Tangible Care: Design as a Vehicle for Materializing Shifting Relationships between Clinicians and Patients

Kathrina Dankl, Canan Akoglu

Historic and Contemporary Means for Virtuoso Listening

What are the concrete items that structure or enable the interaction and relationship between clinicians and patients? Looking back, we find an iconic object that is formative for this interaction: the stethoscope. Invented by French physician René Laennec in 1816, the stethoscope marked a major medical step forward and the transition from a doctor who relied almost entirely on patient self-description in his diagnosis to an expert whose diagnosis was based on independent empiric support. With the use of the stethoscope in the nineteenth century, doctors became "virtuoso listeners, they could hear the body in a way that was inaccessible to laymen."[1] A current strategy for a more person-centered care approach is shared decision making (SDM) and integrating decision aids in the conversation about therapy choices. This aims at a more egalitarian relationship between clinicians and patients by bringing together patients' preferences and clinicians' medical expertise. The goal is a fertile ground for making joint therapy decisions and an empowerment of patients and relatives.[2]

In this article, we focus on the question of to what extent SDM and decision aids concretize and broaden the discourse around the skills required of today's "modern" physicians and "modern" patients and what role designers and design researchers can embrace in shaping these shifting relationships. The focus of this article is a design project in the Danish health care system—a collaboration between a design university and a center for SDM. The method is the analysis of critical discussions among stakeholders that shaped the design of the decision aid. The main contribution of this research is that design in health and social care further expands the definition of "product" in a design process. In this case, the product is a reorganization of the relationship between patients and clinicians, that is, a social relationship. Design in health and social care is exemplary of designers' capacity to act beyond the well-established materialization competencies of the discipline and work on a systemic level.

1 Jonathan Sterne, "Medicine's Acoustic Culture," in *The Auditory Culture Reader,* edited by Michael Bull and Les Back (Oxford: Berg, 2003), 136.

2 Ian Hargraves, active in SDM, reflects on the limits of design in the field of health care, arguing that the role of design as a change maker is challenged in the context of care, where human life and living shall be central. Ian Hargraves, "Care and Capacities of Human-Centered Design," *Design Issues* 34, no. 3 (Summer 2018): 76–88.

3   L. Bruce Archer, "Design of Hospital
    Beds," *British Medical Journal* 1,
    no. 5394 (1964): 1383; Ghislaine Mary
    Lawrence, "Hospital Beds by Design:
    A Socio-Historical Account of the King's
    Fund Bed, 1960–1975," PhD thesis,
    University of London, 2002.

4   Richard Buchanan, "Design Research
    and the New Learning," *Design Issues*
    17, no. 4 (Autumn 2001): 3–23.

5   Emmanuel Tsekleves and Rachel Cooper,
    "Emerging Trends and the Way Forward
    in Design in Healthcare: An Expert's
    Perspective," *The Design Journal* 20,
    sup. 1 (2017): S2258–72.

6   George L. Engel, "The Need for a
    New Medical Model: A Challenge for
    Biomedicine," Science 196, no. 4286
    (1977): 129–36.

7   Albert Farre and Tim Rapley, "The New
    Old (and Old New) Medical Model:
    Four Decades Navigating the Biomedical
    and Psychosocial Understandings of
    Health and Illnessm," *Healthcare* 5,
    no. 4 (2017): 88.

8   Brendan McCormack and Tanya V.
    McCance, "Development of a Framework
    for Person-Centred Nursing," *Journal
    of Advanced Nursing* 56, no. 5 (2006):
    472–79; Eva Hummers-Pradier et al.,
    "Research Agenda for General Practice/
    Family Medicine and Primary Health Care
    in Europe," European General Practice
    Research Network EGPRN (2009); Bob
    Price, "Exploring Person-Centred Care,"
    Nursing Standard 20, no. 50 (2006):
    49–57; Carmel Peek et al., "Towards
    Innovation: The Development of a
    Person-Centred Model of Care for Older
    People in Acute Care," *Contemporary
    Nurse* 26, no. 2 (2007): 164–76.

9   The Health Foundation, "Person-Centred
    Care Made Simple: What Everyone
    Should Know about Person-Centred
    Care," October 2014, https://www.
    health.org.uk/publications/person-
    centred-care-made-simple.

10 Models of health are conceptual
    frameworks for thinking. A biomedical
    model of health is defined as focusing
    on physical and biological aspects of
    disease and illness, while social models
    or biopsychosocial models also take
    lifestyle, economy, or environment into
    account. Nicola Mead and Peter Bower,
    "Patient-Centredness: A Conceptual
    Framework and Review of the Empirical

Design in Health Care

Design's role in health care has a long tradition; Bruce Archer's cross-disciplinary engagement in designing a new standard hospital bed in the early 1960s is a traditional example.[3] This reference sheds light on the fact that designers' engagement was typically bound to a specific field, such as product, graphics, or architecture, and thus remained within design's professional domains.[4] Expanding design commitments beyond these professional domains can be explained by reviewing general trends, opportunities, and challenges.[5] This contemporary research links challenges such as long-term health care due to longevity with opportunities in codesigning health communication and a general trend in person-centered health care. The design briefs stemming from these inclinations tend to touch on the nature of health care delivery by questioning the roles of its various stakeholders, such as clinicians and patients.

The Framework of Person-Centered Care

The critique of a biomedical model of care dates back to 1970s. For instance, Engel points to a more comprehensive model of care that could have a biomedical approach but also takes psychological and social aspects of patients' lives into consideration.[6] Contemporary research reviewing four decades of biomedical and psychosocial understandings of health and illness concludes that "a 'narrow definition' of the object of medical work in terms of disease—as strictly concerned with organic malfunction—will translate into a medicine exclusively concerned with the physical aspects of illness."[7]

Person-centered care (PCC) questions the role of health care stakeholders by focusing on the unique situation of each person and comprehending people as active agents in all aspects of care.[8] The UK-based Health Foundation lists four main principles of PCC: "1. Affording people dignity, compassion and respect. 2. Offering coordinated care, support or treatment. 3. Offering personalized care, support or treatment. 4. Supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life."[9] Thus, PCC is presented as an alternative to the weaknesses of a biomedical model of care[10] by offering different focal points in the context, roles, processes, and outcomes of care delivery.[11] Care in PCC terms is not limited to biomedical aspects but acknowledges that people are diverse and can react in many different ways to the same disease. PCC encompasses the aspiration that patients will become more active agents of their own health and thus complement the clinician's medical expertise. A PCC-tailored process aims at developing "a clear picture of what is important to the patients and in

turn help them make sense of what is happening."[12] Finally, whereas biomedicine defines outcomes in terms of the end of the illness, PCC tries to incorporate aspects of patients' feelings of wellness. SDM is one approach to PCC. It echoes its concerns by concentrating on the communication between clinicians and patients and presenting treatment choices in a more inclusive way and thus wishing for therapy decisions tailored to patients' needs and preferences. In health research terms, Cochrane reviews the best possible evidence available and asserts that SDM can improve patient satisfaction, adherence to treatment, and health outcomes. It also reduces patient complaints and improves their knowledge and empowerment.[13] Although evidence of positive outcomes of SDM exists, implementation rates remain low, and SDM is not without critique. Social anthropologist Annemarie Mol, for instance, by evidence of her research, argues that its focus on choice implies a false simplicity of care in context: "In practice, caring is complex and erratic. Life may be doctored with, but it cannot be controlled."[14] Her account of the complexity of care might be one aspect of the challenges facing SDM; another is grounded in culturally rooted norms regarding roles in health care, guiding how doctors, nurses, therapists, and dieticians work together. In relation to these norms, SDM will also lead to a rethinking of interprofessional relationships in which power is enacted differently in these medical teams, as well as between clinicians and patients. Nugus et al. provide insight into how power is employed, asserting that power is exercised in relation to all phases of patient management, such as diagnosis, treatment, and follow-up care. Because of formal legal authority, organizational and cultural structures, and belief in distinctive roles, doctors determine the treatment process. Nugus and colleagues argue that a future health care scenario "depends on how well environments are shaped to allow staff to publicly navigate the points at which particular roles have maximum impact for patients."[15] SDM suggests a change of how power is applied in the decision-making process and proposes new roles for patients; it would be only natural that this would spur a debate on the interprofessional power balance, too.

SDM Barriers and Their Link to Participatory Challenges

A systematic review by Joseph-Williams et al. explores obstacles from a distinct patient point of view declaring that sociocultural beliefs and patterns of how to be a "good patient" (which is seen as being passive and tactful) is a main barrier for the implementation of SDM. They argue that patients need to receive an explicit authorization to change this behavior toward a more active role that acknowledges their expertise and contribution to a treatment choice. Whereas these researchers agree that knowledge and understanding of treatment options is necessary, it is not sufficient:

Literature," *Social Science & Medicine* 51, no. 7 (2000): 1087–110.

11 McCormack and McCance, "Development of a Framework."

12 Lisa Malmberg et al., "Service Design as a Transformational Driver toward Person-Centered Care in Healthcare," in *Service Design and Service Thinking in Healthcare and Hospital Management: Theory, Concepts, Practice,* edited by Mario A. Pfannstiel and Christoph Rasche (Basel: Springer Nature, 2019), 6–7.

13 Dawn Stacey et al., "Decision Aids for People Facing Health Treatment or Screening Decisions," *Cochrane Database of Systematic Reviews,* no. 4 (2017).

14 Annemarie Mol, "Living with Diabetes: Care beyond Choice and Control," *The Lancet* 373, no. 9677 (2009): 1757.

15 Peter Nugus et al., "How and Where Clinicians Exercise Power: Interprofessional Relations in Health Care," *Social Science & Medicine* 71, no. 5 (2010): 908.

16 Natalie Joseph-Williams, Glyn Elwyn, and Adrian Edwards, "Knowledge is Not Power for Patients: A Systematic Review and Thematic Synthesis of Patient-Reported Barriers and Facilitators to Shared Decision Making," *Patient Education and Counseling* 94, no. 3 (2014): 307.

17 Peek et al., "Towards Innovation"; Price, "Exploring Person-Centred Care"; Isabelle Scholl et al., "An Integrative Model of Patient-Centeredness—a Systematic Review and Concept Analysis," *PloS One* 9, no. 9 (2014): e107828; Hummers-Pradier et al., "Research Agenda"; McCormack and McCance, "Development of a Framework"; Vårdanalys, *Lag utan genomslag* [Act without impact], *Myndigheten för vård-och omsorgsanalys* [Agency for Health Care Analysis] (2017), https://www.vardanalys.se/in-english/reports/act-without-impact/.

18 Kathrina Dankl and Karina Dahl Steffensen, "Shared Decision Making: Empathic Encounters between Design and Healthcare," *Celebration & Contemplation: Proceedings of the 10th International Conference on Design & Emotion 2016.* Pieter Desmet, Steven Fokkinga, Geke Ludden, Nazli Cila, and Hester van Zuthem (2019), Zenodo. http://doi.org/10.5281/zenodo.2635727, 80–89.

19 Julka R. Almquist et al., "Consultation Room Design and the Clinical Encounter: The Space and Interaction Randomized Trial," *HERD: Health Environments Research & Design Journal* 3, no. 1 (2009): 41–78; Joseph-Williams, Elwyn, and Edwards, "Knowledge is Not Power."

20 Lee reports an important concern from Lorna Ross, who has been a manager at the Center for Innovation at Mayo Clinic: according to Ross's experiences, service design has promised health care organizations too much, and only provided quick fixes and simple problem solutions. There is a need to re-examine how service design communicates and implements its value proposition. Kipum Lee, "Beyond Blueprints and Basics: A Service Design Conference Report," *Design Issues* 27, no. 4 (Autumn 2011): 95–100.

21 D. Bender and P. Holyoke, "Bringing Person-and Family-Centred Care Alive in Home, Community and Long-Term Care Organizations," *Healthcare Quarterly* 19, no. 1 (2016): 70–75.

"knowledge provision, acquisition, and expectations to contribute personal preferences are done in the context of a power imbalance between clinicians and patients. . . . Patients need knowledge and power to participate in SDM."[16] Joseph-Williams et al. assert that as long as patients believe they hold less power to participate, active engagement is unlikely.

Although SDM theory argues in favor of patients as equal members in decision making, studies show that many stakeholders are still not ready to accept the concept of SDM.[17] The reason for that is only partially known; however, we may explain it as part of a wider societal transformation toward "participatory democracy" (see EU Contract of Lisbon 2007, Article 11), where citizens are offered opportunities for participation and in return are obliged to take on more responsibility. By looking at other sectors, we can study likely steps of this transformation. Research into health care delivery indicates a shift toward PCC, provided the word "patient" is replaced with the word "person." A similar shift could be mapped out in design. If "human-centered design" replaced "user-centered design," the word "human" would point to a more holistic idea of someone potentially using or interacting with a product or service in the future.[18] This person is perceived as an active agent in all aspects of his or her life that will potentially include the product or service later in an existing personal context. Similarly, a current shift from "patient-" to "person-" centered care is currently taking place in health care, as demonstrated by the literature on PCC and SDM in health care design. Because of changing nature of health care delivery moving toward PCC, the responsibilities of doctors, nurses, patients, and relatives are undergoing a profound change. The role of designers in codeveloping health care services is changing to focus on redesigning relationships rather than staying within disciplinary domains, such as graphics or products. Although health care organizations have started to show interest in service design and invest in it, studies show that the actual engagements remain at an entry level.[19] Lee brought up the discussions on service design and health care at the Service Design Network Conference in 2011, highlighting some concerns about recalibrating service design in the field and the need for a radical reform of the systems despite several systemic constraints.[20] This means that even though service design methods offer enormous potential for working with the organizational context and redefining roles, it is mostly seen as a practice for incorporating patients' and relatives' needs in product and service development processes.[21] For example, service design tools, like stakeholder maps or service walk-throughs, provide participants with a better understanding of existing roles, expertise, and relationships. Methods such as service protoyping, body-storming,

or role-playing foster experiences with existing and potential new roles, for clinicians as well as patients.[22] These service design approaches can also provide new ways of cocreating value and thus may catalyze change at an organizational level. Based on the cross-case analysis of our data, we would like to continue that thought later on in the discussion by giving examples of a potential change of stakeholder roles.

A Cross-Case Analysis of Critical Stakeholder Discussions
This inquiry uses the methodology of case study research in which a number of events, interactions, conditions, and the relationships among those are analyzed through real-life phenomena. Explicit links are established between the collected data and the research questions, after which conclusions are drawn based on "a chain of evidence" to strengthen the reliability and validity of a case study.[23] The empirical section of this article focuses on the development process in connection with a decision aid in the Danish health care system. Five critical case studies have been selected that variously influenced the design of a general decision aid. Case Study 1 covers the addition of a risk profile based on the request of patients. Case Study 2 focuses on clarifying a conflict between steering group members by engaging with patients to check whether they would prefer to have a clear communication of potential complications. Case Study 3 explores whether patients would prefer to know what happens if they reject treatments. Case Study 4 focuses on adding the SURE test, which aims at providing a chance for patients to review their readiness to make decisions. Case Study 5 covers the discussions in the steering committee about adding the word "dying" explicitly to the aid and asking patients what they would prefer. The case studies are selected on the basis of replication logic and their suitability for theory development rather than their uniqueness. The replication is based on cases deemed as leading to the critical change of the design consecutively. These changes were marked as critical and were introduced on request by at least one of the primary user groups, such as patients or clinicians, and touched on wider strategic subject matters. The case studies were selected from steering group meetings, a tool for navigating through the development process to ensure adequate guidance for the design development team. The key actors in this group were five nurses from the hospital's oncology ward, four physicians, a head nurse and two nurses (one of which had the project lead role), a project worker, the director of the Centre for Shared Decision Making and her personal assistant,[24] and four design developers. Seventeen patients and relatives were included via continuous rehearsal of the different versions of the decision aid, and contextual interviews were carried out by the design team.

22   Johan Blomkvist and Stefan Holmlid, "Service Prototyping According to Service Design Practitioners," in *Conference Proceedings,* ServDes. 2010, Exchanging Knowledge, Linköping, Sweden, December 1–3, 2010 (Linköping University Electronic Press, 2012), 1–11.

23   Robert K. Yin, *Case Study Research: Design and Methods,* 5th ed. (Thousand Oaks, CA: Sage, 2014).

24   The Centre of Shared Decision Making forms part of Denmark's Lillebaelt Hospital and aims at implementing SDM at an institutional level. Karina Dahl Steffensen et al., "Lessons in Integrating Shared Decision-Making into Cancer Care," *Journal of Oncology Practice* 14, no. 4 (2018): 229–35.

What and Who Shaped the Design Process?
From August 2015 to November 2017, the development of a general decision aid for cancer care took place in the form of an iterative design process with extensive stakeholder involvement. The goal was to design a decision aid suitable for different wards, consisting of an all-purpose cover and bespoke cards, showing treatment options with their pros and cons.

The following sections explore five case studies in the overall design development process where changes in the decision aid can be deemed as critical.

Case Study 1: A Risk Profile Only on Patient Request
In the decision aid versions up to this point, a statistical template was offered where the doctor was required to explain individual risk to their patients by drawing into the template. Making this illustration an integral part of the decision aid and an issue at every consultation was opposed by some clinicians. They argued that communicating survival rates in percentages or numbers can be potentially misleading because general percentages do not communicate individual risk adequately. "You can use statistics the way you want. I can make some pictograms and make groups that include the patient. But it does not give any overall impression. Therefore, I'm not happy to show survival chances because you do not know where the patient is in these statistics" (Doctor B). However, nurses pointed to the fact that some patients still request more specific information about risk and seem prepared to handle these data: "I think in a way we are holding back information about survival chances; however, there are actually some patients who want to hear it. Some of our doctors are reluctant to give this information" (Nurse C). "We asked for facts about the risk of relapse. I think it is quite important to hear the risk of relapse. You are thinking, will I survive this? They cannot guarantee that it will not come back. It does matter if there is a 10 percent or a 90 percent chance" (Patient A). As a consequence of this stakeholder discussion, the new version of the decision aid would exclude statistics as a general staple only provided on the request of the patient. So if a patient wants to hear about statistics, doctors can decide on an individual basis the most relevant way to indicate risk in the patient's specific situation, and it can be shown on an individual card.

Case Study 2: Highlighting Potential Complications
This discussion in the steering group was split. Some doctors believed that the potential for treatment complications was already covered sufficiently in the conversation about risks; others were convinced that the importance of potential complications was not

sufficiently highlighted and thus left patients uninformed: "We don't talk very much about potential complications. We have many patients who are really surprised by the complications they have and the fact that they are going to live with them for the rest of their lives" (Nurse C). After this discussion, the design team conducted interviews with patients to gather feedback on their approaches. In the interviews, patients requested clear communication and integration of potential complications. "Potential complications should definitely be included. It's a big part of the decision. Complications need to be there. It's not about the doctor's life, but the patient's life" (Patient F). As a result, the potential for treatment complications has been added as a con on the option cards.

Case Study 3: "No Treatment" Added to Option Cards
In iterative decision aid rehearsals, patients emphasized that they found it important to show what happens if they decline treatment. "The option to opt out of chemotherapy has to be shown" (Patient C). Thus the consequences of a rejection of treatment such as chemotherapy was added to the option card with the title "No Treatment."

Case Study 4: The SURE Test is Added
Some members of the steering group had been inspired by the Ottawa Generic Decision Aid and decided that further means were necessary to give patients a chance to review their own decision readiness.[25]

As a result, the wording was changed to the following: "Do you feel SURE about the best choice for you? Do you know the benefits and the risks of each option? Are you clear about which benefits and risks matter most to you? Do you have enough support and advice to make a choice?"

Every question can be scored "Uncertain/Certain." Only after answering the questions of the SURE test is the final question posed: "Are you ready to make a decision? I want post-treatment/I don't want post-treatment."

Case Study 5: Explicit Word "Dying" is Added
The steering group debated whether the word "dying" should be used in the option cards or whether it was too explicit and disturbing. Although the steering group was in doubt about using the word "die" in the decision aid, patients later confirmed that the wording is acceptable and reasonable. "I think it's good that you write 'die'" (Patient O). "Once you have cancer, you should know that you can die of it" (Patient P).

Following this finding, the steering group decided to change the options from "What is your biggest concern? 'Risk of side effects' or 'Risk of relapse'" to the more explicit "What is your

25 The Ottawa Personal Decision Guides, developed by the Ottawa Hospital, were developed to identify decision-making needs, plan further steps, track the process, and share people's perspectives about their decisions. Dawn Stacey et al., "Coaching and Guidance with Patient Decision Aids: A Review of Theoretical and Empirical Evidence," *BMC Medical Informatics and Decision Making* 13, no. 2 (2013): 11.

biggest concern? 'Risk of acute and chronic side effects' or 'Risk of dying of breast cancer.'" Remarkably, input for this change in wording came primarily from the involved patient group.

What Were the Roles of Clinicians, Patients, and Designers?
The analysis of the conversations shows replication phenomena in two areas: the first one is the negotiation of inclusion or exclusion of specific information; the second one concerns the rooted norms in interprofessional relationships and patient–clinician relationships.

Care has been expressed via a negotiation over wording, and these alterations of the communication of therapy options have been initiated by different stakeholders. In the case of the SURE test, doctors brought in outside inspiration; in the case of the risk profile, doctors opted for a more individualized use and being the gatekeeper of this information. They stressed that numeric information on survival rates might be misleading, while patients expressed a wish to hear it. In the case of highlighting possible complications, doctors in the steering group were critical about a further emphasis while nurses were more in favor of it. Interviews with patients brought a shift toward adding this information. Also in the cases of using the explicit words "to die" and adding the option of "no treatment," patients guided the decisions. In the latter case, patients argued for integrating this new option card, which had not existed before. We interpret this is a sign of patients becoming more active agents in health care. The changes led to a more straightforward and explicit wording, and patients seemed to prefer more candid and radical information than clinicians were expecting. Nurses shaped the discussion as observers of the doctor–patient conversations over time and as translators of patients' requests. For instance, nurses pointed to examples where unclear information was provided and where the wording of the decision aid could be more transparent. The nurses' specific role in SDM remained vague, however.

The second aspect of a replication logic is the rooted norms between the patients and doctors and nurses and doctors. Doctors replicated the norm as being the decision maker (and the power holder) for the treatment of patients. For instance, in the case of risk profile information, even though the patients preferred to receive their risk profile information, doctors could still decide individually whether or not to show it to the patients on the card. While the nurses mentioned their observations about patients' preferences and needs, the doctors still had the final say about what information they would share with patients. However, patients also challenged the established norm of the 'good patient' as discussed in the section above. In the case of the 'no treatment' information, the

patients took an even more active role in demanding information that was previously non-existing, which constitutes a contradiction to the traditional patient-doctor relationship norm.

What was the Role of the Design Team?

On a process level, the design team's role was to observe and listen, to absorb the perspectives of the different stakeholders and transfer them to adapted versions of the decision aid. The designers' task was to integrate these strategic decisions into the design of the decision aid and to orchestrate the different voices involved in the process. Designers also worked on merging the design of the decision aid with the clinic's visual identity and to make it clear to patients that the clinic is the disseminator of this initiative. Practicalities have also been taken into account, what type of standard printing of the decision aid is feasible within the ward's infrastructure. These design tasks succeeded the traditional communication design jobs and cannot be deemed innovative. On a meta level, however, the design team's role was to materialize this hospital's attempt to provide equality in medical, shared decision making by making information concrete and visible. Designers acted as power regulators combining top-down and bottom-up input and thus tried to balance the different voices that were not equally equipped with sovereignty.[26] In this sense, designers shaped an attempt to move closer to a more egalitarian position between patients and clinicians.

How Could Design Support the Enactment of PCC?

Based on these findings and knowledge about service design, we speculate about potential new roles and tasks for health care stakeholders. We suggest that design could support a move toward PCC by focusing on a shift in the relationships and helping define new roles for nurses, patients, and doctors. As part of a further development of PCC in general and SDM more specifically, we propose that nurses could have different roles during the preservice (prior to patients' consultations with doctors) and postservice periods (after these consultations), since the medical service delivery might profit from going beyond the consultation itself. The preservice could involve a phase where nurses act as coaches and prepare patients for the consultations. This coaching role might decrease the stress and pressure during consultations, since patients are required to discuss and decide on their treatments with doctors in just 15 minutes (in the case of the Danish system). At a later stage, nurses could evaluate SDM implications in hospitals by systematically documenting their observations. This postservice strategy could improve the quality of SDM altogether. Another hypothetical

26 Canan Akoglu, Karina Dahl Steffensen, and Kathrina Dankl, "Design and Healthcare Collaboration: Developing a Generic Patient Decision Aid in a Danish Hospital Context" (The 21st DMI: Academic Design Management Conference Proceedings, 2018).

role shift could concern patients taking a more active role in the preservice period. In the periods between consultations with doctors, patients could take on a "citizen scientist" role by documenting bodily changes, emotions, quality of life, energy levels, and so forth and thereby gaining structured self-knowledge and providing clinicians with better data. Involving patients and nurses to a greater extent in the pre- and postservice period could enrich the core SDM process and might create a stronger demand for health care transformations on a policy level.

Conclusion

Over time, technology, policies, and techniques have shaped how clinicians and patients have been able to interact. However, just as medical diagnoses have improved under the paradigm of a participatory democracy, the relationship between doctor and patient is also a target for change. The invention of the stethoscope has created a special kind of doctor, the type of evidence-based physician who can make a diagnosis in a few minutes and thus no longer entirely relies on the patient's accounts.[27] As an object, it is revealing because SDM seems to reverse this process and seeks to give more meaning to the patient's narrative. Although the stethoscope supports expert knowledge that does not require patient participation, SDM as discussed here will bring to light the knowledge of a wide variety of people involved in the treatment process and make it a decision-relevant voice. The responsibility for the decisions to be made will be borne not only by the doctor but also by the patient and other stakeholders. This will obviously question interprofessional roles and structures.

Our analysis reveals that care is expressed by discussing the inclusion and exclusion of specific information and the challenge of rooted interaction norms between doctors and patients that have been partly repeated in the course of the discussions and partly opposed by patients. The analysis of the five case studies showed that patients requested information on treatment options and potential consequences in a direct, unmasked way. The designer's role is to show and materialize this change in health care delivery in the shape of the decision aid, where care is expressed by communication and kept, materialized, and designed for print. The virtuoso listening made possible by the stethoscope is again perceived as actually listening to what the patient and other participants have to say, rather than listening to bodily functions alone. In this way, very different factors than those derived from body biology flow into the treatment outcome and become relevant to the decision: the life stories of the patients with all their social and psychological implications.

27   Michael Gerchufsky, "Ode to a Stethoscope, the Umbilical Cord of Health Care," *Advance* 3 (1995): 47–50.

Materializing shifting relationships between clinicians and patients through design has different layers: the cultural achievement of designers in this field is not just the design of a decision aid and not just the cocreation of the medical relationship structure. Above all, it is the illustration of a currently changing medical practice. By materializing the current state of the art of medical relationships of modern physicians and modern patients, design makes the present tangible and possible futures debatable.