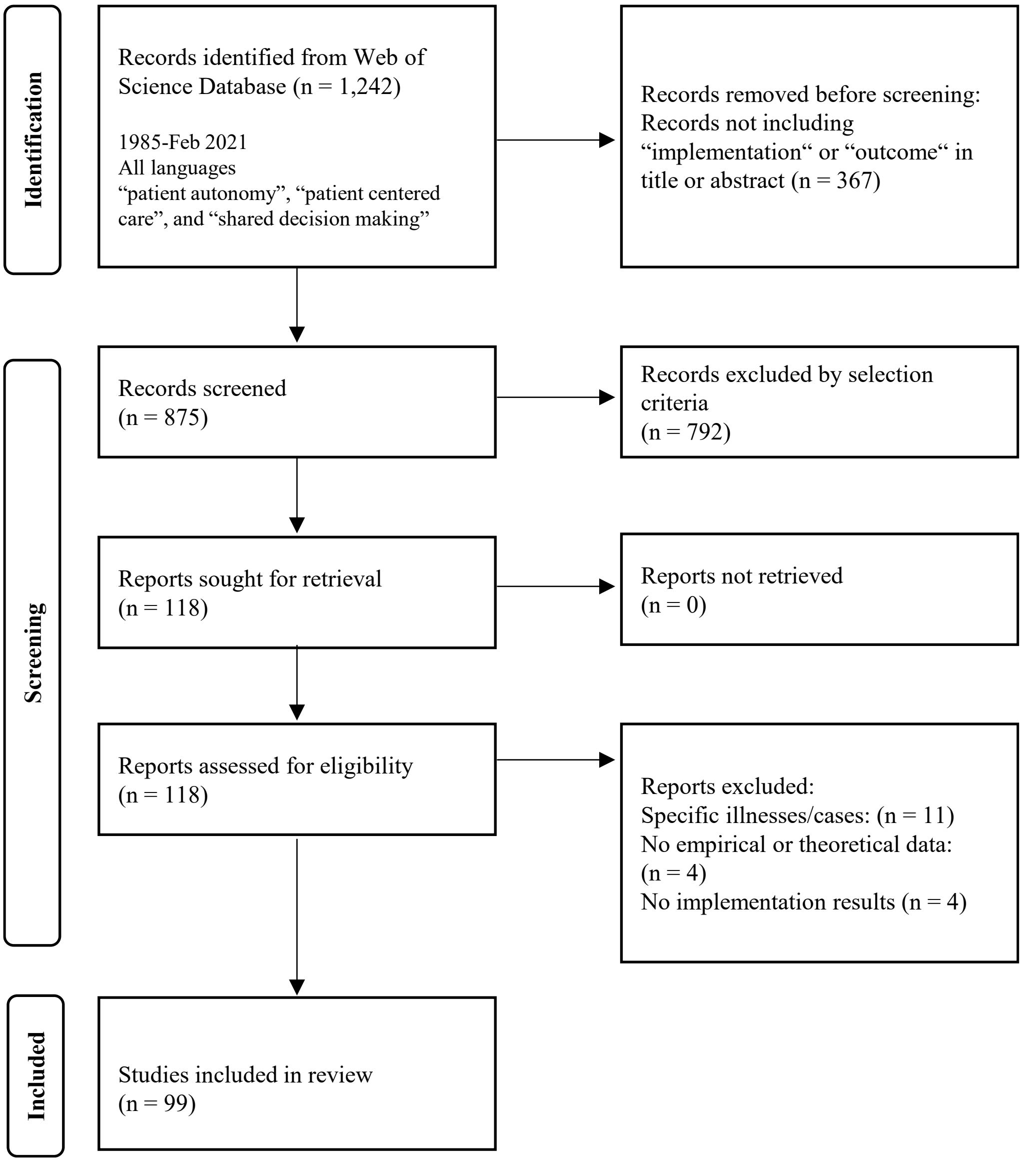
[2] Web of Science returns results with and without hyphenation (e.g. the keyword “decision making“ yields titles that include both “decision-making” and “decision making”)

A study was eligible if: (i) it reported collected empirical findings or theoretical concepts, (ii) included findings on either patients, health professionals, or a health system, and (iii) included findings on the implementation of any of the above concepts, including barriers and/or facilitators. I excluded studies that (i) related to a specific disease or healthcare product and (ii) were not based on a specific scientific method.

Overall, I identified 118 records. I reviewed the full texts for eligibility and excluded an additional 19 publications because they did not meet the selection criteria. A table of these studies and the specific reasons for their exclusion is provided in the Appendix.

I based the quality assessment of included studies on the criteria suggested by Kmet et al. (Kmet et al. 2004). This framework integrates scores for quantitative and qualitative studies, both of which are included in the review. It also provides detailed instructions to reviewers for the assessment.

Figure 2.2. Study Flow Diagram.



I extracted individual study findings/results verbatim and copied them into a coding protocol. In doing so, I assigned the total of 502 results to the 13 categories suggested by the model (e.g., "provider choice" or "system efficiency"). I did not differentiate the findings by source (i.e., literature review or original research).

2.4 RESULTS

This section summarizes the results structured according to the model, describing the pre-intervention status of patient involvement (e.g., patient preferences), processes and interventions (e.g., staff training), and outcomes (e.g., patient empowerment). I integrate and discuss the individual results in the section Discussion and Conclusion. Table 2.1 summarizes the literature used in the review. The quality assessment of the included studies yielded an average score of 80% with a standard deviation of 15%. Overall, the scores ranged from 55% (lowest) to 100% (highest).

Table 2.1. Literature Summary.

No.	Author(s)	Year	Country of publication	Perspective	Method	No. of studies	No. of subjects / trials	Key findings
1	Frosch (1999)	1999	USA	Provider	Literature review	8		A treatment choice should be made based on an individual's preferences and willingness to accept risk.
2	Martin (2000)	2000	Sweden	Provider	Conference report	-		Healthcare design can confer an advantage in a competitive care environment.
3	Stewart et al. (2000)	2000	Canada	Patients	Interview		315	Patient-centered practice improved health status and increased the efficiency of care by reducing diagnostic tests and referrals.
4	Epstein et al. (2004)	2004	USA	Provider	Systematic review	51		Five communication tasks to address: understanding the patient's (and family members') experience and expectations; building partnership; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed

								by clinical judgment and patient preferences; and checking for understanding and agreement.
5	Bieber et al. (2006)	2006	Germany	Provider	Observation		67	An SDM intervention can lead to an improved physician–patient relationship from the patients’ and from the doctors’ perspectives.
6	Geraeds (2006)	2006	Germany	Patients	Survey		1524	Hospital quality reports are used only by a fraction of patients.
7	Gravel et al. (2006)	2006	Canada	Clinicians	Literature review	31		Interventions to foster the implementation of shared decision making in clinical practice will need to address a broad range of factors. It also reveals that there is very little known about any health professionals other than physicians on this subject.
8	Makoul (2006)	2006	USA	Provider	Literature review	418		Definition of SDM.
9	Moser et al. (2006)	2006	Netherlands	Clinicians	Literature review	1236		Nurses cannot rely exclusively on one autonomy model to foster patient autonomy. Instead, it requires in-depth knowledge of and interaction with patients in the context of each particular nursing encounter because people express their autonomy

								through particular courses of action.
10	Charmel (2008)	2008	USA	Provider	Survey		125	The diverse healthcare institutions practicing the Planetree model have individually reported a host of clinical and operational-level benefits resulting from a patient-centered care approach.
11	Joosten et al. (2008)	2008	Netherlands	Patients	Literature review of randomised controlled trials	11		In the context of a chronic illness, SDM can be an effective method of reaching a treatment agreement.
12	Lako-Rosenau et al. (2008)	2008	Netherlands	Patients	Survey		409	Hospital choice is highly related to the importance a patient attaches to his or her physician's opinion about a hospital.
13	Légaré et al. (2008a)	2008	Canada	Provider	Research protocol	-		The study protocol aims to inform researchers, educators, and clinicians on effective strategies to implement shared decision-making in clinical practice using a theory-based dyadic perspective.

14	Légaré et al. (2008b)	2008	International	Provider	Literature review	38		The three most often reported barriers were: time constraints, lack of applicability due to patient characteristics, and the clinical situation. The three most often reported facilitators were: provider motivation, positive impact on the clinical process, and patient outcomes.
15	Wolf et al. (2008)	2008	USA	Clinicians	Randomized trial		36	By focusing on each patient's individual needs, nurses can work collaboratively with patients to develop a plan of care that best meets patients' needs while improving their level of satisfaction and quality of care.
16	Faber (2009)	2009	Netherlands	Patients	Literature review	14		A deeper understanding of consumer choice behavior in health care settings.
17	Bertakis & Azari (2010)	2010	USA	Patients	Randomized trials		509	Patient-centered care was observed more often with family physicians caring for healthier, more educated patients and was associated with lower charges.
18	Dijs Elsinga et al. (2010)	2010	Netherlands	Patients	Questionnaires		2122	Patients intended to use more information for future choices than for past decisions.
19	Longtin et al. (2010)	2010	Switzerland	Patients	Literature review		115	Patient participation can improve the decision-making process and the care of illness.

20	Meterko et al. (2010)	2010	USA	Provider	Survey		1858	Providing patient-centered care may result in important clinical benefits and meeting patient needs and expectations.
21	Abraham et al. (2011)	2011	USA	Patients	Survey		467	Hospital choice depends most notably on the reputation of the physician and the reputation of the healthcare organization
22	Bertakis & Azari (2011)	2011	USA	Patients	Rando-mized trials		509	Patient-centered care was associated with decreased utilization of health care services and lower total annual charges.
23	Coulter (2011)	2011	UK	Health system	Editorial	-		Shared decision making is firmly on the policy agenda in England, and there is evidence of progress.
24	Epstein et al. (2011)	2011	USA	Clinicians	Obser-vation of patients		-	The theoretical concept of shared mind—ways in which new ideas and perspectives can emerge through the sharing of thoughts, feelings, perceptions, meanings, and intentions among 2 or more people.
25	Galesic (2011)	2011	USA	Patients	Survey		498	Shared decision making preferences are related to numeracy skills, country, and age. Education efforts to increase numeracy, as well as using non-quantitative communication formats, may foster involvement of low-

								numeracy patients in decisions about their health.
26	Ketelaar et al. (2011)	2011	Netherlands	Patients	Literature review of randomised controlled trials	4		There is no consistent evidence that the public release of performance data impacts consumer behavior or improvement of care.
27	Ommen (2011)	2011	Germany	Clinicians	Survey		2197	Insufficient physician communication skills can lead to extensive adverse effects on the trust of patients in their physicians. Thus, it becomes clear that medical support requires biomedical and psychosocial skills.
28	Shepherd et al. (2011)	2011	Australia	Patients	Cross-over trial		36	Patients asking three questions received improved information from physicians and increased physician facilitation of patient involvement.
29	Bromley (2012)	2012	USA	Provider	Interviews		35	There is a tight link between the features of the building and a new culture of care that would emerge within it.
30	Elwyn et al. (2012)	2012	UK	Provider	Theoretical model		-	Model of how to do SDM in clinical practice based on three key steps, namely choice talk, option talk, and decision talk.

31	Frosch et al. (2012)	2012	USA	Patients	Focus Groups		48	Participants wanted to collaborate with their physicians when making important clinical decisions. Yet, they were reluctant to do so for fear of being categorized as difficult and less worthy of attention and high-quality care.
32	Glass et al. (2012)	2012	USA	Patients	Survey		488	SDM was positively associated with decision satisfaction and was strongest for three areas of SDM: patients being helped in a healthcare consultation with understanding information, treatment preference elicitation, and weighing options thoroughly.
33	Mansky (2012)	2012	Germany	Patients	Survey		1740	Care quality and reputation are important criteria for hospital choice.
34	Rathert et al. (2012)	2012	USA	Provider	Literature review	40		Patient-centered care could result in overall cost savings by preventing overuse and underuse while increasing the overall quality of care.
35	Stiggelbout et al. (2012)	2012	Netherlands	Provider	Conference report		-	The ultimate goal is that SDM is not seen as a tedious added extra but as the core of good clinical practice.
36	Victoor et al. (2012)	2012	Netherlands	Patients	Scoping review	118		There is no such thing as the typical patient. Different patients make different choices in different situations.

37	Elwyn et al. (2013)	2013	UK	Provider	Ethnography, interviews		52	Option Grids made options more visible, and clinicians found it easier to undertake shared decision making when these tools were available. Used collaboratively, they enhance patients' confidence.
38	Friedberg et al. (2013)	2013	USA	Provider	Interviews		23	Recommendation to carefully plan the implementation of shared decision making and make substantial long-term investments in information systems, provider training, and process reengineering.
39	Légaré et al. (2013)	2013	Canada	Health system	Literature review	45		Health policies that promote additional research into shared decision making and its adoption throughout health care systems will play an essential role in improving the quality and reducing the cost of health care.
40	Lloyd et al. (2013)	2013	UK	Clinicians	Interviews		54	Implementation of shared decision making is more complex than just delivering patient decision support. It requires a shared understanding of the purpose of involving patients in decisions.
41	Montori et al. (2013)	2013	USA	Provider	Essay		-	Getting the right information on options, outcomes, and outcome data is an obligatory prerequisite for considering informed patient preferences.

42	Constand et al. (2014)	2014	Canada	Clinicians	Scoping review	101		The fact that all identified approaches to patient-centered care incorporated strategies to achieve effective communication, partnership, and health promotion indicates that clinicians can select a patient-centered approach from the literature that best suits their patient's needs.
43	Hoffmann et al. (2014)	2014	Australia	Provider	Randomized controlled trial with medical students		107	A one-hour tutorial was effective in improving student clinicians' ability, attitude towards, and confidence in shared decision making facilitation.
44	Hofstede et al. (2014)	2014	Netherlands	Clinicians/ patients	Online survey		246/155	Knowledge, information provision, and a good relationship are the most important conditions for SDM perceived by both patients and professionals.
45	Joseph-Williams et al. (2014)	2014	UK	Patients	Literature review	289		SDM barriers are potentially modifiable and can be addressed by attitudinal changes at the patient, clinician/healthcare team, and the organization. Many patients currently can't participate in SDM, but they want to.

46	Ketelaar et al. (2014)	2014	Netherlands	Patients	Focus Groups		6	Quality information is marginally valued, partly because of conflicting values expressed by consumers, and, as such, it does not yet provide a useful information source on hospital choice beyond consumers’ current selection routines in healthcare.
47	Légaré et al. (2014)	2014	Canada	Health system	Literature review	12		Twelve of the most commonly perceived barriers to scaling up shared decision making across the healthcare spectrum should be termed myths.
48	Lindberg et al. (2014)	2014	Sweden	Patients	Literature reveiw	41		Patient autonomy in a caring context does not need to be the same before, during and after a care episode.
49	Scholl et al. (2014)	2014	Germany	Health system	Literature review	417		Developing an integrative patient-centeredness model allows different stakeholders to speak the same language.
50	Shay et al. (2014a)	2014	USA	Patients	Interview		23	There is no one-size-fits-all process that leads patients to label a decision as shared. Rather, the outcome of ‘‘agreement’’ may be more important than the actual decision-making process for patients to label a decision as shared.

51	Shay et al. (2014b)	2014	USA	Patients	Literature review	39		SDM, when perceived by patients as occurring, tends to result in improved affective-cognitive outcomes.
52	Berghout et al. (2015)	2015	USA	Provider	Survey		34	Healthcare organizations wishing to improve PCC should consider the relative importance of PCC dimensions in their specific context of care provision, which may help to improve levels of patient-centeredness in a more efficient and focused manner.
53	Bravo et al. (2015)	2015	UK	All	Literature review/Interviews	67	19	A novel conceptual map of patient empowerment is described, grounded in published definitions of patient empowerment and qualitative interviews with UK stakeholders.
54	Clarke et al. (2015)	2015	USA	Patients	Observation and data collection		10500	The tested intervention demonstrated a significant reduction in emergency department visits.
55	Elf et al. (2015)	2015	Sweden	Provider	Mixed method		-	Healthcare representatives should collaborate with the construction sector and architecture based on evidence and end-users' perspectives. If carefully and systematically applied, this approach will support and develop a framework for creating high-quality healthcare environments.

56	Shepherd et al. (2015)	2015	Australia	Patients	Survey		121	Enabling patients to view a short video clip before an appointment led to high uptake of questions asking during consultations.
57	Stiggelbout et al. (2015)	2015	Netherlands	Provider	Implemen-tation guideline		-	SDM is the preferred approach for preference-sensitive decisions. It is likely to lead to better professional-patient relationships, better decisions, and better outcomes.
58	Altin & Stock (2016)	2016	Germany	Patients	Interviews, binary logistic regression		1125	Respondents with sufficient health literacy skills were 2.06 times as likely, and those who were involved in shared decision-making by their GP were 4.02 times as likely to be satisfied with the care received by their GP.
59	Elwyn et al. (2016)	2016	USA	Provider	Literature review and theoretic-cal framework		46	A broader conceptualization and measurement of shared decision-making would provide a more substantive evidence base to guide implementation. Outline of a framework that illustrates a hypothesized set of proximal, distal, and distant consequences.
60	Fortune et al. (2016)	2016	USA	Patients	Survey		203	Exploration of the relationship between demographic variables, trust in physicians, risk-taking, and gambling behaviors as predictors of medical decision-making.

61	Hargraves et al. (2016)	2016	USA	Provider	Case study		-	The larger need in evidence-informed shared decision making is for a patient-clinician interaction that offers conversation, not just information, and care, not just choice.
62	Herlitz et al. (2016)	2016	Sweden	Patients	Ethnography, recorded sessions		12	In contrast to core assumptions of standard PCC/SDM, patients need not be robust decision makers who execute autonomous decisions. Therefore, PCC/SDM needs to include a distinctly virtue-ethical dimension, where fostering capacities to take responsibility for self-care may require substantial deviation from the shared rational deliberation focus of standard PCC/SDM.
63	Miedany et al. (2016)	2016	UK	Provider	Randomised controlled trials		174	An evidence-based patient decision aid, developed according to IPDAS criteria, was found to be a simple, user-friendly tool that can be implemented in standard clinical practice.
64	Probst et al. (2016)	2016	USA	Clinicians	Survey		737	Acceptance of SDM among emergency physicians appears to be robust across management categories (diagnostic testing, treatment, and disposition) and in a variety of clinical scenarios.

65	Sanders et al. (2016)	2016	Netherlands	Provider	Randomised controlled trials		175	Training doctors resulted in more SDM behavior and more autonomy for the patient.
66	Sepucha et al. (2016)	2016	USA	Clinicians	Survey		200	Specific training sessions resulted in a more than doubling of the use of patient decision aids, and the increase was sustained over time.
67	Spatz et al. (2016)	2016	UK	Health system	Review of UK case		-	The UK case serves as a reminder that at the heart of a reasonable patient standard is respect for patients' informational needs; preferences, values, and goals; safety; and autonomy. By truly embracing this standard through promoting shared decision making, patients, the health system, and society will benefit.
68	Bae (2017)	2017	Korea	Health system	Literature review	50		As SDM has positive effects not only on patients and physicians (i.e., the actors in decision making processes) but also on the government health authority, SDM facilitation must be a primary foundation of national healthcare policies.
69	Coulter (2017)	2017	UK	Provider	Literature review	10		Quality-assured patient decision aids should be made available at specific decision points via electronic medical records so that they are

								readily accessible during clinical consultations.
70	Coulter et al. (2017)	2017	UK	Health system	Mixed method		-	Interest in SDM has grown considerably. The fact that SDM is not only a legal requirement but simply the right way to support patients is still a message to broadcast.
71	Dahl et al. (2017)	2017	Denmark	Health system	Report on Denmark case		-	SDM is still at an early stage in Denmark, but national and local initiatives appear promising.
72	DeCruppè (2017)	2017	Germany	Patients	Cross-sectional observational study		1925	A majority of patients in the German health system choose their hospitals freely. Hospitals have an impact on patients' future hospital choices through the treatment experience they provide to patients.
73	Elwyn et al. (2017)	2017	USA	Provider	Survey		316	A new three-talk model of shared decision making is proposed, based on "team talk," "option talk," and "decision talk," to depict a process of collaboration and deliberation.
74	Härter et al. (2017)	2017	Germany	Health system	Editorial		-	The international SDM community of researchers, clinicians, and patient representatives is growing. More and more international health systems are making advances in SDM.

75	Joseph-Williams et al. (2017)	2017	UK	Provider	Case study		-	Summary of key challenges faced during a program to implement shared decision making.
76	Liao et al. (2017)	2017	Taiwan	Health system	Case study		-	Introduction to the current status of shared decision making (SDM) in Taiwan.
77	Vander-weijden (2017)	2017	Nether-lands	Health system	Report on best practices in the Nether-lands		-	Combining the efforts and experiences of daily practice (including education) and system factors will be essential for the success of the implementation of SDM.
78	Bertels-mann & Coulter (2018)	2018	Germany	Health system	Literature review, work-shops, inter-views		22	Despite strong political, ethical and evidential support for this approach, SDM has been slow to enter the mainstream medical practice. Greater progress has been made in some countries than in others.
79	Bokhour et al. (2018)	2018	USA	Health system	Inter-views		108	Transforming healthcare systems to focus on patient-centered care and better serve the “whole” patient is a complex endeavor. Efforts to transform healthcare culture require robust, multi-pronged efforts at all levels of the organization; leadership is only the beginning.
80	Haltauf-derheide (2018)	2018	Germany	Clinicians	Inter-views		20	Eliciting patient-related information needs to be adapted in accordance with patient preferences and decision-making styles.

81	Hughes et al. (2018)	2018	USA	Patients	Survey		63931	Poor SDM was associated with worse patient-reported health outcomes, worse established quality indicators, and higher healthcare utilization.
82	Van Veenendaal et al. (2018)	2018	Netherlands	Clinicians	Interviews/ focus groups		43/ 51	Applying SDM made clinicians' jobs more rewarding and indicated that implementation in daily practice needs a ground-up redesign.
83	Dimopoulos (2019)	2019	Australia	Provider	Case study		-	Investments into SDM for all health organizations should be considered an ongoing commitment to enhancing patient experience, evidence translation, and reducing unwarranted variations in care.
84	Driever et al. (2019)	2019	Netherlands	Clinicians	Survey		785	Although most physicians prefer SDM, they often revert to a paternalistic approach and tend to limit SDM to discussing treatment options.
85	Joseph-Williams et al. (2019)	2019	UK	Provider	Ethnography		78	Model for future training and initiatives to promote SDM.
86	Maskrey (2019)	2019	UK	Provider	Essay		-	A more patient-centered encounter results in better patient and doctor satisfaction, and satisfied patients are less likely to lodge complaints or claim malpractice. Good communication is better for

								doctors in terms of greater job satisfaction, less work-related stress, and reduced burnout.
87	Milky et al. (2019)	2019	USA	Patients	Survey		797	Patients with higher SDM were more satisfied with their healthcare.
88	Ousseine et al. (2019)	2019	France	Patients	Survey		2299	Patient support to reach SDM requires high levels of health literacy, particularly in the functional and communicative domains.
89	Pham et al. (2019)	2019	Australia	Patients	Literature review	20		Using educational information provided through interactive multimedia, computer or DVD-based may enhance decision-making.
90	Stacey et al. (2019)	2019	Canada	Provider	Survey		133	Only 44% of patient decision aid trial authors indicated some level of subsequent use following their trial.
91	Van Leersum et al. (2019)	2019	Netherlands	Provider	Case study		-	Appropriateness of care and patient-centered care organization played a central role in quality-driven cost reductions.
92	Danner et al. (2020)	2020	Germany	Provider	Case study		-	Theoretical framework for the first large-scale, long-term implementation of shared decision-making (SDM) in an entire University Hospital involving all stakeholders in patient care in a multicomponent intervention.
93	Kasper et al. (2020)	2020	Norway	Health system	Case study		-	Description of Norway's fast progress into patient centered care.

94	Kheirkhah et al. (2020)	2020	Iran	Patients	Survey		168	In multivariate regression, openness to experience negatively predicted views concerning SDM.
95	Laschet (2020a)	2020	Germany	Provider	Report		-	Description of SDM implementation for outpatient care in Bremen, Germany.
96	Laschet (2020b)	2020	Germany	Provider	Report		-	Description of SDM implementation for a university hospital in Kiel, Germany. Focus on 4 areas: training for doctors and staff, information, and activation of patients.
97	Shaoibi et al. (2020)	2020	USA	Patients	Bayesian CF algorithm/ conjoint analysis survey		500	A Bayesian collaborative filtering algorithm provides accurate cluster treatment recommendations. It serves as a roadmap for incorporating predictive analytics into shared decision making.
98	Spinnewijn et al. (2020)	2020	Netherlands	Clinicians	Interviews		11	Certain features of physician culture hinder the correct implementation of SDM. Medical training and guidelines should emphasize how to elicit patient perspectives.
99	Schaeffer et al. (2021)	2021	Germany	Patients	Interviews		2162	Health literacy declined in Germany declined in the past 7 years. Fostering health literacy should remain a focus of public health policy.

2.4.1 Study Characteristics

As shown in Figure 2.1, most studies in the sample were concerned with hospital strategy (n = 34), patient preferences (n = 29), and patient communication (n = 24). The sample included the fewest number of publications in the focus areas system characteristics (n = 6), patient journey (n = 7), and system efficiency (n = 7). Important countries of origin were the US (n = 31), Netherlands (n = 17), Germany (n = 11), Canada (n = 7), and Australia (n = 5).

2.4.2 Health System Antecedents

Citizen autonomy: From a societal perspective, patient self-determination is a desirable goal clinicians need to support (Elwyn et al. 2012). In many countries, this view has been translated into the Patients' Rights Acts (Kasper et al. 2017; Liao et al. 2017), specifying access to healthcare, the right to be informed and participate in treatment choices, and the right to demand correction of decisions made by health professionals.

System impact: Several publications found that the system level, i.e., the regulator, can have a significant impact on the level of patient involvement in the clinical sector (Kasper et al. 2017; Dahl Steffensen et al. 2017). However, only a few governments have currently integrated patient involvement strategies systematically into their healthcare approach (Coulter 2018). While regulations like the Patient Right Act do not necessarily drive change in the clinical practice (Laschet 2020a), control mechanisms like health sector quality indicators, including patient involvement, were found to be a powerful change agent (Laschet 2020a; Dahl Steffensen et al. 2017). Regulatory incentives, such as the financing of required extra time at the hospital level, also foster patient involvement (van der Weijden et al. 2017).

2.4.3 Healthcare Provider Antecedents

Current state of patient involvement: The selection of articles provides consistent evidence that systematic patient involvement, at present, has not yet been widely implemented in clinical practice (Danner et al. 2020; Kasper et al. 2017; Coulter 2018; Maskrey 2019).

Staff attitude: Most healthcare provider staff are not trained in shared decision-making with patients and, consequently, have limited knowledge of different approaches to patient involvement (Bae 2017). Examples illustrate how staff training can positively impact patient involvement. Accordingly, hotel-like, service-oriented staff training contributes to a significant cultural change that can promote patient involvement (Bromley 2012).

Building: Some studies underscore the importance of a home-like healing environment (Bromley 2012; Martin 2000). One element of this approach is to conceal the work and treatment areas from the public and living areas. This environment was found to positively impact both staff and patient involvement attitudes (Bertakis and Azari 2011a). Today, however, patient-centered hospital design is more the exception than the rule (Elf et al. 2015).

2.4.4 Patient Health Antecedents

Presence of illness: Various papers in the sample conclude that severe illness is a barrier to patient involvement (Fortune et al. 2016; Altin and Stock 2016; Bae 2017; Joseph-Williams et al. 2014; Epstein and Street 2011; Bertakis and Azari 2011b) whereas good health is a facilitator (Joseph-Williams et al. 2014; Frosch and Kaplan 1999; Milky and Thomas 2020). However, patient preferences may change after an illness. For instance, a person under the emotional impact of a newly diagnosed serious illness often undergoes a cognitive state characterized by difficulties in processing complex information and ambiguity (Fortune et al. 2016; Epstein and Street 2011). Thus, time to adjust to a new health status becomes a facilitator for patient involvement. However, even among seriously ill patients, a positive attitude towards involvement was found (van der Weijden et al. 2017; Frosch and Kaplan 1999). One study found that involvement can depend on the phase of illness and prior exposure to illness-related decisions, indicating that involvement follows a learning curve (Joseph-Williams et al. 2014).

Type of illness: Several studies have indicated that the degree of patient involvement should depend on the type of illness. Generally, multimorbidity and chronic illness are seen as principal target groups for involvement (Laschet 2020a; Liao et al. 2017; Coulter 2018; Yasser et al. 2017; Longtin et al. 2010). This is primarily due to the fact that there are usually several treatment options for these types of illnesses, and the selection of the most suitable option depends on the patient's situation, thereby necessitating their involvement (Laschet 2020a).

2.4.5 Patient Characteristics Antecedents

Patient diversity: The review shows that most patients prefer the idea of being involved in medical decisions (Légaré and Thompson-Leduc 2014; Dahl Steffensen et al. 2017; van der Weijden et al. 2017; Longtin et al. 2010; Dimopoulos-Bick et al. 2019; Frosch and Kaplan 1999; Kheirkhah et al. 2020). For example, 98% of a Dutch patient panel mostly or always chose a shared decision making model (van der Weijden et al. 2017). On the other hand, not all patients want to participate in medical decisions (Bae 2017; Haltaufderheide et al. 2019), and not all patients are cognitively or emotionally capable of doing so (Laschet 2020a; Herlitz et al. 2016; Elwyn et al. 2017). Incorrect or insufficient information and knowledge are barriers to patient involvement (Bae 2017; Fortune et al. 2016; Herlitz et al. 2016; Longtin et al. 2010; Coulter 2018; Ousseine et al. 2019), as demonstrated by the example of teenage diabetes patients having difficulties considering short- and long-term risks and benefits (Herlitz et al. 2016). Unassisted, patients' decisions might be neither truly informed nor autonomous because patients may have limited insight into their own cognitive biases and limitations (Epstein and Street 2011). Other patients may be over-confident or ultimately made responsible for decisions that they are not capable of making (Lindberg et al. 2014). A decline in health literacy, as observed in Germany, is another factor that can hinder patient involvement (Schaeffer et al. 2021).

Sociodemographic criteria: The evidence on the contribution of demographic statistics is mixed (Bae 2017; Longtin et al. 2010; Pham et al. 2020; Légaré and Witteman 2013; Galesic and Garcia-Retamero 2011; Milky and Thomas 2020; Kheirkhah et al. 2020). One study found a significant contribution of socioeconomic status, gender, age, and race for autonomy preference, but not for decision-making (Fortune et al. 2016). Other studies found education and income to be significant factors influencing involvement preferences (Fortune et al. 2016; Bertakis and Azari 2011b; Lako and Rosenau 2009; Hughes et al. 2018). Overall, sociodemographic data provide relatively low predictability for patient preferences (Altin and Stock 2016; Probst et al. 2016).

Understanding preferences: Some researchers conclude that involving patients requires understanding their characteristics and preferences (Bae 2017; Makoul and Clayman 2006; Longtin et al. 2010), especially in situations where patients find it difficult to articulate these (Haltaufderheide et al. 2019; Herlitz et al. 2016; Pham et al. 2020). Clinicians misinterpreting patients' preferences for shared decision making are a significant barrier to successful patient involvement (Légaré et al. 2008).

Process: Overall, patient characteristics are not static but change over time (Lindberg et al. 2014; Epstein and Street 2011). Patients can go through stages of autonomy in both mental and physical abilities, demanding more involvement as they do so (Lindberg et al. 2014). When educated to participate in their care, patients can contribute to improved disease control (Longtin et al. 2010). Furthermore, patients who initially may be reluctant to participate in medical decisions can change their minds after decision options are explained to them, even if their health literacy is low (Stiggelbout et al. 2012). Such an increase in patients' self-efficacy will also foster their motivation to participate in medical decision-making. Active encouragement by health practitioners will significantly facilitate this effect (Joseph-Williams et al. 2014), as will patient decision aids (van der Weijden et al. 2017).

2.4.6 Healthcare Provider Choice by Patients

Decision criteria: Several studies have shown that patients primarily choose healthcare providers based on personal experiences with hospitals, hospital reputations, recommendations from relatives or outpatient service providers, and proximity to home (Cruppé and Geraedts 2017; Abraham et al. 2011; Dijs-Elsinga et al. 2010; Lako and Rosenau 2009). Some studies have found that provider quality becomes increasingly important as patients' illnesses become more severe (Böcken et al. 2013). No study in this review identified patient involvement as a significant factor in patients' choice of healthcare provider.

Information sources: When choosing healthcare providers, patients rely on personal knowledge of hospitals, relatives, outpatient health professionals, and the internet as major sources of information (Cruppé and Geraedts 2017; Abraham et al. 2011). Patients' desire for independent and reliable information is pronounced (Geraedts; Ketelaar et al. 2014). Most publications in the review agree that patients did not consider provider quality information and hospital performance reports, as these were either unknown or deemed of minor importance (Cruppé and Geraedts 2017; Abraham et al. 2011; Faber et al. 2009; Geraedts; Ketelaar et al. 2014; Ketelaar et al. 2011; Lako and Rosenau 2009; Victoor et al. 2012).

However, patients are increasingly searching the internet for healthcare provider quality information (Geraedts; Faber et al. 2009).

2.4.7 System-Level Processes and Interventions

Regulation: Governments can influence patient involvement through legislation. For example, shared decision making became a legal requirement in the United Kingdom in 2015 (Coulter 2017). Germany introduced the Patients' Rights Act in 2013 (Danner et al. 2020). However, a regulatory framework alone does not directly translate into more patient involvement at the provider level, where profitability considerations often take precedence over shared decision making (Coulter 2018).

Societal patient protection and support: Work in this area has concentrated on patient involvement facilitators, which are best developed independently of specific providers, such as at the association or government level. These facilitators include assessment tools and quality indicators to measure the extent and outcome of patient involvement (Bae 2017; Härter et al. 2017); patient decision aids in conjunction with clinical guidelines that consider appropriate standards and multiple treatment options (Coulter et al. 2017; Danner et al. 2020; Härter et al. 2017; Montori et al. 2013; Stiggelbout et al. 2012; van Veenendaal et al. 2018; Kasper et al. 2017; van der Weijden et al. 2017; Stacey et al. 2019); curricular standards for medical and nursing schools (Coulter 2017; Härter et al. 2017; Kasper et al. 2017), and establishing a national or international database with best-practice patient involvement support tools (Härter et al. 2017; van Veenendaal et al. 2018).

2.4.8 Healthcare Provider Processes and Interventions

Staff training: Many studies in the sample argue that healthcare providers need to train their personnel for effective and time-efficient patient involvement, especially with regard to IT tools, hard and soft skills, and attitudes toward patients (Bae 2017; Joseph-Williams et al. 2014; Danner et al. 2020; Dimopoulos-Bick et al. 2019; Epstein et al. 2004; Joseph-Williams et al. 2017; Légaré et al. 2008; Légaré and Witteman 2013; Liao et al. 2017; Longtin et al. 2010; Pham et al. 2020; Sepucha et al. 2016; Laschet 2020b; Spinnewijn et al. 2020; Coulter 2018; Stiggelbout et al. 2012; Driever et al. 2020; Friedberg et al. 2013; Hoffmann et al. 2014; Joseph-Williams et al. 2019; Sanders et al. 2017; van Veenendaal et al. 2018).

Tools: Clinical practice guidelines and patient decision aids, guided by patient involvement, are considered an important (but not the only) prerequisite for discussing relevant information within a limited time during clinical examinations (Bae 2017; Joseph-Williams et al. 2014; Gravel et al. 2006; Dimopoulos-Bick et al. 2019; Härter et al. 2017; Légaré and Witteman 2013; Liao et al. 2017; Yasser et al. 2017; Pham et al. 2020; Sepucha et al. 2016; Laschet 2020a; Stacey et al. 2019; Coulter 2018; Stiggelbout et al. 2012; Elwyn et al. 2013; Légaré and Thompson-Leduc 2014; van Veenendaal et al. 2018). Furthermore, effective patient involvement requires interfaces with patient electronic health records (Bae 2017; Sepucha et al. 2016). This can also ensure continuity of care and avoid redundancy when multiple clinicians are involved (Joseph-Williams et al. 2014).

Expert networks: Collaboration among health experts was found to promote patient involvement (Bae 2017; Légaré and Witteman 2013; Coulter 2018; Berghout et al. 2015; Hofstede et al. 2014; Constand et al. 2014). Some studies argue that the presence of coaches during clinical consultations contributes to effective involvement (Joseph-Williams et al. 2014; Danner et al. 2020; Laschet 2020a; Friedberg et al. 2013).

Implementation process: Several studies have shown that patient involvement initiatives are more successful when they target all hospital staff and patients and have full leadership support (Coulter 2017; Dimopoulos-Bick et al. 2019; Joseph-Williams et al. 2017; Sepucha et al. 2016; Coulter 2018; Bokhour et al. 2018; Lloyd et al. 2013; van Veenendaal et al. 2018; Coulter et al. 2011). One study added hospital architectural layout to this holistic implementation perspective (Elf et al. 2015). Sufficient funding was also an essential prerequisite to circumvent time constraints and economic pressure (Coulter 2018).

2.4.9 Patient / Doctor Communication

Relationship level: Patient involvement requires a trusting relationship between doctors and patients (Bae 2017; Elwyn et al. 2012; Joseph-Williams et al. 2014; Frosch et al. 2012; Ommen et al. 2011; Shay and Lafata 2014). Many publications suggest specific communication techniques or attitudes that support patient autonomy and facilitate patient involvement (Bae 2017; Elwyn et al. 2012; Gravel et al. 2006; Constand et al. 2014; Joseph-Williams et al. 2014; Makoul and Clayman 2006; Epstein and Street 2011; Shay and Lafata 2014; Joseph-Williams et al. 2017). An authoritarian clinician will likely discourage patient involvement (Joseph-Williams et al. 2014; Frosch et al. 2012). Several papers argue that a trusting patient-doctor relationship is an essential prerequisite for effective learning, and that providing information or evidence without patient trust in the physician is insufficient to facilitate patient involvement (Constand et al. 2014; Hargraves et al. 2016; Joseph-Williams et al. 2017). Time constraints and medical terminology were frequently cited as barriers in this context (Joseph-Williams et al. 2014; Maskrey 2019; Schaeffer et al. 2021; Dimopoulos-Bick et al. 2019; Joseph-Williams et al. 2017; Gravel et al. 2006; Légaré et al. 2008; Longtin et al. 2010).

Information level: The "Three Questions" intervention enables patients to facilitate their involvement by asking their physicians specific questions: “what are my options? what are the benefits and harms? and how likely are these?” (Shepherd et al. 2011). This intervention and its amendments were found to effectively facilitate doctor/patient information exchange (Danner et al. 2020; Elwyn et al. 2017; Shepherd et al. 2016; Shepherd et al. 2011; Stiggelbout et al. 2012; van Veenendaal et al. 2018; Légaré and Witteman 2013). It also increased the likelihood that physicians would solicit more involvement from patients (Longtin et al. 2010). Patient decision aids that describe options for specific medical conditions are considered effective for facilitating patient involvement (Danner et al. 2020; Longtin et al. 2010; Frosch et al. 2012). Lastly, understanding individual patient preferences and resulting perspectives on benefits, risks, and costs were considered an essential element for shared decision making (Makoul and Clayman 2006; Maskrey 2019; Joseph-Williams et al. 2017; Légaré and Witteman 2013; Stiggelbout et al. 2012; Stiggelbout et al. 2015).

2.4.10 Patient Journey

Diagnosis: While there are opportunities for patients to participate in diagnosis, such as expert consultations for secondary opinions and additional diagnostic tests, few studies in the survey examined these. Evidently, patients are less involved in performing diagnostic procedures (Longtin et al. 2010). Diagnoses at later stages of the patient journey (e.g., post-initial diagnosis) offer more opportunities for patient involvement, such as options for additional testing (Spinnewijn et al. 2020). In particular, the option to perform a CT scan was mentioned as a way to initiate patient involvement at later stages of the diagnostic journey

(Probst et al. 2016). At this point, physicians can discuss with their patients whether they would like to use CT scans as an additional diagnostic option to better rule out certain risks.

Treatment: Researchers found that specialists allow less patient participation than general practitioners (Longtin et al. 2010). Emergency care offers limited opportunities for patient involvement, but it can be utilized for decisions regarding invasive procedures and patient discharge (Probst et al. 2016). In a broader context, the Three Questions intervention (Shepherd et al. 2011) has been shown to successfully contribute to finding the appropriate treatment option (Kasper et al. 2017; Danner et al. 2020; Coulter 2017).

2.4.11 System Efficiency Outcomes

Improved performance: Some papers argue that more patient involvement will result in a better quality of nationwide healthcare while cutting costs (Stewart et al. 2000; Bertakis and Azari 2011a; Légaré and Witteman 2013; Clarke et al. 2015; Elwyn et al. 2016; Bae 2017). One reason may be that patient involvement leads patients to choose more conservative treatment options on average (Légaré and Witteman 2013).

System know-how: Setting up national clinical guidelines and patient decision aids requires upfront investment. Because this knowledge base, once created, is available to all physicians and patients, it is likely to reduce consultation times and lead to long-term health care savings (Laschet 2020a).

2.4.12 Healthcare Provider Performance Outcomes

Patient relationship: With increased involvement, patients are likely to feel more satisfied and loyal to their healthcare provider (Charmel and Frampton 2008; Wolf et al. 2008; Glass et al. 2012; Elwyn et al. 2016; Bae 2017; Milky and Thomas 2020). They also rate the interaction and service quality higher (Bieber et al. 2006; Wolf et al. 2008; Altin and Stock 2016; Sepucha et al. 2016; van Veenendaal et al. 2018). A potential drawback is the increased risk that, as patient-centered service and courtesy gain importance, professional expertise may diminish in value, since patients tend to prioritize interpersonal skills over technical competence (Bromley 2012).

Economic value: Some studies mentioned financial benefits of patient involvement, such as reduced length of stay, lower cost per case, higher patient volumes, fewer adverse events and malpractice claims (Probst et al. 2016), and even better employee retention (Elwyn et al. 2016; van Veenendaal et al. 2018) and lower operating costs (Charmel and Frampton 2008). A case study describes that a patient-centric hospital reorganization resulted in a 16% cost reduction within three years (van Leersum et al. 2019). At the same time, patient recommendation rates increased from 77% to 93%, and the Hospital Specific Mortality Rate decreased from 106 to 102 cases.

Time constraints: The articles in this review present mixed evidence on whether a patient involvement-oriented approach is more time-consuming than non-involvement healthcare. While some studies did not find an increase in required time, others reported neutral effects or significantly longer consultation periods (Longtin et al. 2010; Légaré and Witteman 2013; Pham et al. 2020). One study concluded that the data was insufficient to support an association between patient involvement and consultation time (Stiggelbout et al. 2012).

2.4.13 Patient Health Outcomes

Direct health outcomes: Overall, the studies in the review indicated neutral to positive health outcomes when favoring patient involvement-oriented healthcare over traditional approaches. Seven studies reported positive associations between patient involvement and health outcomes (Gravel et al. 2006; Joosten et al. 2008; Meterko et al. 2010; Rathert et al. 2013; Légaré and Witteman 2013; Shay and Lafata 2015; Hughes et al. 2018). Five papers found a neutral effect or a lack of empirical research (Bieber et al. 2006; Légaré et al. 2008; Scholl et al. 2014; Stiggelbout et al. 2015; Spinnewijn et al. 2020). Two papers reported that patient involvement was beneficial for chronic disease recovery (Joosten et al. 2008; Légaré and Witteman 2013).

Indirect health outcomes: Some studies found that adherence to medications and medical advice improved with patient involvement (Gravel et al. 2006; Yasser et al. 2017; Bae 2017). In addition, patient involvement fostered patient self-monitoring and treatment safety (Bae 2017). Patient involvement also improved satisfaction with the decision made (Gravel et al. 2006).

2.4.14 Patient Empowerment Outcomes

Cognitive: Several studies found that patient involvement increased patient health literacy and accuracy of risk perception (Joosten et al. 2008; Elwyn et al. 2012; Stacey et al.

2019; Laschet 2020b). Patient decision aids often contributed as a critical success factor to this outcome. In contrast, one study reported no statistically significant association between patient involvement and health literacy (Altin and Stock 2016).

Emotional: Several studies identified increased motivation, enhanced comfort with decisions made, and improved confidence or self-efficacy as direct outcomes of patient involvement (Gravel et al. 2006; Bromley 2012; Elwyn et al. 2012; Rathert et al. 2013; Légaré and Witteman 2013; Scholl et al. 2014; Shay and Lafata 2015; Elwyn et al. 2016; Fortune et al. 2016; Stacey et al. 2019; Danner et al. 2020; Laschet 2020b). These positive effects on patient autonomy can also alter patient communication behavior. As patients acquire communication skills and gain confidence in their abilities, they are likely to interact more assertively with their physicians (Charmel and Frampton 2008; Légaré and Witteman 2013).

2.5 DISCUSSION AND CONCLUSION

2.5.1 Discussion

I systematically reviewed key findings on patient involvement, highlighting what is known, contested, and unknown. Below, I synthesize and discuss the results to draw conclusions for each level: policy issues for health systems, managerial implications for healthcare providers, and patient implications. Additionally, I illustrate salient interdependencies across these levels.

System level: Progress in implementing patient involvement at the health system level remains slow. The cases of Norway, Taiwan, and Denmark (Kasper et al. 2017; Liao et al. 2017; Dahl Steffensen et al. 2017) suggest that regulatory authorities can accelerate patient involvement by simultaneously pursuing: (i) patient rights legislation, (ii) financial incentives or investment grants, and (iii) national information frameworks with a library of patient decision aids, appropriate clinical guidelines, and guidelines for training medical personnel. Similarly, other researchers propose national coordination of shared decision making resources and criteria for healthcare reimbursement (Hahlweg et al. 2022) or recommend central coordination of patient involvement plans, guidelines, and health education curricula (Dahl Steffensen et al. 2022; Kasper et al. 2022; Coulter et al. 2022).

The review highlights several positive outcomes of patient involvement. Key benefits include the potential to both save costs and improve healthcare quality, health literacy, and patient autonomy.

Provider level: Implementation of patient involvement is also slow at the provider level, with economic pressures, staff attitudes, and inadequate staff training cited as major barriers. Patient involvement is a skill that both patients and doctors have yet to learn (Dimopoulos-Bick et al. 2019). I found that mutual trust and a dialogue of equals facilitate patient involvement. This is directly promoted through the use of patient decision aids, interventions like the "Three Questions," and other inquiries about patient preferences.

This study presents extensive evidence of the positive effects of combining health staff training with the introduction of patient decision aids. Using decision aids from an independent, national library is likely to increase patient trust. This finding supports the recommendation to make quality-approved decision aids publicly available (Dahl Steffensen et al. 2022). Furthermore, this study found that expert networks among organizations (e.g., hospitals, outpatient services, and physiotherapists) also contribute to the successful implementation of patient involvement.

At the provider level, the findings of this study suggest mixed outcomes from increased patient involvement. Time and budget constraints are perceived as major barriers, while evidence of financial benefits is mixed. However, qualitative benefits such as higher patient satisfaction and fewer legal claims are very likely to result from patient-centered strategies.

Overall, I found limited evidence that patients prefer providers who practice patient involvement. However, this preference could change if provider quality data becomes more accessible through digital sources, such as user ratings or easy-to-understand quality reports. As more patients rely on these resources to choose their providers, patient involvement could translate into financial benefits as providers increase their market share (van Leersum et al. 2019).

Patient level: The analyzed studies indicate that shared decision making, a key component of patient involvement, is only beneficial when multiple realistic treatment options are available. Patients should be given time to adequately reflect on severe diagnoses before being involved in decision-making.

The review found consistent evidence that patients do not use available information tools. Their desire for independent, reliable information is often unmet by current offerings. Active patient encouragement can change this. When patients are encouraged and provided with reliable information, such as patient decision aids, they are more likely to prefer involvement. Because publicly available decision aids do not meet the population's health literacy needs, their introduction should be accompanied by a national health literacy strategy, recognizing that both patients and providers need to develop involvement skills (Muscat et al. 2021; Tracy et al. 2022).

Being more responsive to patient preferences is challenging because such preferences are diverse, often unknown, poorly communicated, or constantly changing. When encouraged and provided with objective information, such as patient decision aids, patients are likely to prefer more involvement. Very little is currently known about effectively assessing patient preferences, other than that doctors should take them into account (Makoul and Clayman 2006; Maskrey 2019; Joseph-Williams et al. 2017; Légaré and Witteman 2013; Stiggelbout et al. 2012; Stiggelbout et al. 2015). In this context, one study suggested Bayesian collaborative filtering of patients to create preference clusters (Shaoibi et al. 2020).

Overall, I found a neutral to slightly positive effect of patient involvement on patient health. In contrast, with respect to patient empowerment, the evidence for positive cognitive and emotional effects was convincing. Most importantly, these effects appear to accumulate over time, meaning that patients can and will learn (Légaré and Witteman 2013), thereby improving their health literacy and autonomy. This, in turn, creates opportunities for more involvement. NHS England's Universal Personalized Care strategy builds on this effect. It aims to give patients greater control based on their strengths, needs and preferences (NHS England 2019) to improve outcomes and reduce health inequalities. Consequently, it seems advisable to involve even those patients who are initially reluctant to participate.

Future research directions: I found little research on the economic benefits of more patient involvement at the provider level (e.g., by increasing market share or reducing treatment costs). Relevant insights in this area could help encourage more healthcare organizations to practice patient involvement.

Additionally, most of the research in the study focused on restoring health, i.e., disease management. This may overlook patient involvement opportunities for managing individual health and disease prevention.

Limitations: This systematic review is subject to limitations. The keyword and language criteria may have been too limited to capture the full body of evidence in the research field. Furthermore, the results may not apply to specific illness types or healthcare departments, such as emergency care. Rather, this study highlights general guidelines for how involving patients can facilitate access to new healthcare resources.

2.5.2 Conclusion

The concept of patient involvement is grounded in an implicit vision. Accordingly, patient-centered healthcare providers service a health-conscious and literate population within a health system that continuously improves quality at manageable costs. Clearly, for this vision to materialize, the health system, providers, and patients are interdependent. I showed that improving healthcare quality and population health literacy requires policymaker interventions. These include incentivizing providers to educate their patients through conversation and decision aids, adapting medical education curricula, and managing a repository of reliable health information and patient decision aids. Lastly, health system guidelines can foster collaboration between sectors, such as through a common digital health data infrastructure and managed patient data access.

2.6 PRACTICAL VALUE

This study highlights the importance of integrating interventions at the level of the healthcare system, healthcare providers, and patients. Systematic patient involvement is likely to be more effective than isolated interventions in promoting population health literacy and quality of healthcare.

Additionally, the findings offer guidance for providers intending to implement patient involvement. A pilot in a department with multiple relevant treatment options, such as chronic disease, is likely the most appropriate learning environment. Testing and ensuring commitment of all relevant stakeholders, staff, managers, leadership, and patients will increase the likelihood of success. Staff training for processes, supporting tools, and communication skills are essential. Using validated approaches like the “Three Questions” intervention can help in this area. Patients are more likely to prefer patient decision aids from reliable sources, i.e., national or international best practice initiatives like the International Patient Decision Aids Standards collaboration. Finally, patients' health literacy will benefit further if physicians help them to connect with other trusted health experts.

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2.8 APPENDIX

I assessed 118 reports for eligibility and subsequently excluded these 19 publications because they did not meet the selection criteria.

Table 2.2. Excluded Publications.

No.	Author(s)	Title	DOI	Reason for exclusion
1	Bornkessel et al. (2018)	Social Media: Opportunities for Quality Improvement and Lessons for Providers—A Networked Model for Patient-Centered Care Through Digital Engagement	10.1007/s11886-014-0504-5	Focus on cardiology
2	Bot et al. (2014)	Informed Shared Decision-Making and Patient Satisfaction		Limitation on specific disease
3	Butterworth & Campbell (2014)	Older patients and their GPs: shared decision making in enhancing trust	10.3399/bjgp14X682297	No implementation related results
4	Charif et al. (2020)	Strategies for Involving Patients and the Public in Scaling-Up Initiatives in Health and Social Services: Protocol for a Two-Pong Study	10.21203/rs.3.rs-63534/v1	Research protocol without results
5	Stacey et al. (2017)	Decision aids for people facing health treatment or screening decisions (Review)	10.1002/14651858.CD001431.pub5.	Specific focus on decision aids, results presented and updated in later article (2019)
6	Weiss et al. (2018)	Gaps in the Implementation of Shared Decision-making: Illustrative Cases	10.1542/peds.2018-3055	Focus on clinical pediatric practice

7	Groenewoud et al. (2015)	What Influences Patients' Decisions When Choosing a Health Care Provider?	10.1111/1475-6773.12306	Limitation on specific disease
8	Hardiman et al. (2016)	Patient autonomy–centered self-care checklist reduces hospital readmissions	10.1016/j.surg.2016.05.007	Limitation on specific disease
9	Heen et al. (2021)	A framework for practical issues was developed to inform shared decision-making tools and clinical guidelines	10.1016/j.jclinepi.2020.10.002	No implementation related results
10	Kalsi et al. (2019)	Shared decision-making across the specialties: Much potential but many challenges	10.1111/jep.13276	No specific collection of empirical or theoretical data
11	Légaré et al. (2013)	Core Competencies for Shared Decision Making Training Programs: Insights From an International, Interdisciplinary Working Group	10.1002/chp.21197	No implementation related results
12	Lux et al. (2010)	The era of centers: the influence of establishing specialized centers on patients' choice of hospital	10.1007/s00404-010-1398-0	Focus on breast cancer
13	Memear et al. (2011)	Factors associated with shared decision making among primary care physicians: Findings from a multicentre cross-sectional study	10.1111/hex.12603	Focus on primary care only
14	Ozkaynak et al. (2013)	Patient-centered care requires a patient-oriented workflow model	10.1136/amiajnl-2013-001633	No specific collection of empirical or theoretical data
15	Ruland & Bakken (2002)	Developing, implementing, and evaluating decision support systems for shared decision making in patient care:	10.1016/S1532-	No specific collection of

		a conceptual model and case illustration	0464(03)00037-6	empirical or theoretical data
16	Schoenthaler et al. (2018)	Medication Adherence Improvement Similar for Shared Decision-Making Preference or Longer Patient-Provider Relationship	10.3122/jabfm.2018.05.180009	Focus on patients with hypertension
17	van der Eijk et al. (2013)	Using Online Health Communities to Deliver Patient-Centered Care to People With Chronic Conditions	10.2196/jmir.2476	Focus on chronic care
18	Visser et al. (2014)	Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: a systematic review	http://ccforum.com/content/18/6/604	Focus on specific disease
19	Dolan (2008)	Shared decision-making – transferring research into practice: The Analytic Hierarchy Process (AHP)	10.1016/j.pec.2008.07.032	No specific collection of empirical or theoretical data

PATIENT PREFERENCES FOR INVOLVEMENT IN MEDICAL DECISIONS: A CLUSTER ANALYSIS

3.1 ABSTRACT

Health policy makers expect physicians to involve patients in medical decision-making, implicitly assuming that all patients want to be involved in a similar manner. This study challenges this assumption, investigating whether and how patients differ in their preferences for involvement in medical decisions. We carried out a questionnaire-based cross-sectional field study with 463 patients. To identify distinct patient involvement preference groups, we used k-means cluster analysis. We found three distinct preference groups, which differed in terms of their motivation to take responsibility for their own health and to inform themselves, their trust in the health care system, and their use of digital tools. “Autonomists” are motivated to take charge of their own health. “Networkers” trust the health system and prefer healthcare providers that are well connected and digitally skilled. “Consultees” have confidence in healthcare providers and are less motivated to educate themselves about their condition. Knowing about these preference groups, physicians can more accurately determine what level and nature of involvement in medical decisions a particular patient requires. Our findings help to promote patient involvement and, subsequently, patient trust, satisfaction, and adherence to treatment.

Keywords: Patient preferences, patient involvement, patient-centered care, shared decision making, healthcare strategy

JEL classification: I12 (health behavior), I11 (analysis of healthcare markets)

3.2 INTRODUCTION

Health policymakers expect physicians to involve patients in medical decision-making (van der Heide et al. 2018). Consequently, healthcare providers have explored collaborative approaches for patient involvement, particularly patient autonomy, shared decision making and patient-centered care (Miller and Reihlen 2023; Constand et al. 2014; Altin and Stock 2016; Bravo et al. 2015; Bensing 2000; Rubinelli et al. 2009). Patient autonomy encompasses rights, responsibilities, and opportunities that promote patients' self-determination (Bravo et al. 2015) without external control or influence (Fortune et al. 2016). Shared decision making is closely related to patient autonomy as it aims to restore or promote patient autonomy by integrating patient values and preferences into medical decisions (Bae 2017; Epstein and Street 2011; Epstein 2000). In shared decision making, clinicians and patients work together to decide on tests, treatment options, and therapies based on the best available evidence and patient preferences (Coulter 2018). Similarly, patient-centered care designs healthcare around individual patients' values, needs, and desires, thereby most strongly emphasizing patient autonomy and decision-making authority (Constand et al. 2014).

Whereas regulators support patient involvement, it is not yet widespread in medical practice (Coulter 2018). One possible explanation for this is that patient involvement approaches are often not fully aligned with patients’ individual preferences which can differ greatly between individuals (Khunkhun et al. 2022; D'Andrade and Strauss 2012; Holland 2012; Strauss and Quinn 2006). Indeed, not every patient desires involvement, and if they do, their expectations, preferences and motivations for action may vary (Flynn et al. 2006; Say et al. 2006). Involvement may even become harmful, especially if based on misinformation (Rubinelli et al. 2009; Siliquini et al. 2011). On the other hand, more and more patients want to take their health into their own hands, rather than rely solely on the healthcare system (Day 2019). Patients today can utilize "smart" technologies and digital healthcare providers (Berger 2019). These factors may influence variations in patient involvement preferences.

Unrecognized differences in patients’ involvement preferences may partly explain why certain patient involvement interventions have failed to improve clinical outcomes (Khunkhun et al. 2022; Clayman et al. 2016). Patients’ varying preferences for involvement in medical decisions often remain unknown, even when physicians explicitly inquire about them (Coulter 2018; Joosten et al. 2008). This makes it considerably more difficult to exploit the full potential of patient involvement, for example because doctors unconsciously give their patients too little or too much autonomy (Hess Jr. et al. 2003). Consequently, understanding varying preferences is an essential step toward advancing patient involvement (Gerteis et al. 1993). Based on this understanding, physicians can develop personalized patient involvement strategies that maximize benefits while mitigating associated risks and potential costs (Stiggelbout et al. 2015; Stiggelbout et al. 2012; Légaré and Witteman 2013; Joseph-Williams et al. 2017; Makoul and Clayman 2006).

However, "much work needs to be done in order to further elaborate on patient preferences" (Khunkhun et al. 2022) Understanding individual patient preferences is not merely an end in itself; rather, it likely enhances patients' motivation, comfort with the chosen decisions, confidence in the treatment plan, and adherence to it (Miller and Reihlen 2023; Coulter 2018; Gravel et al. 2006; Légaré and Witteman 2013). Moreover, medical decisions that align with patient preferences have been shown to enhance therapy success (Fortune et al. 2016; Gravel et al. 2006; Légaré and Witteman 2013; Rathert et al. 2013; Say et al. 2006; Shay and Lafata 2015; Stacey et al. 2019; Danner et al. 2020). This connection between addressing patient preferences and therapy success further underscores the importance of physicians understanding their patients' preferences better. Despite this, there is still little information available to support clinicians in understanding different patient preferences within the medical decision-making process (Flynn et al. 2006). Hence, the question remains how physicians can effectively determine the personal involvement preferences of a specific patient – even when operating under the considerable time constraints they typically face.

The objective of this study is to determine whether distinct groups of patients with similar preferences regarding their involvement in medical decision-making exist and, if so, to examine the factors that shape each group's set of involvement preferences. To this end, we conducted a survey and applied cluster analysis to examine the existence and characteristics of potential patient involvement preference groups.

Practically, this study offers physicians a guide to efficiently, accurately, and comprehensively identify patient involvement preferences, including those that patients may not express during consultations. This approach enhances the likelihood of successful therapy outcomes.

3.3 METHOD

Insights into patient preferences on a broad scale require data that can be easily standardized, compared, and categorized, for which a survey-based field study approach is appropriate. Because currently no surveys exist that address all relevant aspects of patient involvement (Khunkhun et al. 2022), we developed a survey. To this end, we first derived an integrative framework (Constand et al. 2014), which we then used as the basis for developing our survey measures. In the following, we provide a detailed description of the methodological steps taken.

3.3.1 Integrated Framework for Patient Involvement Preferences

We based our analytical framework primarily on systematic literature reviews on patient involvement (Bravo et al. 2015; Gravel et al. 2006; Légaré et al. 2008; Joseph-Williams et al. 2014). At the individual patient level, these literature reviews differentiate between barriers and facilitators to patient involvement, typically categorizing them into different domains. Although the categorizations vary slightly across studies, they generally include barriers and facilitators related to (1) health literacy and patients' knowledge of their condition, as well as resulting expectations of healthcare services; (2) a desire for autonomy, including motivation, self-information, and peer networking; (3) context factors such as illness, values, and social support; and (4) experiences with healthcare. Using these four categories (i.e., knowledge, autonomy, context, and experiences), we integrated the identified patient involvement factors, barriers, and facilitators into the framework shown in Figure 3.1. This built the basis for our questionnaire development.

Figure 3.1. Integrated Framework for Patient Involvement Preferences.

Category:	**Knowledge**
Barriers/facilitators:	Health literacy, individual health management, networking, knowledge of the illness, expectations regarding physician expertise, customer orientation, information offerings, sector cooperation, holistic focus on health
Sample measures:	“Sometimes I feel that my health knowledge is superior to some doctors’ knowledge”, “I try to manage my own health”, “I am informed enough and able to discuss health issues with doctors”

Category:	**Autonomy**
Barriers/facilitators:	Motivation, agreement, desire for autonomy, personal values, confidence, self-efficacy, personal control, taking an active role, self-information, use of digital tools
Sample measures::	“I welcome more patient autonomy”, “I try to manage my own health”, “Telemedicine will offer me more choices to find the right expert for a health problem”

Category:	**Context**
Barriers/facilitators:	Health condition, trust, social support
Sample measures::	“Even the case of illness, there are free choices that I can take”, “When everybody takes responsibility for their own health, overall health expenditures in society are likely to decrease”, “Sometimes I feel that some doctors or clinics are more interested in profits than in patients' well-being”

Category:	**Experiences**
Barriers/facilitators:	Clinical experiences, experiences with patient involvement and health management
Sample measures::	“My collected healthcare data is used in diagnosis and therapy during doctor visits”, “Doctors actively encourage me to manage my own health”, “What I do for my health management has a proven positive impact on my health”

Knowledge: This category addresses health literacy, individual health management, networking (e.g., self-help groups), knowledge of the health condition, and expectations regarding expert knowledge of practitioners, customer orientation, information offerings, sector cooperation, and a focus on health rather than illness.

Autonomy: This category contains motivation, agreement, desire for autonomy, personal values, confidence, self-efficacy, personal control, taking an active role, and self-information. Because the digitization of healthcare is a mega-trend that supports patient autonomy (Day 2019), we added patients’ use of digital health tools, such as telemedicine or health data monitoring via wearables (Berger 2019) to this category. Digital health tools can promote patient engagement, make patients more demanding and inquisitive during consultations, and can highlight relevant points for discussion during consultations (Horton and Lucassen 2019), all of which enhance autonomy.

Context: This category includes health status, trust in practitioner competence, and social support. Serious illness will likely limit patient involvement, whereas trust in a practitioner’s competence is a crucial prerequisite for shared decision making (Miller and Reihlen 2023). Social support is likely to influence trust in a practitioner or medical decision (Ommen et al. 2011).

Experiences: This category includes previous clinical experiences, the extent to which health professionals have or have not involved the patient in the past, as well as experiences with individual health management.

3.3.2 Survey Development

Using our integrated framework for patient involvement preferences (Figure 3.1), we developed survey items to measure patient involvement preferences in a web-based survey. To ensure practical relevance and item validity, we discussed the developed items with a panel of four experts from hospitals, health-care providers, and health-technology companies. This led to changes in the wording of some items and the addition of some more items. We then pretested the survey with a group of 6 respondents, after which we again made minor changes to some item wordings. The final survey consisted of 31 items, which are listed in Table 3.1.

Table 3.1. Survey Items with Mean Score.

Item	**Mean score**
I am informed enough and able to discuss health issues on equal footing with doctors	4.07
Sometimes I feel that my health knowledge is superior to some doctors' expertise	3.13
I expect doctors to customize therapies personally for me instead of prescribing a one-size-fits-all therapy	4.75
I expect the health system to support me with tools similar in user friendliness and level of sophistication to what I am used to from tech companies like Google, Amazon, and Apple	4.14
In the case of illness, I expect doctors to take into account my individual data	4.63
Generally, I would prefer a doctor that uses both human judgement and digital sources when deciding on a diagnosis or therapy (instead of relying on judgement alone)	4.52
Being healthy is a top priority for me	4.93
I try to manage my own health*	4.61
In the case of illness, the measurement of my individual health data is likely to improve both diagnosis and therapy	4.21
I use resources from the internet to make myself more knowledgeable about specific health issues	4.28
I want to maintain superiority over my health data and decide myself who will get what kind of information*	4.61
I want to choose my doctor or hospital based on reliable quality data	4.69
Telemedicine will offer me more choices to find the right expert for a health problem	3.73

I welcome more patient autonomy	4.23
I welcome the increased responsibility associated with more patient autonomy	4.31
I would invest this amount of time [0-4 days] for important health decisions	4.61
The health system should be driven more by supply and demand	2.86
The health system should function more like a free market	2.39
Even the case of illness, there are free choices that I can take	4.38
Even when I am sick, I can be autonomous	4.15
More patient autonomy is likely to improve public health	3.80
The fact that doctors make money only with illness and not with health worries me*	4.06
When everybody takes responsibility for their own health, overall health expenditures in society are likely to decrease	4.31
I expect organizations like employers, schools, and associations to play a more active part in health management in the future	4.44
In the future, health knowledge will be expanded not only through studies and scientific experiments, but also with big data approaches covering large parts of the population that make their data available*	3.91
My health insurance offers benefits for the management of my health	3.81
What I do for my health management has a proven positive impact on my health	4.42
My collected healthcare data is useful for doctor visits	3.89
My collected healthcare data is used in diagnosis and therapy during doctor visits	3.26
Doctors actively encourage me to manage my own health	3.27
Sometimes I feel that some doctors or clinics are more interested in profits than in patients' well-being	3.98

* added after discussion with panel of industry experts

3.3.3 Survey

We conducted the study in Germany, using a two-stage sampling approach. In the first stage, we surveyed statutorily insured individuals, which make up 87% of the German population (Statistisches Bundesamt). In the second stage, we used purposive sampling. The survey was accessible via computer or mobile phone so that the largest possible proportion of the population could participate.

We contacted potential participants from August 2022 to April 2024. Three organizations included the link to our survey in their regular newsletters: (i) a statutory health insurance (average population), (ii) a healthcare industry congress (health experts), and (iii) a wearable hardware and software company in the field of heart rate variability measurement (wearable users). All recipients had previously opted in to receive the respective newsletter.

Every group received the same electronic survey link. Participants provided their informed consent. The relevant institutional review board waived ethics approval in line with regulations by the German Research Foundation.

Participants answered all survey items on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with a sixth "do not know" option. Across all items, a higher response score indicates a more pronounced preference for involvement. In addition to the 31 patient involvement items, we measured participants age and gender.

We received 465 unique responses out of a total of 3,700 recipients of the email newsletters. We deleted entries with more than ten unanswered items (n = 2). Our final sample constitutes 463 individual patients.

3.3.4 Analysis

We used cluster analysis to identify groups of respondents based on their answers to our survey items on patient involvement. Cluster analysis assigns objects, in our case survey item responses, to distinct groups based on the similarity of observed characteristics (Flynn et al. 2006). It is an established technique for categorizing persons based on psychographic criteria (Backhaus et al. 2016).

In a second analytical step, we segmented the survey responses based on gender, health expertise, and the utilization of health data monitoring via wearables to determine if these subgroups exhibited significantly different results.

The final data set contains a total of 119 unanswered items and 325 "do not know" responses. We treated both as missing. We used datasets containing missings in our model but excluded missings for specific calculations. We addressed nonresponse bias in two ways: nationally representative weighting and a comparison of early and late respondents (after a follow-up survey invitation). We analyzed our data using means, frequencies, and cross-tabulations to calculate descriptive statistics.

3.3.5 Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

3.4 RESULTS

3.4.1 Preference Clusters

With the cluster analysis, we identified three distinct groups of patient involvement preferences (i.e., preference clusters). Of the 463 respondents, 406 (87.7%) fell into one of the three preference clusters. The score means of the three preference clusters were significantly different ($p < 0.001$), as Table 3.2 shows.

Table 3.2. Cluster Metrics.

Cluster	1	2	3
n	170	145	91
Explained proportion of within-cluster heterogeneity	0.34	0.32	0.34
Within sum of squares	638.94	610.33	639.81
Silhouette score	0.25	0.19	0.10
Mean score in cluster	4.34	4.09	3.70
p	< 0.001		

n = number of respondents within cluster.

Explained proportion of within-cluster heterogeneity = explained cluster variation / total cluster variation (JASP Team).

Silhouette score = similarity of data points within the same cluster vis-à-vis data points in different clusters. It ranges from -1 (poor clustering) to +1 (perfect clustering). Clusters are considered distinct and independent with a score above 0 (JASP Team).

p = probability for no significant difference between the means of all clusters.

The cluster analysis results suggest that three distinct patient groups with different involvement preferences exist, but do not provide information about which preferences characterize these groups. To outline the differential qualitative aspects of each cluster, we compared the item response scores, focusing on items that showed clear differences between the cluster means (i.e., those strongly associated with the clusters' characteristics). A higher mean score indicates a greater overall preference for involvement and more agreement on aspects such as the importance of health data collection and the willingness to seek out information. Table 3.3 shows that the degree of agreement with the individual items varied between the respondents within the individual clusters. It expresses this variation by the difference between the cluster mean score for a particular item and the overall item mean score ("max – min" in Table 3.3). For example, Cluster 1's mean score for the item "Sometimes I feel that my health knowledge is superior to some doctors' knowledge" is 0.58 points higher than the overall item mean score, while the mean score of Cluster 3 is 1.17 points lower, resulting in a pronounced "max-min" difference of 1.74.

Table 3.3. Mean Item Scores, Standard Deviations and Cluster Deviations from the Mean.

			Cluster deviation from mean			
Question	μ	σ	Cluster 1	Cluster 2	Cluster 3	Max-min
Being healthy is a top priority for me	4.93	0.34	0.00	0.04	-0.05	0.09
I try to manage my own health	4.61	0.62	0.07	0.05	-0.19	0.27
I expect the health system to support me with tools similar in user friendliness and level of sophistication to what I am used to from tech companies like Google, Amazon, and Apple	4.14	1.09	-0.09	0.40	-0.64	1.05
In the case of illness, the measurement of my individual health data is likely to improve both diagnosis and therapy	4.21	1.04	-0.02	0.48	-0.80	1.28
In the case of illness, I expect doctors to take into account my individual data	4.63	0.68	-0.06	0.24	-0.26	0.51
I use resources from the internet to make myself more knowledgeable about specific health issues	4.28	1.09	0.36	0.21	-0.86	1.22
Sometimes I feel that my health knowledge is superior to some doctors' knowledge	3.13	1.25	0.58	0.18	-1.17	1.74
Sometimes I feel that some doctors or clinics are more interested in profits than in patients' well-being	3.98	0.99	0.14	0.04	-0.15	0.29
The fact that doctors make money only with illness and not with health worries me	4.06	1.09	0.28	0.02	-0.36	0.65
I expect doctors to customize therapies personally for me instead of prescribing a one-size-fits-all therapy	4.75	0.50	-0.01	0.07	-0.08	0.15
I want to maintain superiority over my health data and decide myself who will get what kind of information	4.61	0.77	0.05	-0.02	0.03	0.07
Generally, I would prefer a doctor that uses both human judgement and digital sources when deciding on a diagnosis or therapy (instead of relying on judgement alone)	4.52	0.70	0.14	0.17	-0.48	0.66
I want to choose my doctor or hospital based on reliable quality data	4.69	0.58	0.02	0.16	-0.29	0.44
Telemedicine will offer me more choices to find the right expert for a health problem	3.73	1.10	0.17	0.44	-0.97	1.41
When everybody takes responsibility for their own health, overall health expenditures in society are likely to decrease	4.31	0.96	0.06	0.12	-0.31	0.43

I expect organizations like employers, schools, and associations to play a more active part in health management in the future	4.44	0.83	-0.02	0.17	-0.16	0.33
In the future, health knowledge will be expanded not only through studies and scientific experiments, but also with big data approaches covering large parts of the population that make their data available	3.91	1.04	0.05	0.52	-1.02	1.54
I welcome more patient autonomy	4.23	0.81	0.03	0.21	-0.41	0.61
I welcome the increased responsibility associated with more patient autonomy	4.31	0.84	0.08	0.11	-0.31	0.42
I would invest this amount of time for important health decisions	4.61	0.68	0.13	0.01	-0.21	0.35
Even when I am sick, I can be autonomous	4.15	0.81	-0.07	0.13	-0.15	0.28
I am informed enough and able to discuss health issues with doctors	4.07	0.98	0.02	0.19	-0.27	0.45
Even the case of illness, there are free choices that I can take	4.38	0.75	-0.10	0.22	-0.26	0.49
The health system should be driven more by supply and demand	2.86	1.29	0.03	0.25	-0.41	0.67
The health system should function more like a free market	2.39	1.22	0.10	0.28	-0.36	0.64
More patient autonomy is likely to improve public health	3.80	0.97	0.02	0.25	-0.46	0.71
What I do for my health management has a proven positive impact on my health	4.42	0.73	0.11	0.04	-0.30	0.41
My collected healthcare data is useful for doctor visits	3.89	1.15	-0.42	0.62	-0.43	1.05
My collected healthcare data is used in diagnosis and therapy during doctor visits	3.26	1.29	-0.90	1.07	-0.35	1.97
Doctors actively encourage me to manage my own health	3.27	1.15	-0.96	0.83	-0.02	1.79
My health insurance offers benefits for the management of my health	3.81	1.33	-0.29	0.26	-0.08	0.55

μ = mean score.

σ = standard deviation.

Cluster deviation from mean = difference between the cluster mean and the mean for all 463 responses for the respective item.

Max – min = largest distance between the cluster deviations from the mean for a particular item

The analysis of cluster-specific score deviations allows for the characterization of each Cluster based on pronounced differences in their preferences:

Cluster 1: Patients in Cluster 1 make up 35.7% of respondents with an overall item mean score of 4.3, which is the highest of the three clusters. Respondents in Cluster 1 have the highest motivation to learn and inform themselves about their health status. They tend to trust the healthcare system less than patients in the other clusters. For example, they scored highest in the item “Sometimes I feel that my health knowledge is superior to some doctors’ expertise”. Their trust is based more on digital tools, data, and personal responsibility. They are motivated to take control of their health, as their experience has shown that doctors and health insurance companies are less likely to help them achieve this goal. We labeled this preference cluster “autonomists”.

Cluster 2: Patients in Cluster 2 make up 41.9% of respondents with an overall item mean score of 4.09. They prefer to be involved. They are digitally savvy and prefer to manage their own health – including conducting their own internet research – and are willing to share their health data. For example, they scored high in the item “My collected healthcare data is used in diagnosis and therapy during doctor visits”. They prefer healthcare providers who are digitally skilled. When making medical decisions, they prefer a mix of expert advice, collaboration, and digitally available information. We labeled this preference cluster “networkers”.

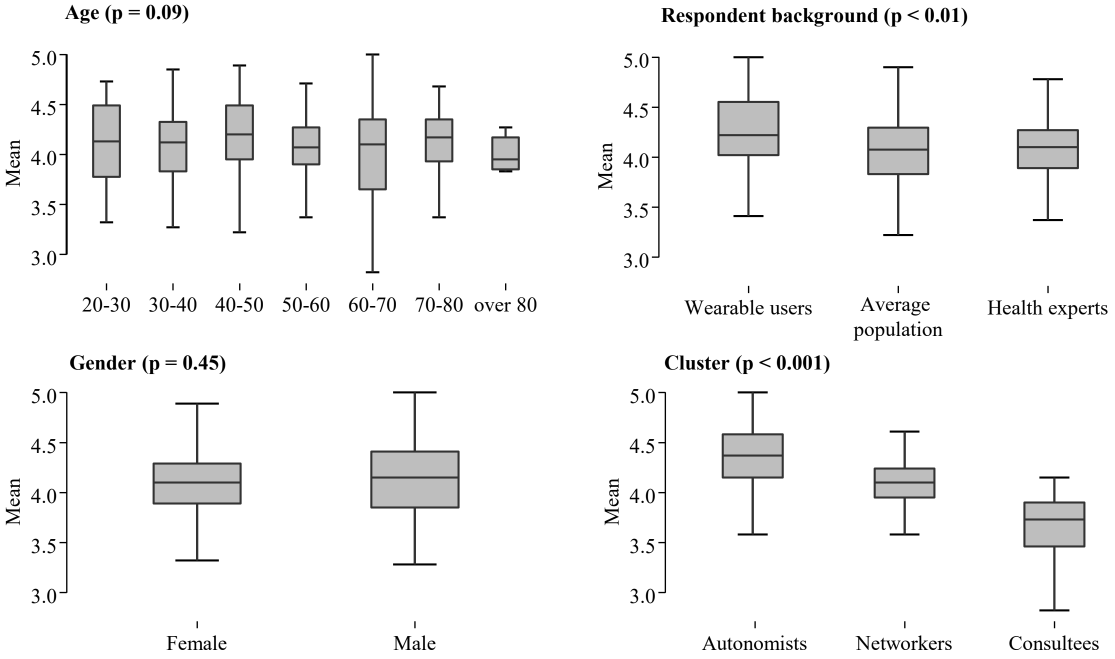
Cluster 3: Patients in Cluster 3 make up 22.4% of respondents. They have a lower overall preference for involvement (overall item mean = 3.7), place comparatively less value on self-responsibility, trust healthcare providers more than patients in the other two clusters, and are less motivated to educate themselves about their health conditions. For example, they scored low in the item “I use resources from the internet to make myself more knowledgeable about specific health issues”. We labeled this preference cluster “consultees”.

3.4.2 Involvement Preference by Subgroups

In this section, we investigate whether there could be alternative categorizations of the response scores that are statistically significant, in addition to our clustering. To achieve this, we divided the respondents into subgroups based on the sociodemographic data collected alongside the survey responses, age, gender, and respondent background (wearable user, health expert, neither of both). The respondent background subgroups consist of health professionals from their own perspective as patients, wearable users who track their health data, and the patients that neither are health experts nor monitor their health (labelled “average population” in Figure 3.2).

Figure 3.2 represents our analysis of differences in survey item mean scores (i.e., patient involvement preferences) by subgroups as well as the clusters from the previous section (autonomists, networkers, consultees). Differences in survey item mean scores were not significant between age groups or genders. The wearable user group had a statistically significant ($p < 0.001$) higher preference for involvement than the average population and health experts groups. In none of the subgroups—age, respondent background, or gender—are the differences in the survey item mean scores as pronounced as in the clusters we identified (as shown in Figure 3.2, bottom right). This result indicates that the clusters differentiate the patients' involvement preferences better than any of the subgroups.

Figure 3.2. Survey Scores by Age, Gender, Survey Groups, and Cluster.

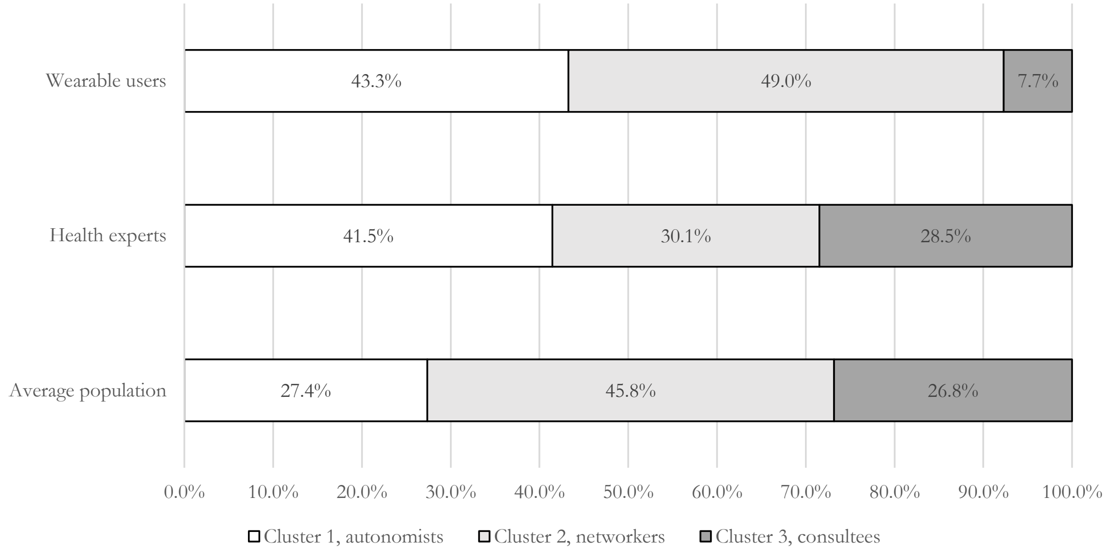


p = probability for no significant difference between the means of all clusters. Values below 0.01 indicate a significant difference between the means of the respective groups. Descriptive statistics provided in the supporting documentation

Lastly, we analyzed the connection between subgroups and clusters. We only examined the subgroup "respondent background" because, in contrast to the age and gender subgroups, their survey item mean scores were significantly different. "Respondent background" subgroups are: wearable users, health experts, and the average population. Our aim was to determine whether certain clusters are disproportionately represented within these subgroups. To achieve this, we calculated the percentage of autonomists, networkers, and consultees within them.

Figure 3.3 shows that the subgroup of wearable users had the highest proportion of autonomists, 43.3%. Autonomists had the highest motivation to inform themselves about their health while valuing personal responsibility. Moreover, wearable users had the smallest proportion of consultees, at 7.7%. Consultees were characterized by a lower overall preference for involvement and placed comparatively less value on self-responsibility. In summary, patients from the subgroup of wearable users prefer more self-responsibility vis-à-vis health experts and the average population. This is particularly noticeable compared to the average population, where autonomists make up only 27.4% (compared to 43.3% among wearable users). Conversely, consultees are much more represented in the average population (26.8% versus 7.7% among wearable users).

Figure 3.3. Distribution of Preference Clusters Within Purposive Sampling Groups.



3.5 DISCUSSION

In a field survey study with 463 participants, we investigated patients' preferences for involvement in medical decision making. Using cluster analysis, we found three groups of patients with distinct involvement preferences, differing both in terms of quantitative and qualitative aspects. Table 3.4 summarizes the main qualitative characteristics of the three identified clusters (i.e., patient involvement preference groups).

Table 3.4. Summary of Involvement Preferences in the Three Identified Groups.

Autonomists	Networkers	Consultees
Show a strong drive for self-education	Research & discuss information	Are less willing to research information
Are personally responsible for one's own health	Prefer to be involved and share responsibility with healthcare provider	Prefer to put oneself in the hands of a professional
Tend to mistrust the health system or healthcare providers, control and manage health with (digital) tools	Trust the health system & want healthcare providers to be digitally skilled and advanced	Place a high level of trust in healthcare providers and rely on their expertise
Experience that healthcare providers do not always help to manage health	Have good experience with mix of expert advice, collaboration, and (digitally available) information	Feel generally comfortable with healthcare providers

In this section, we discuss the scientific and practical implications of these results for patient involvement research.

Scientific implications

To date, patient involvement preferences have received limited attention in the literature and remain largely unexplored (Khunkhun et al. 2022). Our study shows that patients do indeed differ in their preferences for involvement in medical decision-making. Current one-size-fits-all patient involvement approaches may not thoroughly capture these differences, leading physicians to unintentionally overlook or misinterpret them. Consequently, current involvement approaches are less likely to achieve optimal therapy outcomes and enhance patient satisfaction (Shay and Lafata 2015; Khunkhun et al. 2022; Gerteis et al. 1993). Given that the scientific literature has largely neglected a systematic analysis of patient involvement preferences, there is a lack of sufficient information to support clinicians in understanding and distinguishing between these preferences (Flynn et al. 2006). Our results contribute to their patient-specific recognition and consideration.

We identified three distinct groups with significantly different patient involvement preferences: autonomists, networkers, and consultees. These groups differ in key characteristics, including their motivation to gather and discuss information, the degree of desired self-responsibility, and confidence in provider expertise based on personal experiences. Each group exhibits similar preferences within itself, facilitating group-specific approaches to patient involvement. For example, physicians can inform and involve autonomists and networkers through patient decision aids, as their motivation to seek and discuss information provides a suitable basis. In contrast, consultees have less motivation in this regard and expect more explanation and guidance from their physician before they are ready to be involved in medical decisions. Our results provide initial insights into key differences in patient preferences, which can be used as a starting point to make patient involvement more effective.

The involvement interventions proposed in the current literature may not help to completely understand patient involvement preferences, even when they explicitly inquire about them. The example of the Three Talk Model, a prominent method of involvement discussed in the literature, can illustrate this. It employs a uniform multi-stage process for each patient, explicitly evaluating patient preferences prior to joint medical decision-making (Charles et al. 1999; Elwyn et al. 2017). However, it is unlikely that involvement preferences can be fully captured in such consultations. For example, autonomists might not want to convey to a physician that they independently seek information on the internet or mistrust doctors. Simultaneously, consultees may feel overwhelmed by being involved but choose not to disclose this to the physician. The fact that they would rather rely on the advice of experts than get involved themselves may go unrecognized, and involvement based on the patient's own responsibility may not be the best intervention for them. In this context, our study can provide deeper insights into the preferences of a particular patient group, including those that might not come up in a consultation. It therefore allows for more effective approaches to patient involvement.

The partial neglect of different patient preference groups may be one explanation for the sometimes contradictory effect of patient involvement interventions on patient satisfaction (Clayman et al. 2016). Our results show that patients may, depending on their preferences, react differently to similar interventions. This suggests they may not be equally satisfied with certain interventions. Even if they generally wish to be involved in medical decisions, their view on the ideal approach to involvement can vary depending on an autonomist, networker, or consultee perspective. We argue that explicitly considering these preference groups during interventions would increase patient satisfaction and thus the adoption of patient involvement in medical practice.

Conclusions based on sociodemographic factors regarding patients' involvement preferences may be misleading. We found in our study three significantly different preference groups based on survey scores. However, sociodemographic factors did not predict which patient belonged to which group. In other words, the differences between the groups are due to preferences, not sociodemographic factors. Thus, we have demonstrated that it is more effective to infer patients' involvement preferences based on their preference group rather than on sociodemographic factors. Our findings align with the literature, indicating that sociodemographics are not significant determinants of involvement preference (Fortune et al. 2016; Bertakis and Azari 2011; Lako and Rosenau 2009; Hughes et al. 2018; Légaré and Witteman 2013). Therefore, we suggest that doctors directly inquire about patients' preferences rather than attempting to infer them from sociodemographic factors.

Practical implications

For each patient preference group we identified, different aspects of patient involvement are particularly relevant. We summarize these aspects below.

Autonomists: Because these patients place a high value on self-reliance, physicians should consider providing them with independent information such as patient decision aids and asking for their opinion rather than making recommendations. Shared decision making is likely their preferred approach. When patients collect their health data, it will help them to see how this can contribute to a therapy. These patients likely appreciate digital interfaces for uploading health data to practice systems or health apps that facilitate data sharing and interpretation.

Networkers: Because these patients value the “personal element” of being embedded in a network of health professionals, physicians should consider their interest in receiving expert advice. This can focus on a specific treatment, but also on health management and recommendations regarding other health experts such as physiotherapists or nutritionists. Patients in this cluster prefer involvement and shared decision making. They likely appreciate it if their self-collected health data is used for their therapy. Patient decision aids are likely to be useful for these patients.

Consultees: Because these patients value personalized care, expert advice, and trust in healthcare providers, physicians should prioritize recommendations over shared decision making and the use of patient decision aids. Preference for data collection and health management is lowest in this cluster. When such interventions are required, doctors should provide as much guidance as possible.

Understanding the particularities of different preference groups will enable practitioners to fine-tune the relevant aspects of involvement for each individual patient. This way, the ethical principle of involving all patients in decision making can be pursued in a more effective way. To give an example: A doctor discusses treatment alternatives and provides a patient with decision aids, i.e., written information describing the advantages and disadvantages of each alternative. Consultees would have little motivation to read this information and would prefer to have it explained; autonomists could doubt the information; networkers likely want to compare it with information they have researched themselves and discuss it. Understanding these different expectations and reactions allows clinicians to address them more openly (or at all) and to address preferences that would otherwise remain unknown. Such fine-tuning of patient involvement can ultimately have a positive impact on patient outcomes (Fortune et al. 2016; Gravel et al. 2006; Légaré and Witteman 2013; Rathert et al. 2013; Say et al. 2006; Shay and Lafata 2015; Stacey et al. 2019; Danner et al. 2020).

Our findings indicate that technological advancements and the proliferation of digital tools, such as wearables, may influence patient preferences. Should patients find these innovations beneficial, they are likely to expect the healthcare sector to integrate and expand upon them. Failure to do so may render healthcare providers as outdated in the eyes of patients. As these technologies evolve, certain patients – specifically autonomists and networkers – will demand increasingly personalized and digitized services, as they favor digital information and tools in medical decision-making. In our study, this is reflected by the fact that autonomists and networkers together account for 92.3% of the wearable users in our sample. Autonomists are particularly susceptible to using digital tools, as they tend to trust their own health management capabilities while utilizing wearables and digital information sources. Physicians who do not accommodate these preferences may find it difficult to gain their trust and engagement. Similarly, networkers, who value a combination of expert advice, collaboration, and digital information, are likely to expect physicians to incorporate these elements into patient care.

Suggestions for practical implementation

To facilitate the translation of our research findings into medical practice, we propose an effective, questions-based approach that enables practitioners to identify individual patients' involvement preferences with just three questions. By understanding the distinct preferences of autonomists, networkers, and consultees, and identifying which group a patient belongs to, doctors can tailor the patient involvement in therapy for optimal outcomes.

We derived the three questions from the most prominent distinctions identified among the three patient preference groups in our research. Table 3.5 presents these questions, along with the most likely responses associated with each patient preference group.

Table 3.5. Three Questions to Ask Patients.

	Likely answer profile by cluster		
	Autonomists	Networkers	Consultees
(i) Is it important for you to collect and share individual health data?	YES	YES	NO
(ii) Is it important for you to inform yourself about your health condition from reliable sources?	YES	YES	NO
(iii) Would you like me to recommend other experts that may help you personally with your specific health condition?	NO	YES	indifferent

Based on patients' responses to these questions, clinicians can identify a patient's most likely preference group. This allows them to effectively determine the aspects of patient involvement that are particularly relevant, depending on whether the patient belongs to the autonomist, networker, or consultee group.

Future research

In general, more research is needed to better understand the relationships between patient preferences for involvement, involvement processes, and therapy outcomes. Accordingly, future studies could address the question of whether a personalized approach to patient involvement that incorporates preference clusters has a positive impact on therapy success, adherence, and patient satisfaction.

Future research can also investigate whether the three questions we propose help to elicit patient preferences more effectively, and thereby improve patient involvement, and ultimately the quality of healthcare.

3.6 LIMITATIONS

This study is subject to limitations. We excluded patients without internet access and those not subscribed to newsletters, which might have led to an overestimation of technology-related patient preferences in our sample. However, statistical tests regarding population representativeness and nonresponse bias mitigate this concern. Additionally, the study's geographic scope, Germany, may not universally represent patient preferences across diverse global contexts.

3.7 CONCLUSION

We identified three patient groups with varying preferences for involvement in medical decision-making. These preferences are influenced by their motivation to educate themselves about health issues, their trust in the healthcare system, and their reliance on digital tools and methods. Physicians can consider these different patient preferences when deciding how to convey information, build a trusting relationship, and make shared medical decisions with the highest likelihood of patient satisfaction and positive outcomes. We contend that understanding preference groups can enhance patient involvement. This understanding provides a framework that enables clinicians to prioritize key elements of patient involvement for each individual, even when time is limited.

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3.8 ETHICS STATEMENTS

3.8.1 Ethical Approval

Ethical approval is not applicable for this research. According to regulations established by the German Research Foundation, voluntary online survey studies are exempt from institutional review board approval in Germany (Deutsche Forschungsgemeinschaft).

3.8.2 Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Institutional Review Board’s approved protocols.

3.8.3 Statement of Informed Consent

The survey data was collected anonymously. Informed consent was obtained from the patients for their survey responses to be published anonymously in research papers on the starting page of the online survey. The starting page informed the participants about the purpose of the study, the protection of their anonymity, and about which data will be assessed. By clicking the "continue" button, participants actively confirmed their voluntary participation. Participants could terminate participation at any time or delete the answers themselves while taking the survey.

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3.10 SUPPORTING INFORMATION

3.10.1 Descriptive Statistics

Table 3.6 details our study sample with mean survey scores and standard deviations.

Table 3.6. Study Sample Subgroups and Tests for Mean Survey Score Difference.

	n	Mean	SD	F	p
Age					
20-30	35	4.12	0.40		
30-40	108	4.11	0.36		
40-50	84	4.19	0.37		
50-60	125	4.07	0.31		
60-70	57	4.00	0.52		
70-80	49	4.10	0.32		
over 80	5	4.01	0.20		
ANOVA test for mean survey score difference				1.86	0.09
Gender					
Female	245	4.09	0.35		
Male	218	4.11	0.39		
ANOVA test for mean survey score difference				0.57	0.45
Survey group					
Wearable users	120	4.25	0.37		
Average population	208	4.05	0.37		
Health experts	135	4.05	0.35		
ANOVA test for mean survey score difference				14.65	< .001
Cluster					
Autonomists	145	4.09	0.25		
Networkers	170	4.34	0.29		

Consultees	91	3.70	0.30		
ANOVA test for mean survey score difference				153.64	< .001

n = number of valid answers.

Mean = mean survey score.

SD = standard deviation.

F = F-Statistic for ANOVA test. The higher the F value, the greater the dispersion between the groups, the more likely it is that there are significant differences between them.

p = probability for no significant difference between the means of all clusters

3.10.2 Nonresponse Bias

We estimated nonresponse bias by (i) extrapolation with successive waves of our survey and (ii) comparison with known values from the population (Armstrong and Overton 1977). Respondents were contacted twice: with the original invitation and, four weeks later, with a reminder. First, we compared the responses to the invitation (“first wave”) with the responses to the reminder (“second wave”), suggesting that persons who responded to the reminder have average scores closer to nonrespondents, because they required more effort to be persuaded to participate in the survey (Armstrong and Overton 1977). A t-tests for the difference between the two groups’ mean scores showed no significant difference (t = -0.70.; p = .49). Based on this test, the two waves do not show a statistically significant nonresponse bias.

In addition, to identify gender or age-related biases, we adjusted the age and gender distribution within our sample so that it corresponds to the distribution in the German patient population (Statistisches Bundesamt). Table 3.7 summarizes the results of this adjustment. Regarding gender, the census-weighted mean response score was 4.07; regarding age, it was 4.06. The overall survey mean response score was 4.07. We conclude that our results are not significantly affected by nonresponse bias.

Table 3.7. Recalculation of Survey Response Averages Based on Census Data.

Gender	Percent survey	Percent population	Mean survey	Mean adjusted
Male	45.7%	48.9%	4.10	
Female	54.3%	51.1%	4.04	

All			4.07	4.07

* Mean survey calculated with population weights

Age	Percent survey	Percent population	Mean survey	Mean adjusted
20-30	5.7%	13.9%	4.05	
30-40	19.8%	16.1%	4.06	
40-50	17.0%	14.7%	4.13	
50-60	28.7%	19.3%	4.07	
60-70	14.6%	16.2%	4.00	
70-80	12.8%	10.9%	4.10	
>80	1.3%	9.0%	4.01	
All			4.07	4.06

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UNDERSTANDING PATIENT PERSPECTIVES: FOUR MENTAL MODELS TO GUIDE PATIENT INVOLVEMENT IN MEDICAL DECISION-MAKING

4.1 ABSTRACT

Patient involvement has become a vibrant topic in the multidisciplinary healthcare field. As previous studies show, involving patients in medical decision-making can improve patient motivation, well-being, confidence, and treatment outcomes. Despite much progress, large-scale patient involvement remains limited. Paradoxically, while most patients and physicians prefer involvement, they refrain from practicing it. This study examines this contradiction by investigating patients' mental models and sensemaking guiding their understanding of patient involvement. Based on 24 in-depth patient interviews, we used the Zaltman Metaphor Elicitation Technique to identify four mental models reflecting the patient's thoughts and feelings about patient involvement. We refer to them as "the proactive patient ", guided by the desire to maintain control, "the collaborative patient", preferring to share control, "the reliant patient", preferring a paternalistic doctor-patient relationship, and "the belief-centered patient", primarily driven by strong convictions. Historical antecedents from the literature corroborate our model characteristics and provide insights into how physicians can approach the four mental models for promoting involvement. Our findings explain some of the current shortcomings of patient involvement and guide the use of patient decision aids. Healthcare practitioners can use them to more effectively involve patients, i.e., to find the "right" level of acknowledging beliefs, establishing trust, providing control, or sharing responsibility that corresponds to a patient's sensemaking.

Keywords: Patient preferences, patient involvement, patient-centered care, shared decision making, healthcare strategy, mental models

JEL classification: I12 (health behavior), i11 (analysis of healthcare markets)

4.2 INTRODUCTION

Involving patients in medical decisions has received strong governmental support (Coulter 2018). The rationale behind such initiatives is to improve the quality of nationwide healthcare while avoiding unnecessary costs (Elwyn et al. 2016; Légaré and Witteman 2013; Bae 2017).

An extensive body of research into patient involvement has shown that involving patients in medical decision-making can improve patient motivation, well-being, confidence, and treatment outcomes (Miller and Reihlen 2023). Consequently, health providers have begun implementing patient involvement in individual healthcare settings (Danner et al. 2020). Nevertheless, such involvement has been slow to enter the mainstream of medical practice (Coulter 2018) and "isn't happening" (Coulter 2017) on a large scale.

The literature examines patient involvement in the contexts of patient autonomy, shared decision making, and patient-centered care (Altin and Stock 2016; Bensing 2000; Bravo et al. 2015; Constand et al. 2014; Rubinelli et al. 2009). Patient autonomy involves the rights, responsibilities, and opportunities for self-determination (Bravo et al. 2015), ideally allowing decisions free from external influence (Fortune et al. 2016). Shared decision making enhances patient autonomy by considering patient values and preferences into healthcare decisions (Bae 2017; Epstein and Street 2011). In a broader sense, patient-centered care aims to integrate patients' values, needs, and preferences into healthcare decisions (Constand et al. 2014).

Patient involvement can significantly enhance the likelihood of achieving positive treatment results, improve the quality of care, and increase patient satisfaction (Marzban et al. 2022). These significant benefits are largely due to the fact that involving patients can foster their motivation, commitment, and empowerment. Consequently, they are more likely to adhere to a therapy plan and avoid complications, unnecessary visits, or emergency admissions (Danielson et al. 2019). However, to achieve these benefits, patients need to be meaningfully involved, which has often proved difficult (Abdelhak 2016).

These opportunities and challenges of patient involvement have created a vibrant topic in the multidisciplinary healthcare field. Studies exploring the preconditions of patient involvement found that most patients prefer the idea of it (Dahl Steffensen et al. 2017; van der Weijden et al. 2017; Légaré and Witteman 2013), but also that they feel their own understanding of it and their individual barriers and facilitators are not sufficiently considered (Herlitz et al. 2016; van der Weijden et al. 2017; Elwyn et al. 2017; Haltaufderheide et al. 2019; Bae 2017; Joseph-Williams et al. 2017; Joseph-Williams et al. 2014). From these insights, scholars have formulated various tools and methodologies that have demonstrated efficacy in enhancing patient involvement. Patient decision aids, describing options for specific medical conditions, promote involvement (Danner et al. 2020; Longtin et al. 2010; Elwyn et al. 2012). However, these aids alone will not involve patients (Constand et al. 2014; Joseph-Williams et al. 2017; Hargraves et al. 2016), as physicians need to explain them during consultations (Joseph-Williams et al. 2017). An example of an intervention structuring involvement conversations is the Three Talk Model designed so that physicians and patients work together, discuss alternatives, and make preference-based decisions (Elwyn et al. 2017). Another approach to structuring consultations, Three Questions, encourages patients to inquire about treatment options, benefits, harms, and their likelihood (Shepherd et al. 2011; Shepherd et al. 2016; van Veenendaal et al. 2018). Overall, the literature offers valuable insights into the preconditions for patient involvement, effective tools, and the design and outcomes of interventions.

Despite advancements in the field, the success of patient involvement in healthcare decisions remains a topic of ongoing research with mixed results (Driever et al. 2020; Altin and Stock 2016; Bensing 2000; Bravo et al. 2015; Constand et al. 2014; Rubinelli et al. 2009; Fortune et al. 2016; Epstein and Street 2011; Coulter 2018; Hughes et al. 2018). Overall, patient involvement cannot yet be universally heralded as a success (Timmermans 2020).

The question arises as to what potentially overlooked issues could undermine the effectiveness and intended value of this approach to healthcare. One possible explanation could be that the challenge of patient involvement demands significantly more from physicians than helping with medical expertise (Opel 2015). Physicians are expected to facilitate patient decision buy-in, ensuring that patients feel comfortable with a medical decision (Cribb and Entwistle 2011). The manner in which physicians involve patients in decision-making is largely at their discretion. Physicians bear the significant responsibility of selecting the most effective approach to secure patient involvement in each unique situation. This task is further complicated by the necessity for physicians to assist patients in comprehending and critically evaluating their choices (Cribb and Entwistle 2011). In certain instances, physicians may need to persuade patients of the importance of specific health-related values, particularly when patients exhibit a lack of understanding regarding pertinent health issues or potential interventions. In such scenarios, it may be insufficient for physicians to merely solicit patient preferences and incorporate them uncritically into the decision-making process. Thus, understanding the appropriate level of patient involvement, tailored to the specific context and individuals involved, presents a substantial challenge for physicians (Cribb and Entwistle 2011). Nevertheless, mastering this challenge is crucial for effective patient involvement (Abdelhak 2016).

An important step into this direction is to develop approaches that can adapt to individual consultations while being grounded in robust theoretical foundations and capable of practical application in diverse healthcare settings. These approaches should consider the heterogeneity of patients (Emanuel and Emanuel 1992). This heterogeneity is reflected in the fact that, depending on their disposition and situation, patients react differently to the requirement to make decisions with a certain degree of autonomy (Bae 2017; Haltaufderheide et al. 2019). What goes too far for one patient may be not enough for another (Herlitz et al. 2016). Determining the most suitable method for patient involvement in a timely manner in an individual situation requires theoretical guidance. Currently, there are no overarching theoretical frameworks for this purpose, which significantly hinders the implementation of patient involvement practices (Coulter 2018; Joosten et al. 2008; Khunkhun et al. 2022; Resnicow et al. 2022).

We therefore suggest to systematically investigate patients' thoughts, feelings, and preferences – i.e., their mental models – vis-à-vis healthcare providers as a crucial factor contributing to their effective involvement in medical decisions. Specifically, we seek to answer the following research question: *How do mental models influence patients' sensemaking in determining their desired level of involvement in medical decision-making?*

To investigate this question, we follow the Zaltman Metaphor Elicitation Technique (ZMET), a qualitative image-based interview method (Zaltman 2007). This technique allows for a deep exploration of patients' thoughts and feelings during consultations, revealing both conscious and unconscious motives shaping mental models. Drawing on 24 in-depth interviews with patients, we offer four archetypical patient mental models that set the stage for how patients perceive providers and thus determine their preference for interacting with them in different ways. To provide a theoretical grounding, we validate our models with findings from the literature on professions and the client-expert relationship, i.e., "historical antecedents" (Ringberg et al. 2007).

Our findings enhance the body of research on patient involvement by offering insights into the diverse mental models patients utilize vis-a-vis healthcare providers. Each mental model sets the stage for a unique patient-provider interaction. Recognizing and understanding these mental models offers providers the opportunity to refine their patient-centered approaches, increasing the chances that patients will accept and support medical decisions. This, in turn, helps to realize the benefits of patient involvement, particularly in improving treatment results and patient satisfaction.

4.3 A MENTAL MODEL PERSPECTIVE ON PATIENT INVOLVEMENT

Mental models symbolically represent the essence of external situations or objects in an individual's mind (Rickheit and Sichelschmidt 1999; Johnson-Laird 1983; Gentner and Stevens 2014). While there is no generally recognized definition of mental models (Rickheit and Sichelschmidt 1999), research highlights that mental models become internalized socio-cultural representations of how individuals perceive the physical and social world (Seel 2001). Thereby, they influence how individuals interpret information, understand events, reflect on causes, and make decisions (Zaltman and Higie 1993). They are therefore crucial for individuals' capacity to understand, make inferences, predictions, decisions, and manage complex issues (Suomala 2020; Daft and Weick 1984; Kempton and Lave 1983; Senge 1990; Johnson-Laird 1983). "It is through our mental models that we make sense out of the environment" (Johnson-Laird 1983). Like cognitive "schemas", or maps, they enable individuals to navigate through familiar and unfamiliar terrains (Rickheit and Sichelschmidt 1999). Thus, mental models represent stable, individual interpretive frames (Ringberg et al. 2007) that enable sensemaking and action in specific situations (Glenberg 1999; Weick 1995; Snook et al. 2012).

Given the defining characteristic of mental models in patient sensemaking – what and how they perceive and evaluate, the basis on which they decide, and the actions they deem appropriate – this makes them a highly relevant research field for patient involvement. Different mental models vis-à-vis healthcare providers, even with identical facts, inevitably lead to different perceptions, evaluations, and decisions. Understanding these models would help practitioners enhance their engagement and interaction with patients, mitigating potential misunderstandings (Ganz-Blättler 2003), and achieve active patient support for therapy. However, attempting to understand these different characteristics and effects of mental models solely within consultations is unrealistic. They are too complex on one hand, and patients may not be open enough to share their inner motivations for decisions with a doctor on the other. Therefore, we argue that it is necessary to investigate mental models and their different internal logics outside of consultations. Although studies also confirm this important role of patients' mental models (Holtrop et al. 2021), they remain under-researched in healthcare. Their critical role, however, has been addressed in other fields such as management and marketing (Lilien 2011; Wind 2009; Gary and Wood 2011; Porac and Thomas 1990). These insights further support our motivation to investigate patients' mental models of healthcare providers.

The challenge in identifying mental models lies in making the implicit model components explicit (Zaltman 1997). In the subsequent section, we outline a metaphor-based methodology for comprehending mental models in the context of patient involvement with medical providers.

4.4 RESEARCH DESIGN

4.4.1 Method

The ZMET method, at its essence, discusses topic-related images personally selected by the interviewees with the help of laddering questions to explore interviewees‘ thoughts and feelings on the subject matter (Zaltman and Higie 1993). ZMET's semi-structured, in-depth interview process (Zaltman 2007) focuses on surfacing unconscious and tacit constructs and mental structures (Christensen and Olson 2002). ZMET can identify particularly rich mental models (Christensen and Olson 2002), some of which build on core values and are therefore less susceptible to change (Longbottom and Modjahedi 2013). Consequently, various academic studies employed this method to delineate and analyze the constructs and their causal relationships within mental models, e.g., (Rydén et al. 2015; Christensen and Olson 2002; Coulter et al. 2001; Lee et al. 2003; Ling et al. 2015; Kokko and Lagerkvist 2017; Hancock and Foster 2019).

The ZMET method is particularly well-suited for exploring patients' mental models because it enables both reason and emotion to surface (Zaltman 1997). This ability is crucial in the context of medical decision-making, which involves a mix of facts, hidden knowledge, thoughts, and feelings, emphasizing the equal importance of emotion and reason (Timmermans 2020). Current approaches to patient involvement assume that patients and physicians make joint medical decisions largely on the basis of rational criteria and objective information (Joseph-Williams et al. 2019). But the assumption that decision-making is driven largely by logical inference is only half right and therefore also half wrong (Kahneman 1997). Rather, complex emotional and rational reasoning systems orchestrate the decision-making process (LeDoux 1998). We argue that it is essential to understand the key elements of these systems in the context of patient involvement. ZMET is explicitly designed to understand them (Zaltman 1997).

We used ZMET in a sequence of four stages (Coulter et al. 2001). In Stage 1, before the actual interview, we briefed informants and asked them to select images for later interviews that resonated with informants' own experiences, thoughts, feelings, and associations related to medical consultations. In Stage 2, the interview itself, informants described their pictures along with their associated experiences and narratives. We recorded and documented significant constructs and emerging themes throughout the interview process. In instances where an emerging construct was not represented within an informant's pictures, we transcribed it onto an adhesive note and affixed it alongside the corresponding pictures for further contextualization and integration. We used "laddering questions" to help reveal the connections between tangible product attributes and intangible personal values, providing insights into the deeper motivations driving individuals' behavior. Laddering questions are a form of probing used to move from surface-level responses to deeper, more abstract thoughts and emotions (Zaltman 1997). The technique is based on the idea that people's attitudes and behaviors are driven by a hierarchy of cognitive and emotional constructs, ranging from concrete attributes to abstract values (Reynolds and Gutman 2009). Laddering helps researchers climb this hierarchy by asking a series of questions to uncover the underlying motivations and meanings behind a person's initial responses, for instance "Why is this important to you?". This process allowed us to unveil crucial constructs. At this juncture, we also asked informants about their experiences, thoughts, and feelings in relation to *involvement* in the medical decisions about their treatments. Stage 3 concluded the interview by asking informants to arrange the individual images into a meaningful order, such as by importance, chronological sequence, and thematic categories. This unveiled chronological or hierarchical connections between pictures and constructs, shedding light on which constructs hold central significance. In Stage 4, we transcribed the interviews and supplemented the respective interview transcripts with visual materials, including images, adhesive notes, and montages. This rich dataset formed the basis for subsequent analysis and coding.

4.4.2 Sampling

Rehabilitation patients are suitable informants because of their extensive experience with the health sector (Proot et al. 2007). The rehabilitation groups engaged in this study specialized in various diseases, including cancer, Parkinson's disease, sports injuries, and heart disease. Participants were eligible for the study if they had experienced at least two hospitalizations or had moderate or severe diseases, each requiring medical treatment. This purposive selection process aligns with the qualitative interview criteria suggested by Corbin (2015). The interviewees exhibited diversity in age and gender, as outlined in Table 4.1. The study received ethical approval from the relevant institutional review board. We collected no personal data beyond gender and age. All participants provided their written consent to participate in the study. Table 4.1 provides a summary of the characteristics of the interviewees and the identified mental models. We changed interviewees' names to ensure their anonymity.

Table 4.1. Interviewees and Mental Models.

No.	Subject	Age	Gender	Experience	Primary mental model			
1	Lena	26	F	Cancer				B
2	Carl	54	M	Morbus Crohn	P			
3	Emily	81	F	Arthrosis	P			
4	Ella	71	F	Injury, various		C		
5	Hannah	83	F	Cancer		C		
6	Sophia	71	F	Various				B
7	Elias	26	M	Injury			R	
8	Noah	62	M	Diabetes	P			
9	Finn	46	M	Surgery		C		
10	Ida	23	F	Injury			R	
11	Jan	25	M	Various			R	
12	Mila	79	F	Various	P			
13	Felix	73	M	Cancer, various			R	
14	Marie	81	F	Cancer, various				B
15	Jasper	23	M	Surgery			R	
16	Theo	88	M	Surgery, various	P			
17	Michael	22	M	Injury			R	
18	Alina	57	F	Injury			R	
19	Julia	29	F	Various			R	
20	Leonie	41	F	HELLP		C		
21	Nora	67	F	Heart attack		C		
22	Luisa	42	F	Surgery, various			R	
23	Stefan	83	M	Cancer, various	P			
24	David	23	M	Injury			R	
	m / n	53,2	M:11, F:13		5	5	11	3

Mental models: P (the proactive patient), C (the collaborative patient), R (the reliant patient), B (the belief-centered patient)

As suggested by Zaltman (1997), we continued to interview new informants until we could no longer identify any new constructs or associations, i.e., until we reached the point of saturation. The duration of the interviews ranged between 44 and 121 minutes. In total, we recorded 29 hours of interviews, resulting in 688 pages of transcript. Of the 24 informants, 11 were male and 13 were female. The interviewees’ age ranged from 22 to 88 years.

4.4.3 Analysis

We designed our six-step analysis to yield validated and objective results from rich data.

Line-by-line coding: Following a discovery-oriented coding process (Corbin 2015), we identified and labeled unique codes line-by-line in each interview transcript. We then examined, compared, and categorized the data (Strauss and Corbin 2003). As necessary, we modified the codes to ensure consistency and to confirm that they referred to analogous constructs. Through this process, we generated a total of 1923 lines of code and 34 cross-interview code captions such as “Doing own research” and “Feeling unable or unwilling to research illness-related information”.

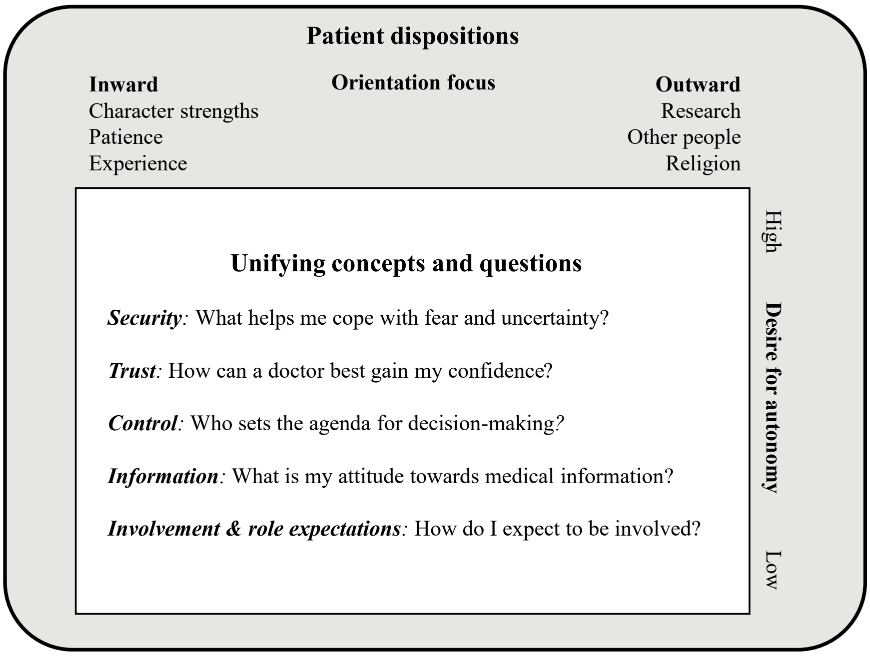
Axial coding: We used axial coding to categorize and link our first-order cross-interview codes to second-order themes (Strauss and Corbin 2003). This approach facilitated the identification of emerging patterns in the data, thereby revealing the more abstract drivers of patients’ mental models. For instance, we connected first-order concepts such as “Having experienced that doctors are more interested in making money than helping patients” to the second-order theme “Protection against doctors and health system”.

Code networks: Code networks map the relationship between concepts for each interviewee (Miles et al. 2014). We established a connection between two concepts when a respondent indicated that one concept caused, prevented, or otherwise influenced another.

Cross-case analysis: We identified and analyzed unifying concepts (Miller 1987) across all respondents to formulate more generalizable mental model archetypes. We identified five unifying concepts, each representing a core aspect of a patient's thoughts, feelings, needs, and preferences. (i) *Security* centers on the question, “What helps me cope with fear and uncertainty?” in the context of serious illnesses. (ii) *Trust* addresses the question, “How can a doctor best gain my confidence?" outlining essential conditions. (iii) *Control* pertains to the question, “Who sets the agenda for decision-making?” reflecting a patient's perspective on taking or relinquishing control. (iv) *Information* encompasses the desire for personal research and the extent of medical information needed to make informed decisions, i.e., “What is my attitude towards medical information?” (v) *Involvement and Role Expectations* include the often tacitly understood roles assumed by patients during consultations, expressed by the question, “How do I expect to be involved?”

While our cross-case analysis revealed that these five concepts were universally significant for all informants, we found that informants answered the questions around security, trust, control, information, and role expectations in categorically different ways. We found that two dispositions determine these categories: (i) informants’ *desire for autonomy* and active participation in diagnosis, treatment, and decision-making, and (ii) whether they are oriented *inward or outward* when answering their questions on security, trust, control, information, and role expectations. Figure 4.1 depicts the five unifying concepts and patients’ dispositions.

Figure 4.1. Unifying Concepts and Patient Dispositions.

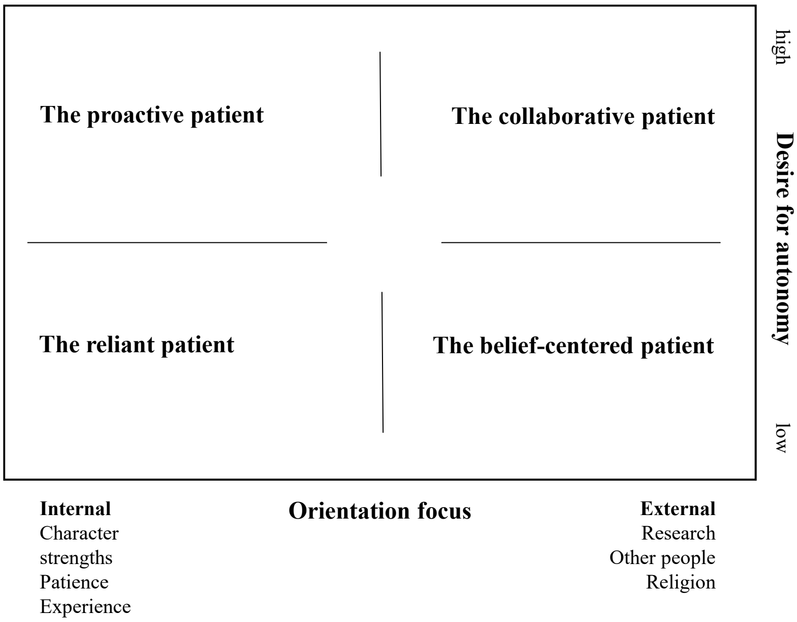


We illustrate the interplay of unifying concepts (i.e., questions on security, trust, control, information, and role expectations) and dispositions (i.e., inward/outward orientation and desire for autonomy) using the concept “security” as an example. For all informants, managing uncertainty arising from illness was a critical concern. However, their dispositions diverged: Informants who emphasized personal autonomy found security from their competence and decision-making capability. Conversely, informants with a lower desire for autonomy felt more secure when deferring decisions to experts. On the other hand, informants with an outward orientation sought reassurance from external sources such as information channels or religious communities, while those with an inward orientation tended to rely on their mind and body for strength.

The different patient dispositions are particularly useful for categorizing patients' mental models. This is because they can represent very different, even opposite, positions. A patient with a high need for autonomy may disregard medical advice, while a less self-reliant patient may depend heavily on it. Additionally, these dispositions are deeply rooted in personality traits, making them both stable and influential in a patient's thinking, feeling, and decision-making during consultations, even under exceptional circumstances such as severe illness. For example, an inward-oriented patient who has learned to rely on patience or past experiences may be resistant to advice regarding external information sources or support groups.

For these reasons, we used the dispositions on autonomy and orientation to categorize four generic patient types. Subsequently, we grouped the interviews based on their similarity in terms of autonomy and orientation. This process yielded the four primary mental models depicted in Figure 4.2. The proactive patient desires autonomy and relies on personal experience and strengths. The collaborative patient also values autonomy but prefers to rely on external information sources, experts, or support groups. The reliant patient has little desire for autonomy and is guided by inner values such as patience and trust. The belief-centered patient is similarly low in autonomy but relies more on adopted opinions or religion rather than internal values.

Figure 4.2. Four Patient Mental Models Based on Autonomy and Orientation.



To further examine generic patient types, we computed the code frequency (the recurrence of a code in an interview) and code density (the instances in which a code is associated with others) within the interview-specific code networks. The ensuing “interview attribute matrix” presented in Table 4.2 exhibits the dominant code frequencies and densities, highlighting the core themes within the four mental models (Miles et al. 2014).

Table 4.2. Central Themes According to the Interview Attribute Matrix.

	Mental models							
	The proactive patient		*The collaborative patient*		*The reliant patient*		*The belief-centered patient*	
Central constructs	frequ.	density	frequ.	density	frequ.	density	frequ.	density
Outward orientation								
Using 3rd party information sources	4	0	**45**	**45**	2	1	**2**	**1**
Beliefs as source for security and optimism	1	0	**5**	**5**	2	1	**49**	**48**
Mistrusting medicine or health system	26	1	**60**	**29**	71	33	**50**	**33**
Inward orientation								
Having a positive and accepting attitude	**6**	**1**	9	6	**108**	**52**	2	1
Trust in own competence	**131**	**114**	13	1	**34**	**5**	1	0
Good experience with doctors and health system	**15**	**11**	7	4	**37**	**24**	3	4
High desire for autonomy								
Negative experience with doctors and health system	**78**	**73**	**3**	**2**	36	17	1	1
Mistrusting physician competence	**47**	**41**	**90**	**53**	60	28	32	4
Participate actively in treatment strategy	**43**	**3**	**65**	**60**	6	1	0	0
Low desire for autonomy								
Accept doctoral advice	43	19	66	55	**60**	**18**	**5**	**1**
Resonance with physician	3	3	3	4	**2**	**2**	**19**	**19**
Trust in professional competence	21	9	9	2	**94**	**80**	**6**	**3**
Trust in human competence	29	16	29	5	**169**	**77**	**2**	**0**

The figures highlighted in the interview attribute matrix provide evidence that the four mental models exhibit distinct perspectives concerning autonomy and orientation. For example, the central codes for the proactive patient lie in inward orientation (e.g., “trust in own competence”) and high desire for autonomy (e.g., “negative experience with doctors and health system”). In contrast, for the belief-centered patient, outward orientation and low desire for autonomy are central, as expressed by the 2nd order themes “beliefs as source for security and optimism” and “resonance with physician”.

Code synthesis: Following Gioia et al. (2013), we aggregated first-order codes, second-order themes, and consolidated mental models to construct the data structure illustrated in Figure 4.3 (Gioia et al. 2013).

Figure 4.3. Concepts and Themes by Mental Model.

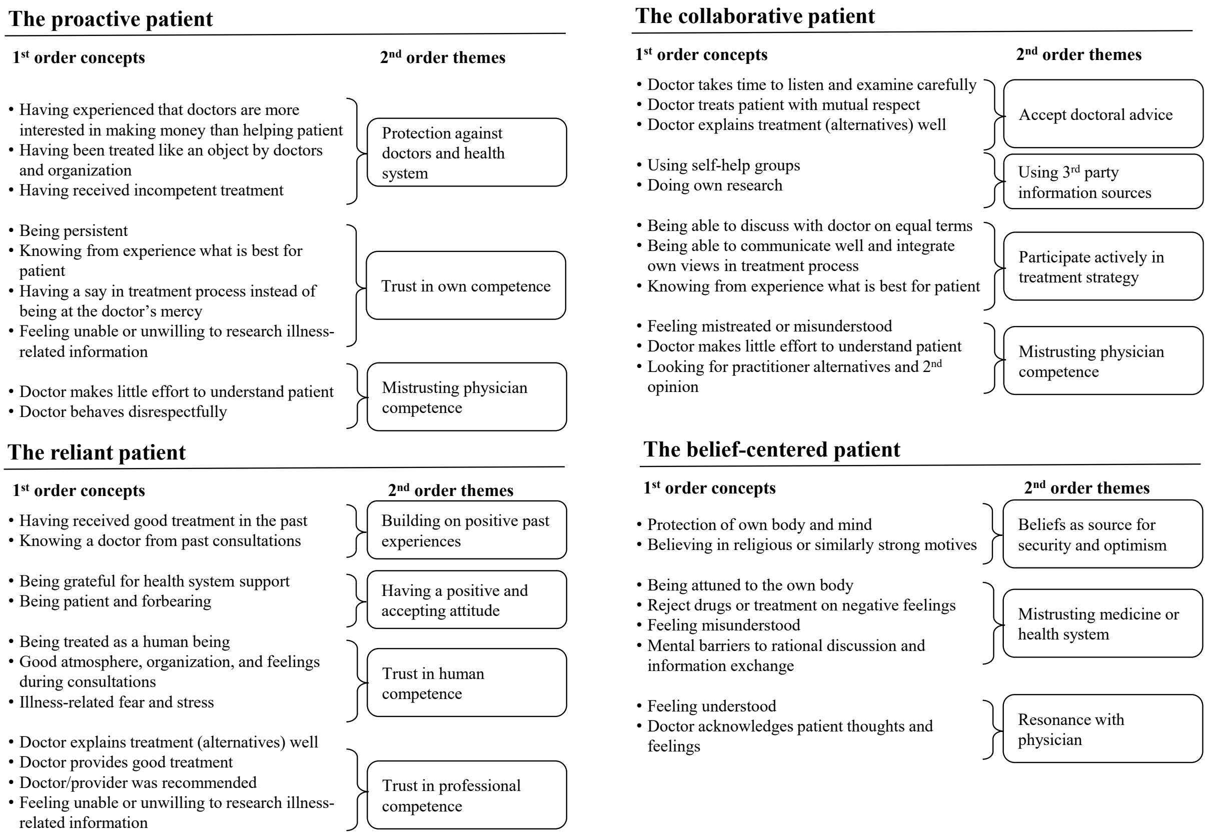


Table 4.3 provides a comprehensive representation of the outcomes from our first five steps of analysis. It includes examples of interview quotes and demonstrates how they align

with our structure, ranging from first-order codes and second-order themes to the ultimate four mental models.

Table 4.3. Examples of Quotes and Their Position in the Data Structure.

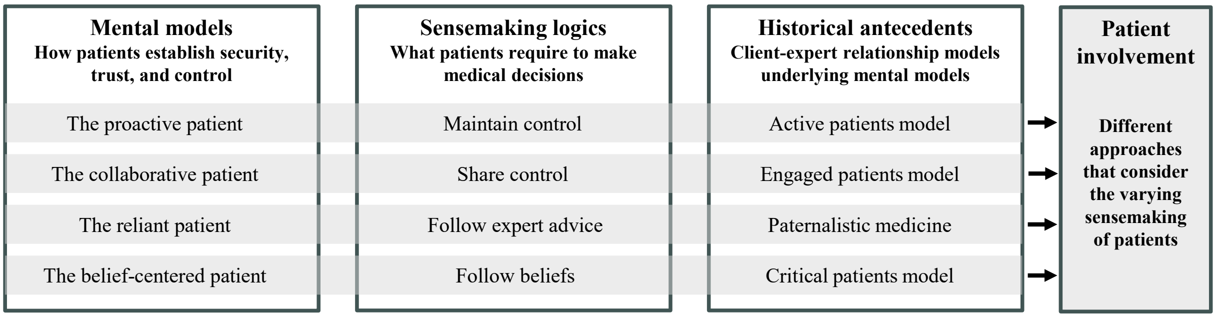
Interviewee	Mental Model	1st order concept	2nd order theme	Quote
Carl	The proactive patient	Having experienced that doctors are more interested in making money than helping patient	Protection against doctors and health system	This concern may be wrong, but I would be happy if we could perhaps tackle the causes rather than just the symptoms. But of course you can make a lot more money in the long term by combating symptoms.
Theo	The proactive patient	Knowing (and telling) from experience what is best for patient	Trust in own competence	I put my dentist off after I said the teeth cleaning wasn't necessary. If you clean the tooth stone properly, everything is fine.
Noah	The proactive patient	Feeling mistreated or misunderstood	Mistrusting physician competence	But then he wrote a report. But my family doctor didn't even look at the report. She just put it aside. Her boss used to do the same with other things. He put it aside.
Hannah	The collaborative patient	Doctor explains treatment (alternatives) well	Accept doctoral advice	It also helped me a lot that the doctor said that patients look for the causal connection and find it so difficult because it is so difficult from a human point of view. It is difficult to understand. There are no tangible reasons. And because there are not. He can't turn anything off to have a guarantee of never getting that again.
Finn	The collaborative patient	Doing own research	Using 3rd party information sources	Yes, and then I thought about whether or not to do it for 3/4 of a year. Then I was ready.
Ella	The collaborative patient	Being able to communicate well and integrate own views in treatment process	Participate actively in treatment strategy	It says that I had given it to her to read, I think she had even read it through or photographed it or something. And nothing was done about it.
Nora	The collaborative patient	Feeling mistreated or misunderstood	Mistrusting physician competence	So it was like being treated like a child.
Jan	The reliant patient	Having received good treatment in the past	Building on positive past experiences	But obviously they would still have like they would still know everything about me. And just because obviously I was probably in their charts or whatever and and they kind of felt like they knew me, you know, like it kind of felt like I mean, when I was going on going in there, it didn't feel like I'm just introducing myself again to someone else. It's like they already knew who I was and. Knew how to handle the situation or whatever.
Ida	The reliant patient	Being grateful for health system support	Having a positive and accepting attitude	I would feel comfortable just because I. I personally, I have nothing to hide. So I don't care if people see my medical history, but. I'm sure some people that other people obviously have have different things that they deal with. So I'm not sure that they would be too comfortable, but personally, I would feel comfortable
Stefan	The reliant patient	Good atmosphere, organization, and feelings during consultations	Trust in human competence	I call it atmosphere, but there are also organisational aspects to it. How is it set up, how is it organised? And also a bit of behaviour from the doctors, a bit of humour, taking a bit of time and perhaps a bit more time than would be dictated by economics. And also a little bit on the needs. Children's paradise, treatment in the rocket. That goes a bit beyond atmosphere, because it is also very well geared to the needs of the patients.
Elias	The reliant patient	Doctor explains treatment (alternatives) well	Trust in professional competence	And I felt quite, yeah, happy about it because I saw exactly what happened.
Marie	The belief-centered patient	Believing in religious or similarly strong motives	Beliefs as source for security and optimism	That you do look inwards, or I learnt to look inwards through meditation, which then paved the way for me a little.
Sophia	The belief-centered patient	Feeling mistreated or misunderstood	Mistrusting medicine or health system	So. If I interpret it correctly, it means that we are being treated badly here. They don't take care of us properly. And that manifests itself in this food.
Lena	The belief-centered patient	Feeling understood	Resonance with physician	And there I felt like she took my my concern serious and yeah, took the time to talk to me about it and realized it was important to me and also just realized the actual medical urgency of it. So, yeah.

Historical antecedents: Our final analytical step corroborates the mental models with socio-historical factors from the literature. To contextualize our results, we employ historical antecedents to theoretically reflect upon and ground our empirical findings. This stage offers supplementary explanations and establishes a theoretical foundation for our study.

4.5 FINDINGS

The following sections will explore informants' mental models and sensemaking, including relevant quotes, and associate them with relevant historical antecedents. They present each model based on previously defined patient dispositions, namely inward / outward orientation and autonomy. As described above, these dispositions vary significantly regarding questions of security, trust, and control, thereby shaping four distinct mental models. Each mental model determines a unique capacity to understand and make sense of medical information, make inferences, decisions and identify with a role for involvement in medical decision-making. We supplement the individual mental models with relevant socio-historical factors outlined in the literature to investigate how these findings can assist physicians in understanding a model's sensemaking logic. Each section concludes by evaluating how physicians can optimally involve the respective mental model. Figure 4.4 illustrates how the four distinct mental models drive individual sensemaking, supported by historical antecedents.

Figure 4.4. Involvement Guided by Patient Mental Models, Sensemaking, and Historical Antecedents.



Mental models **How patients establish security, trust, and control**	**Sensemaking logics** **What patients require to make medical decisions**	**Historical antecedents** **Client-expert relationship models underlying mental models**	**Patient involvement**
The proactive patient	Maintain control	Active patients model →	**Different approaches that consider the varying sensemaking of patients**
The collaborative patient	Share control	Engaged patients model →	
The reliant patient	Follow expert advice	Paternalistic medicine →	
The belief-centered patient	Follow beliefs	Critical patients model →	

4.5.1 The Proactive Patient

Central themes: Emphasizing autonomy and purposefulness characterizes the proactive patient mental model. Individuals with this mindset showed a strong desire for independence and a sense of empowerment that comes from being used to deciding themselves. As a result, they prioritized self-actualization and self-efficacy over fear or surrendering control, even when facing illness. Their inward orientation primarily reflects personal life experiences and encounters with the healthcare system, shaping unique perceptions of what is right or wrong and fostering a strong sense of assertiveness.

Relevant dispositions regarding security, trust, and control: The proactive patient informants felt secure when they were able to take actions that aligned with their ideas. Their self-reliance could manifest in challenging interactions with healthcare practitioners.

> And then the doctor wanted to pull me onto the X-ray table. So I said, stop! Out of the question. He asked if I did not want to be x-rayed. I said, all I ask is that two of you lift me carefully onto the table. They did that. Then I was x-rayed. After ten minutes the doctor told me: rupture of the spine. You are lucky. You are not paraplegic. You are not allowed to move for three weeks now. See, this is how I saved myself from paraplegia.
>
> (Theo, 88)

Theo’s “stop!” exemplifies his perception of the physician’s competence and his desire for self-care. Blindly yielding to a physician made him feel insecure. Stefan takes this concept to the extreme, desiring to exert control over the ultimate uncertainty, the timing of his own death:

> Of course, I'm sensitive to that. Ultimately, because I always think, I can control this. [...] No one can expect to determine my life. But at least I want to have the feeling of self-determination. That I can determine this [my own death]. I don't want to say now that I have it [the poison pill] on my bedside table, but that I could go and say I don't want to live any longer, and that's good.
>
> (Stefan, 83)

Due to their perception of security, informants defaulted to placing greater trust in themselves than in their doctors. Consequently, they often harbored diminished expectations regarding physicians’ trustworthiness, often caused by negative experiences with the healthcare system.

> I have since stopped seeing [this doctor] because he has refused to do certain diagnoses. He tells me I can't go for a CT or MRI because of such a small thing. That costs a lot of money. He said “small thing” because he never found anything! Because he only did ultrasound, and there was nothing to see. But that it could be something else, yes, he never thought of that. First I had to get kidney failure. Only then did the [name] clinic make the proper diagnosis.
>
> (Noah, 62)

Noah felt that his doctor had endangered his life, which understandably led to ambivalent expectations regarding the trustworthiness of physicians in general. However, his statement also suggests that it is feasible to earn the trust of patients with this mental model.

The term “proper” is pivotal here, indicating that the second clinic’s actions were in alignment with Noah’s personal standards of appropriate conduct.

The trust prerequisite necessitated that informants assessed and monitored the behavior of physicians. Being able to maintain control during consultations was pivotal to this model. The term “proper” once again encapsulates this sentiment, this time as used by Stefan:

> I was a project manager, I managed the production, I managed the clerk, I managed the other things. And that's what I also expect from the doctors, that they have the whole picture in mind and not just the area they are dealing with at the moment. [...] A doctor today has to be top-trained, but that's not enough. They also need to be able to talk to people and approach them. But only that is also too cheap for me. I expect them to take proper care.
>
> (Stefan, 83)

Sensemaking: maintain control

This mental model understands sensemaking, the prerequisite for actions and decisions, primarily as being able to exercise control according to self-imposed standards of proper behavior. This suggests that prioritizing medical information is not the central focus for sensemaking. The forthcoming quote from Carl illustrates his tendency to prioritize his own experiences in decision-making.

> If a doctor told me what to do [because of my illness], I would ignore it. Just for the reason that I've met enough people who have the same disease, and I see how they look and how they feel, how they move, how they're doing. And I'm really miles [better off]. You have to tell that to doctors because I never had or almost never had any of the problems they talk about.
>
> (Carl, 54)

The statement “I would ignore it” exemplifies an attitude characteristic of this mental model, where trust in personal experience supersedes medical advice or information. If a practitioner’s advice did not align with this model’s expectations, involvement became virtually unattainable.

Historical antecedent: active clients and informative model

The power relationship and values of this mental model align with the historical concepts “active clients” and “informative model”. Both describe a power relationship in which the patient sets the agenda and goals and takes sole responsibility for decisions (Roter 2000). “Active” patients value intrinsic motivation, being able to proactively exercise autonomy, and establishing their own rules (Ryan and Deci 2017). Consequently, they critically and systematically select, manage, and evaluate practitioners (Deelmann and Mohe

2006; Sturdy and Wright 2011). Conversely, they resist being coerced into conforming to specific behaviors (Deci and Ryan 2012).

From this point of view, patients see physicians as experts, service providers, and technical advisors who should provide all available facts and services from which the patient can determine the proper treatment (Emanuel and Emanuel 1992). Ultimately, remaining in control is essential for the patient (Emanuel and Emanuel 1992). This makes autonomy an important antecedent for engagement, persistence, and motivation (Deci and Ryan 2012). "Active" patients expect to be presented with treatment options and the necessary information to make informed decisions. They believe physicians should offer advice and recommendations in a manner that supports autonomy and respects their choices (Deci and Ryan 2012).

Conclusions for involvement

Practitioners who want to involve patients with this mental model can adopt a perspective posited by the active client model, "both client and practitioner are experts of their own experience" (Bohart and Tallman 1996). If both parties acknowledge each other and share congruent ideas about the "proper" therapy, a successful knowledge transfer will become more likely (Ringberg and Reihlen 2008). In practical terms, physicians can inquire about the patient's past experiences with their current health issue. How the patient articulates these experiences will likely reveal if a patient is driven by the proactive patient mental model. Subsequently, physicians can empower the patient with opportunities to manage their treatment and recovery process actively and autonomously. A purely paternalistic approach is not likely to foster the involvement of this mental model.

4.5.2 The Collaborative Patient

Central themes: Patients applying the collaborative patient mental model favor integrating diverse inputs to develop a problem-solving strategy. Interdependence is central for these patients which means that, although autonomy and control matter to them, they see value in sharing responsibility with practitioners. Beyond that, they are very interested in what other people or sources of information can contribute to their case. For them, integrating these various inputs should precede making important decisions.

Relevant dispositions regarding security, trust, and control: In metaphorical terms, informants with this mental model constructed a safety network to confront health-related challenges. They devised a problem-solving strategy that integrated a range of information sources via discussions to foster a sense of security. Therefore, solutions emerged from discussions, rather than from pre-established opinions, as Ella's quote summarizes:

> Then last year I was at a cardiology practice. We liked it very much, it was the second time I've been there. You sort of got rid of everything that you had heard and read before. Yes, they also took that in and understood it, yes, and then gave something back with an explanation, so to speak. We processed that and decided on a plan. I walked away feeling satisfied.
>
> (Ella, 71)

Given this emphasis on discussion and dialogue, these informants rather trusted physicians who were open to deliberate treatment options with them. In Hannah's quote, the statement "Conversation is part of the therapy" captures how she understands to build a trusting relationship.

> But when a patient comes in and says, I have back pain, and the doctor is there with his very quick diagnosis and gives cortisone right away. Then the chance of finding the right diagnosis is very small. It takes time to say, how does this manifest itself? How do you have it? How do you feel otherwise? This is the time that would actually be needed to arrive at the diagnosis. The conversation is part of the therapy.
>
> (Hannah, 83)

Leonie provides another example of how interdependence and shared control manifested in a practical context. Her phrase "backed me up so that I could do it" underscores a physician's attitude that fostered her trust and resonated with her. Her doctor did not impose decisions on her but provided advice based on objective information and personal impressions gleaned from their conversation.

> And that was one of the points where my gynecologist advised me and said, "I think it would do you good if you gave birth to your child in a normal way [despite HITT syndrome]". I would have to take blood thinners, but that went great. And I am incredibly grateful to him for that, because he backed me up so that I could do it.
>
> (Leonie, 41)

Sensemaking: share control

This mental model understands sensemaking primarily as being able to source enough information to be able to jointly reflect on it with the physician. This makes information and its validation central. Whereas practitioners, if trustworthy, can serve as important advisors and providers of information, they should acknowledge that patients with this mental model will contextualize their advice with other sources of information. Involvement, therefore, requires physicians who understand that patients want to inform themselves and discuss during the consultation.

> I don't know anyone with this disease and I didn't hear anything about it before, even though Dr. [name] had told me about this surgery. So of course I looked on the Internet. [...] There I found this self-help group and simply had conversations there. And that helped me a lot, that I heard reports about what kind of experience someone had had. Before my operation, I talked to the people in the group about it and that helped me a lot in my decision. It helped the doctor, too, she actually did not know anyone who had done this before.
>
> (Nora, 67)

Informants with the collaborative patient mental model did not necessarily make decisions in the presence of the physician, but after, and in some cases even before, a consultation, as long as they felt they knew enough.

Historical antecedents: engaged patients and reflective practitioner

The power relationship and values of this model align with the historical concepts “engaged patients” and “reflective practitioner”. Both concepts favor a balance of power in which the parties negotiate the objectives, agenda, and decisions of a consultation on a relatively even footing (Roter 2000). The physician’s goal is to empower the patient not simply to follow unexamined preferences but to consider various approaches and their implications in dialogue (Emanuel and Emanuel 1992). This attitude accents the autonomy of both patient and physician where empowerment suggests a process that occurs over time rather than during a particular consultation (Childress and Siegler 1984). Engaged patients, in turn, actively express their preferences, ask more in-depth questions, and do not view the clinician as the sole authority (Timmermans 2020). Before deciding, patients take the experience with a practitioner as one input with other resources and decide how to proceed with a problem (Bohart and Tallman 1996).

Consequently, engaged patients expect practitioners to take into account their desire to contribute in diagnosing and problem-solving (Schön 1983; Schein 2008). They believe that both patient and practitioner possess valuable knowledge which needs to be incorporated into the medical decision (Nikolova et al. 2009). This is why they prefer to jointly diagnose their health issues and negotiate solutions through balanced interactions (Nikolova et al. 2009). In this process, they expect to share authority and control with physicians (Schein 2008; Schön 1983). Effective involvement occurs when patients can fully understand and make sense of a physician's expectations and actions in the context of their own problem-solving strategies (Nikolova et al. 2009).

Conclusions for involvement

Patients with the collaborative patient mental model are well-suited for involvement. The engaged patient and reflective practitioner models provide valuable frameworks for physicians to understand and involve these patients as they underscore the patients' preference for balanced interaction and collaborative problem-solving. Involving this mental model requires a physician's ability to recognize and discuss differing opinions to achieve a mutually acceptable result. The concept of "negotiated knowledge transfer" (Ringberg and Reihlen 2008) provides a perspective for this purpose. It acknowledges that patient and physician may have discrepancies and divergent mental models, but are interested in finding a resolution for a particular case.

4.5.3 The Reliant Patient

Central themes: The reliant patient mental model prefers to rely on experts for resolving health issues. Unlike the proactive and the collaborative patient models, this model assumes a more subordinate role. This diminished desire for autonomy stems from the belief that experts possess superior knowledge about what actions to take. Patients draw on inward resources like patience, gratitude, and forbearance, which they consider essential strengths when following clinicians' leadership and advice.

Relevant dispositions regarding security, trust, and control: Informants with the reliant patient mental model turned to a professionally and personally competent expert to alleviate uncertainties and fears. As with Alina in the following quote, they tended to portray a doctor's skills in a favorable light, reinforcing their sense of security.

> So I can say what impresses me about her is that she is a top craftswoman who knows exactly what she's doing. She never duplicates a single action. She looks at what she has to do. And she doesn't just dodge around. So when it hurts, it hurts right then and there. And that is a good feeling. As a patient.
>
> (Alina, 57)

As informants relied on practitioners' professionalism, they expressed a general inclination to trust clinicians. They especially appreciated practitioners who inquired about their lives, situations, medical history, and preferences, including private ones. They also valued clear and accurate explanations. After establishing a trusting relationship, they found relinquishing control reassuring. This distinguishes them from the proactive / collaborative patient models, for which a loss of control felt discomforting.

> That is already a kind of loss of control. [And as the picture] with heaven and paradise says, I then gladly surrender to it. And that requires trust in these things, if you will, being at the mercy [of the doctor] and so on. [This can] be really nice in one case. And in another case, maybe not so nice. […] Overridingly, I feel gratitude in any case. Even in the case of unpleasant experiences, I am also grateful in a way.
>
> (Luisa, 42)

The metaphor Luisa selected, likening her experience to a paradise, conveys her gratitude for the opportunity to be taken from the real world's problems to a "heavenly" state of care provided by professionals.

Sensemaking: follow expert advice

The reliant patient mental model effectively "outsources" sensemaking, i.e., comprehending a situation sufficiently to make a decision, to clinicians. The central question patients ask themselves in relation to sensemaking is whether they can trust clinicians enough to give them control. If they answer in the affirmative, patients tend to rely on the clinician's recommendations for further decisions.

> We had a preliminary conversation about the procedures of the surgery and the question of whether I wanted anesthesia. And because I'm so inexperienced and had no experience and no opinion at all, I asked him how you would do it if it were your leg. And he said, no question, I would want to sleep. I said, well, then I want to sleep, too. Like this. And it was also in the conversation from the very beginning, where we also discussed risks and so on. It was very pleasant, very, very human.
>
> (Alina, 57)

Alina's quote highlights the challenge of involving these patients. The phrase "had no experience and no opinion at all" underscores Alina's perception of lacking the capacity to contribute significantly to medical decisions. Consequently, this mindset diminishes the inclination to seek out patient decision aids or external knowledge sources for informed decision-making. Overall, patients with this mental model exhibited limited expectations of being involved.

Historical antecedents: paternalistic medicine and expert model

The power relationship and values of this mental model are consistent with two historical concepts from the medical and general professional literature, "paternalistic medicine" and "expert model". Both concepts reflect a power relationship that dates back to the Hippocratic ideal of the physician (and, today, the nurse or other staff) as the caretaker of the patient's interest. Accordingly, a medical decision may fail to involve the patient in the process, and may also go against her wants, or ignore the patient's perspective in other ways, as long as the patient benefits (Sandman and Munthe 2010). As such, the physician holds the interpretive monopoly in sensemaking and decision-making (Roter 2000). The two historical antecedents consider the physician's knowledge, derived from general medical education and training, superior to the patient's specific, context-dependent understanding of their own health and circumstances (O'Farrell and Moffat 1991).

In the view of these two models, patients expect that practitioners solve their problems using scientific theories and techniques (Moore 1970; Schön 1983). Patients can provide information to diagnose the problem, but otherwise do not want to be actively involved in the creative part of problem-solving (Nikolova et al. 2009).

Conclusions for involvement

Paternalistic medicine implies that physicians transfer knowledge with a high degree of expertise. They advise the client with an approach that allows little involvement and customization (Ringberg and Reihlen 2008). Our interviews have shown that patients adhering to the reliant patient mental model tend to prefer this approach along with the paternalistic power dynamics as long as they have confidence in the physician to entrust their care. Historical antecedents offer limited strategies for motivating the reliant patients to become actively involved. Most likely, this motivation will require a physician to understand the patient's situation, including fears. From there, the physician can offer targeted recommendations for increased patient responsibility while simultaneously providing expert guidance.

4.5.4 The Belief-Centered Patient

Central themes: Prioritizing personal and/or religious beliefs characterizes the belief-centered patient mental model. This mindset finds orientation in narratives, religious teachings, or doctrines. These then serve as the primary guidepost for justifying – or refusing – actions. This mental model ranks such outward orientation above personal experiences or individual personality traits such as patience, resilience, or determination. Because it perceives its beliefs as given and stable, this mental model allows less flexibility for discussing or developing decision alternatives. If these patients' beliefs can be realized, they will accept a decision; if not, they will tend to withdraw from the situation.

Relevant dispositions regarding security, trust, and control: Belief-centered informants often felt exposed to the unpredictable, surprising, perhaps fated, or predetermined imponderabilities of the world. This led to one informant refusing to go to a hospital because she considered such a place life-threatening. Indeed, fear and mental blocks arising from it were fundamental concepts for these informants. Simultaneously, their beliefs provided an effective sense of protection. This effect was often so pronounced that this mental model ensured optimism and composure even in deeply emotional or existentially threatening circumstances:

> The image of Leonardo, the Vitruvian man, yes. Actually, this is supposed to be a study of the center of man. Here is the crucified man. In the corners. Here. Trapped in the square. And then he reaches the circle, the round shape. And there he has opened himself to the divine. The image has always fascinated me. [Question: What does it mean to you?] The vastness of the universe. The happiness, joy, zest for life. So it's real. Yes, it's just the sunshine, the light. It opens up everything to you. If you open up yourself to the divine.
>
> (Marie, 81)

The phrase "he has opened himself" reflects a predominantly reactive stance. The Vitruvian man does not symbolize action; instead, for Marie, it represents an appropriate attitude toward events in general. The expression "it opens up everything to you" underscores the significance of the divine in providing guidance and orientation.

The clearcut convictions of this model also entailed that it tended to answer the question of whether a doctor was trustworthy with a simple either/or. When physicians validated their beliefs, informants felt resonance. Conversely, if physicians dismissed their ideas, they often withdrew or sought a more compatible physician who could better comprehend their perspective:

> So I was just kind of feeling like they were not actually listening. [This form of cancer] is a big topic in our family. And so, [the gynecologist] said I shouldn't worry about it at my age, which I didn't think was

> very accurate. So that's the reason I then ended up with a new gynecologist. And there I felt like she took my concern seriously and yeah, took the time to talk to me about it and realized it was important to me and also just realized the actual medical urgency of it.
>
> (Lena, 26)

The expression “not actually listening” reflects a categorial attitude characteristic of this mental model. Conversely, “realized it was important to me” indicates the “right” category of a physician.

It follows from such categorical thinking that physicians who diverged from these informants' convictions delegitimized themselves. For the belief-centered patient mental model, the concept of control resembled assessing whether a physician took into account its convictions.

> My friends made me aware of all the really extremely dangerous health side effects of the pill. When I started taking the pill, there was never a mention of any of this. Of possible side effects, risks, or questions like, if I smoke, which seems to be a very dangerous combination, smoking and taking the birth control pill. And to this day, when I go to the gynecologist, there's no mention of these things, which I found very, very shocking because it's clearly all over the Internet and very well common knowledge to my shock.
>
> (Lena, 26)

"Very, very shocking" vividly captures Lena’s emotional response after the doctor "failed" her assessment. It reflects how a profoundly ingrained skepticism fuels Lena’s perception and, subsequently, sensemaking.

Sensemaking: follow beliefs

Persistent adherence to specific beliefs or opinions renders this model less receptive to external input, constructive dialogue, and collaborative efforts with the treating physician. Additionally, informants who adhere to this model demonstrate a marked reluctance to consider alternative viewpoints or new information.

> And I was told, get vaccinated [against Corona]. But my meditation said, This is not for you. You can't get vaccinated. In the meditation I had the picture, my [genetic] double helix is intact. If this vaccination interfered, then my healthy helix would have been violated.
>
> (Marie, 81)

Marie is convinced that a vaccination will violate her body. Consequently, she will hardly let herself be talked out of her conviction during medical consultations. In a broader context, a physician's well-intentioned efforts to educate or involve belief-centered patients may not resonate with this model if they run counter to patients' beliefs, which are pivotal for sensemaking.

Historical antecedents: critical patients and health identities

In the socio-historical discourses on how patients engage with healthcare providers, the "critical model" and "health identities" describe key components of the belief-centered patient mental model. Both concepts reflect similar attitudes toward power dynamics and values. The critical model views professional knowledge as shaped by social recognition and legitimacy (Clark and Salaman 1998; Alvesson 1993, 2001; Alvesson and Kärreman 2000). Consequently, it challenges established power structures and the interpretive monopoly of experts suggesting that medical knowledge is, to a considerable extent, influenced by beliefs (Kärreman 2022; Alvesson 2001). More specifically, "health identities" (Fox and Ward 2006) describe individuals (e.g., anorexia patients) whose identity grounds in particular values, behaviors, and cognitions while, at the same time, being highly resistant to conventional health notions (Fox and Ward 2006).

From the perspective of such patients, surrendering their personal convictions in favor of conventional health notions will cause an almost existential vulnerability. Having one's convictions addressed by a physician becomes an essential value in this context. This requires "social construction" (Alvesson 2001), where patient and physician interact to mutually confirm their suitability to address a specific health issue.

Conclusions for involvement

Findings from historical antecedents enhance understanding and involvement of patients with the belief-centered mental model. Clinicians should first inquire about and address the patient's personal beliefs before providing information. Actively seeking "social construction" and mutual confirmation (i.e., being recognized as the "right" physician) is crucial for engaging these patients.

4.6 DISCUSSION AND CONCLUSION

4.6.1 Discussion

We investigated how mental models guide patients' sensemaking and involvement in medical decisions. Our analysis has shown how consultations activate four different mental models which have a significant impact on sensemaking, i.e. the way in which patients process information, expect to be involved and make decisions. Table 4.4 summarizes our findings.

Table 4.4. Summary of Mental Model Characteristics.

	Mental model			
	The proactive patient	**The collaborative patient**	**The reliant patient**	**The belief-centered patient**
Central themes	Maintaining control, self-dependence	Sharing control, interdependence, deliberation	Following expert advice	Following beliefs
	Unifying concepts of the mental model: security, trust, control			
Security: What helps the patient to cope with fear and uncertainty?	Assess physician competence based on own experience and criteria	Develop a problem-solving strategy from several sources	Feel in good hands	Be able to act by and find support for beliefs
Trust: How can a doctor best gain the patient's confidence?	Be professional & ask about experiences & opinions	Show competence & willingness to deliberate	Demonstrate competence and offer concrete advice	Take into account patient's beliefs and convictions
Control: Who sets the agenda for decision-making?	Patients to remain in control, decide based on own views	Share control, mutual support in problem-solving & decision-making	Patients desire to entrust themselves to a physician who takes control	Patients veto actions that do not align with their own convictions
	Unifying concepts of sensemaking: information, involvement & role expectations			
Information: What is the patient's attitude towards medical information?	Physicians must be medical experts & good service providers	Patients research & discuss information with physician and others	Patients do not want to be burdened with too much information	Patients rely more on beliefs than on medical information
Involvement & role expectations: How does the patient expect to be involved?	Patients should be able to control physicians' professional services	Patients and physicians share responsibility, and both should take it seriously	Physicians should be trustworthy and help patients	Physicians should understand and take patients' beliefs into account

Until now, patients' thoughts and feelings have largely been a black box in the healthcare literature. The mental models presented here bring four tangible sensemaking logics out of this opacity. At the same time, insights from historical antecedents support strategies for healthcare professionals to involve these individual mental models. Our findings extend previous research in various respects.

Implications for patient involvement implementation

Overall, our results offer a theoretical explanation for the limited implementation of patient involvement. Something in the relationship between doctor and patient is “not right”, physicians continue to make paternalistic decisions more often than they would like because they see patients as incapable of participating in decision-making (Driever et al. 2020). Reverting to a paternalistic approach is, on one hand, an essential reason for the limited prevalence of patient involvement (Coulter 2017). On the other hand, this reflex could overlook the fact that sometimes it is not incapability that hinders patient involvement. Instead, it could be the case that a doctor tries to involve a patient, but overlooks the particularities of the patient’s mental model and, against better judgment, does not act in accordance with it. For instance, asking patients with the reliant patient mental model about their preferences for anesthesia may stress them, as shown by Alina’s quote in section 4.3. This could change as soon as the physician takes into account central codes of this model, e.g., reducing disease-related anxiety and stress and explaining the treatment (alternatives) well. Hannah’s quote from section 4.2 is an example of how involving her (from her collaborative patient mental model perspective) first requires a thorough diagnosis and conversation. Compared to Alina, she therefore sets completely different priorities for her involvement. These two examples demonstrate how understanding individual patient mental models can significantly enhance the shared decision-making process between doctor and patient. At the same time, they demonstrate that ignoring specific patient mental models hinders the implementation of patient involvement, as it can lead physicians to draw incorrect conclusions about patients' abilities.

Implications for providing medical information

How doctors ideally incorporate medical information into the decision-making process depends on the personal sensemaking of the individual patient. Information offerings such as patient decision aids are important tools for patient involvement. Still, few patients use them and appear satisfied with their content (Tracy et al. 2022). Viewing this discrepancy through the lens of mental models can explain this: Three of the four mental models are unlikely to rely solely on information for their decision-making process, even if that information is well-prepared and valuable. Patient decision aids may be most effective with the collaborative patient mental model, but they face competition from alternative information sources even then. On the other hand, considering decision aids within the context of a patient’s mental model may enhance acceptance. Prior research emphasizes that clinicians should employ intuition, self-awareness, curiosity, and flexibility when presenting information (Ruiz-Moral 2010). We provide specific approaches for this. For example, Carl's quote from section 4.1 suggests that his doctor can present him more effectively with medical information if he understands Carl's experiences and viewpoints (driven by the proactive patient mental model) and presents information material in this context, with a critical evaluation if necessary. However, such an approach would tend to discourage patients with the mental model of the reliant patient, as they expect personal advice from doctors and want to be convinced of their competence before considering information.

Implications for involvement interventions

Patient involvement interventions discussed in the literature could benefit from considering patients’ individual mental models and sensemaking. As previously described, the literature presents various interventions and procedures for patient involvement, such as the Three Talk Model (Elwyn et al. 2017). They basically consist of a multi-phase approach to evaluate patients’ initial preferences and change them if necessary (Charles et al. 1999; Elwyn et al. 2017; Elwyn et al. 2016; Elwyn et al. 2012). Subsequently, physicians and patients jointly work together, discuss alternatives, and make preference-based decisions (Elwyn et al. 2017). So far, these interventions have not significantly increased acceptance of patient involvement (Coulter 2018). To enhance this acceptance, we propose that involvement interventions consider a patient’s sensemaking rather than just preferences. Preferences may be vague, such as a dislike of tablets, and may overlook factors that truly influence patients' decision-making logic, such as distrust or negative experiences. Understanding patients' mental models and sensemaking reveals their decision-making logic and relates it to their fundamental dispositions, such as their need for autonomy and internal or external orientation. From this understanding, doctors are able to identify conditions for each mental model that must be met for an intervention to be effective. These conditions can vary significantly depending on the mental model: For example, for a patient like Nora with the collaborative patient mental model (section 4.2), sensemaking requires researching external sources of information, discussions with a number of experts and members of her self-help group, and reviewing her viewpoints with her physician. Stefan, on the other hand, is driven by a proactive patient mental model. For him, sensemaking requires that he is convinced of a physician's competence and that he will receive proper care. Moreover, he requires to remain in control of the diagnosis and treatment process and to bring in his views and experiences. Involvement interventions that disregard the importance of patient-specific preconditions for sensemaking reduce their chances of effectively involving patients. However, these chances increase significantly when patients perceive that "their" conditions, essential for medical decision-making, are met. The mental models we present for patient involvement provide a theoretical framework for assessing and considering these conditions. We suggest incorporating this framework into the existing involvement interventions.

4.6.2 Practice Implications

Informants in our study recognized certain physicians as exceptionally helpful and motivating. This was the case when clinicians struck the right balance in acknowledging patients' beliefs, establishing trust, providing control, and sharing responsibility. Such alignment, even if coincidental, has often proven effective in motivating them to address their health issues. The mental models presented here can help make these positive patient-reported outcomes less of a matter of chance. For instance, some patients fear the responsibility of difficult decisions; others strongly advocate for retaining it. Paternalism helps the reliant patient mental model but deters proactive patients. Unacknowledged beliefs held by belief-centered patients can render a physician's efforts futile. In light of these findings, we argue that physicians can use our patient mental model framework to be more helpful and motivating to patients.

4.6.3 Limitations

This study is subject to limitations. The categories employed in our conceptual model are analytical constructs. In empirical reality, most of these categories manifest as hybrid forms with potential overlaps. In addition, situational factors, especially consultations in serious health situations, can have a significant influence on sensemaking. The interview data, while insightful, do not represent a fully representative sample of the entire patient population, thus limiting the generalizability of our findings. However, we reached saturation during the interviews, ensuring we identified the most crucial constructs. While our recommendations for patient involvement may not always align seamlessly with everyday practice and time constraints, physicians can still leverage the study's findings to involve patients more effectively. Future research should focus on how physicians can most appropriately address mental models to involve patients more effectively.

4.6.4 Conclusion

Integrating patients into healthcare decision-making processes has long been a focal point for researchers and clinicians. However, despite ongoing efforts, patient involvement remains inadequately established. Our investigation reveals that existing involvement tools and interventions often overlook individual patients' unique mental models, sensemaking, and decision-making expectations. To bridge this gap, we propose a mental model approach to foster patient involvement. Drawing insights from 24 in-depth interviews, we delineate four distinct patient mental models: The proactive, the collaborative, the reliant, and the belief-centered patient. Each model encapsulates specific patient characteristics and preferences. By recognizing these archetypes, we aim to equip researchers and practitioners with novel approaches for enhancing patient involvement.

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AI STATEMENT

In preparing this dissertation, I utilized artificial intelligence (AI) tools such as ChatGPT and Microsoft Copilot to assist with editing and spell-checking of the document. These tools were employed solely for augmentative purposes to enhance the efficiency and accuracy of routine tasks. I maintained complete oversight over the intellectual content, ensuring that all AI-generated outputs were critically evaluated and adjusted as necessary to align with academic standards and the thesis' argumentative structure. This statement confirms that while AI tools supported the research process, the core analysis, arguments, and conclusions are my original intellectual contributions. (Gatrell et al. 2024)

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