Lessons in Integrating Shared Decision-Making Into Cancer Care

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Abstract

The benefits of shared decision-making (SDM) in health care delivery are well documented, but implementing SDM at the institutional level is challenging, particularly when patients have complex illnesses and care needs, as in cancer. Denmark’s Lillebaelt Hospital, in creating The Patient’s Cancer Hospital in Vejle, has learned key lessons in implementing SDM so that the organization’s culture is actually being transformed. In short, SDM is becoming part of the fabric of care, not a mere add-on to it. Specifically, the hospital chose and structured its leadership to ensure that SDM is constantly championed. It organized multiple demonstration projects focused on use of decision aids, patient-reported outcome measures, and better communication tools and practices. It designed programs to train clinicians in the art of doctor-patient communication. It used research evidence to inform development of the decision aids that its clinicians use with their patients. And it rigorously measured SDM performance in an ongoing fashion so that progress could be tracked and refined to ensure continuous improvement. Initial data on the institution’s SDM initiatives from the Danish national annual survey of patients’ experiences show substantial progress, thereby motivating Lillebaelt to reassert its commitment to the effort, to share what it has learned, and to invite dialogue among all cancer care organizations as they seek to fully integrate SDM in daily clinical practice.

Optimal care of patients with complex illness requires clinicians and patients to share several distinct types of information. Clinicians rely on medical evidence, clinical training, and experience; patients rely on self-knowledge—what matters most to them. Neither party owns all the important information. Shared knowledge, transmitted in both directions, can prevent silent misdiagnoses, whereby patients are unaware of all options and probable outcomes and clinicians are unaware of patients’ circumstances and preferences.

Shared decision-making (SDM) is a collaborative process that allows patients and health care professionals to make care decisions together, taking into account the best scientific evidence available, as well as patients’ values, preferences, life situation, and willingness to know about disease process and prognosis. SDM is a process in which health care decision-making is performed with the patients and not for the patients. SDM will not always lead a patient (or a patient’s family) and clinicians to agree. It is not a panacea; rather, it entails focused effort to combine medical and patient self-knowledge and evaluate available alternatives in light of these perspectives. For SDM to be relevant, multiple options must be available (ie, there must be a real choice). It is especially important in serious illnesses like cancer, for which treatment may cause particularly adverse effects or where evidence is insufficient to clearly inform decision-making.
The benefits of SDM are well documented. A 2017 Cochrane review of > 100 randomized trials shows that patients’ use of decision aids improved their knowledge of options, outcomes, and risks. Patients are more likely to make decisions consistent with their values and preferences and less likely to choose surgical treatment options. Despite the promise of SDM to truly engage patients in making decisions as consequential as how or whether to treat cancer, research suggests that oncologists often do not involve patients in decision-making to the extent patients desire. In addition, little attention has been paid to organizational and system-level factors in which these interactions and decisions are embedded, or how to modify those factors to ensure that SDM becomes an expected, normalized part of practice.

Lillebælt Hospital is a public hospital in southern Denmark with 5,000 employees, 700 beds, and > 500,000 patients annually. In Denmark, there is one national, tax-funded health plan for all Danes. The health plan offers specialized medical services mainly from public hospitals, governed by elected regional councils but closely regulated by the Danish government. The government’s new national cancer plan IV aims at increasing patient engagement and SDM.

In 2011, Lillebælt Hospital teamed with the Danish Cancer Society to create The Patient’s Cancer Hospital in the town of Vejle. Their vision was to establish a specialized cancer hospital where putting patients’ needs first would permeate the culture. Establishing SDM was, and is, a central tenet of this vision, leading to the creation of a Centre for Shared Decision-Making in 2014, directed by one of this article’s authors (K.D.S.), an oncologist on the hospital staff. In planning its work, the Centre’s leadership visited cancer centers in the United States and United Kingdom known for SDM and studied relevant literature, identifying five factors likely to be instrumental in effectively implementing SDM across an organization. These factors formed the basis for assessing progress: (1) leadership: organizational, clinical, and patient leaders who will champion and facilitate SDM, including practical support to overcome obstacles; (2) skills development: awareness-building, preparation, training, and support for clinicians and patients; (3) tools: availability of patient decision aids and other materials to support SDM, together with a means of embedding them into clinical pathways to ensure ease of use; (4) performance measures: instruments for monitoring effect on decision quality and patient outcomes; and (5) proof of concept: demonstration projects and evidence that SDM can be beneficial in the local context.

The purpose of this article is to build on the literature by sharing key lessons from the Centre’s start-up experience that are pertinent to closing the gap between SDM’s promise and its effective use. Barriers must be overcome, even in a hospital called The Patient’s Cancer Hospital.

**EMBED SDM IN THE ORGANIZATION’S CULTURE**

SDM often requires clinicians to not only master new skills but also mentally shift roles from decider to partner. Organizational culture is how individuals in the organization behave. Changing a culture means changing the behavior of those who work in the organization. It is neither an easy nor a finite task. Organizational culture is dynamic, requiring continual attention.

Cultural barriers may be the biggest hurdle to implementing SDM. Many clinicians will need to break the habit of formulating treatment plans based solely on their training, clinical experience, and standard treatment protocols. Many will need to abandon their mentors’ teachings that advised maintaining a clinical distance from patients so as not to get too close. And many will need to relinquish the mindset that doctors are the only experts in the room.

From its inception, the Patient’s Cancer Hospital chief executive officer (CEO) invested in building a patient-first culture underpinned by SDM. Establishing the Centre, appointing a senior staff oncologist as its director, and having the director report directly to the CEO were important early steps that conveyed seriousness of intent. The hospital’s culture-change efforts are a work in progress, and each of the lessons that follow plays a cultural-development role. Together, the lessons represent a conscious effort to integrate SDM into clinical practice so that it enhances the clinician’s practice. Perceived benefits must exceed perceived burdens to meaningfully change behavior.

**CREATE OWNERSHIP THROUGH INVOLVEMENT**

Creating a sense of personal ownership for those asked to change their behavior is integral to cultural change. The Centre benefited from early involvement of not just administrators and clinicians in the SDM journey but also patients and faculty from the Design School Kolding (to help design decision aids). Health care organizations too often are stymied by a climate of us (ie, those on the front lines of care delivery) versus them (ie, senior administrators). Sustainable cultural change requires minimizing this tension by having those affected by the change actually create it. Key clinician opinion leaders were enlisted to...
lead demonstration projects in their areas of specialization, with the Centre providing project management assistance.

More than 300 patients and 100 clinicians (ie, doctors, nurses) participated in developing and testing decision aids in workshops including clinicians, patients, and designers. In addition, 709 patients voted on the visual design of the decision aid. The decision aid is in paper format because the patients preferred a tangible tool that they can review rather than a digital version or application, which they found harder to use. The Centre created a board of partners, including three representatives of patients with cancer, along with Danish Cancer Society representatives, Design School Kolding faculty, risk-communication researchers, general practitioners, and Lillebaelt Hospital nurse researchers specializing in patient communication and patient-centered cancer treatment. It was a priority to involve a design school to help identify and execute design elements that would improve decision aids.

From 2015 to 2017, the Centre initiated 10 demonstration projects on the development and use of decision aids, patient-reported outcome measures (PROMs), and improving communication. All projects involved teams of doctors, nurses, department managers, the project manager, the Centre director, Design School Kolding faculty, and patients. Project plans, progress, and challenges were discussed intensively at team meetings and lessons learned were distributed to the hospital’s CEO, chief medical officer, board of partners, international advisory board, and department management teams.

An early challenge was clinicians’ and designers’ unfamiliarity with each other’s work. Therefore, the Centre instituted monthly “Share & Care” workshops during which clinicians and designers discussed their respective methods, realities, and goals, and also reviewed key SDM literature to supplement their knowledge. Another inspiration at the meetings was reviewing ideas and proposals from the Design School’s graduate students for new SDM projects and initiatives.

**PREPARE CLINICIANS AND PATIENTS FOR SDM**

Health care organizations committed to creating the SDM culture need to formally prepare clinicians and patients for what are often new roles. Physicians may need to improve their skills in encouraging patients to openly share their values, fears, and preferences. Many patients will require encouragement and guidance to truly engage with their clinicians in SDM. Too often, patients put doctors on a pedestal, are reluctant to disagree with them for fear of offending, or underestimate the value of their self-knowledge. Many patients, especially those with serious illness, behave like hostages when interacting with doctors (eg, understating a concern or requesting less than they desire). Although most physicians clearly do not wish for their patients to feel like hostages, patients often do anyway. When this occurs, SDM is impossible because patients may feel unable, not merely unwilling, to share in decision-making.

The why and what of SDM are as important as the how. Clinicians may believe they are practicing SDM when they tell patients: “It’s you the patient who decides,” without understanding that SDM is a process of helping patients identify what is most important to them and facilitating decision-making together.

Lillebaelt Hospital offers a clinician training program in doctor-patient communications for its 19 clinical departments. A 1-day training course for oncology clinicians in how to communicate options and share decisions with patients was developed as an add-on to the hospital’s existing 3-day mandatory course. Clinicians from other specialties also now take the 1-day course, which is based on the train-the-trainers principle: Selected clinicians (ie, doctors and nurses) receive the training so that they, in turn, can teach SDM in their units.

A tenet of the ASCO consensus guideline on patient-clinician communication is that good interpersonal skills do not substitute for good health care communication skills. The guideline specifically recommends that before discussing treatment options with patients, clinicians clarify the goals of treatment (eg, cure v prolonging survival v improving quality of life) so that patients understand probable outcomes and can relate the treatment goals to their own goals of care.

Combining communication skills and SDM training with evidence-based medicine and guideline updates is a practical approach. SDM training, in particular, can focus on effectively using decision aids in the clinical encounter; explaining the benefits, risks, and uncertainties of options in a balanced way; and eliciting patients’ values, goals, and preferences.

Patients can be prepared for SDM before and during the clinical encounter. Before the medical appointment, they can be directed to a website or other information sources that explain SDM and its importance, offer guidance on questions to ask, and reassure them that clinicians want and need their input. However, not every patient wants to participate in SDM, preferring the doctor to be the decision maker. This is...
generally accepted as a decision in itself and, as a request, that should be met.

During the clinical encounter, clinicians’ use of well-considered, open-ended questions such as “What concerns you most about your illness?” and “I value your thoughts. What are your concerns about the alternatives we are discussing?” invite reflection and candor at a deeper level. Clinician body language (eg, sitting rather than standing and assuming a posture that conveys openness) signals a genuine desire for patient participation in SDM, as does minimizing interruption and distraction during the encounter.25,32-34

USE EVIDENCE TO DESIGN DECISION AIDS

Clinicians and patients have to be comfortable in using a decision aid to guide and inform their discussion. Relying on evidence rather than instinct or personal bias bolsters confidence in the tool’s value and, therefore, facilitates its use.

The Centre decided early to develop a generic decision-aid template that could then be adapted to specific kinds of decisions and rigorously tested in demonstration projects for conditions such as breast and ovarian cancer. One team, for example, tested, adapted, and retested a breast cancer decision aid 21 times before proceeding to beta testing. The Centre leadership specifically learned that contemporary design requires traditional design skills, such as sketching and prototyping, and research skills, such as design theory and methodology. The project profited from including both skill sets.

The design of decision aids is based on the 6C Model,35 a human-centered design process. The model progresses from the phases Collect and Comprehend, focusing on design and user research, to Conceptualize and Create, focusing on ideation and innovation in designing the communication itself. Collaborate and Communicate unify the other four categories, which must be executed collaboratively through open and effective communication. The design process is

1. Item 1 presents the purpose of the conversation and decision-support tool. Here it must be made clear whether the patient is in favor of a choice and wishes to jointly find the right decision for him or her.

2. Item 2 defines what is to be decided. The patient is informed about which (treatment) options are available, or whether there is an opt-in or opt-out choice. It also asks how much knowledge or level of information the patient wants (ie, as little as possible v the most necessary; moderate; or everything, including prognosis).

3. Item 3 concerns identifying what matters to the patient. The patient is asked to relate to a question and some answers. It is important that the questions are used as an opening to the dialogue with the patient and what is important or what concerns the patient the most is clarified and discussed. In this way, it becomes clear to the patient and clinician what personal values and attitudes are to be taken into account when making a decision and what benefits and disadvantages are most important for the patient.

4. Item 4 consists of loose cards listing the options the patient is facing. The cards present the pros and cons of the different (treatment) options. There must be one card per option. In this way, patients can compare benefits and disadvantages side by side with the available treatment options. There must also be a card of patient stories with authentic stories or thoughts from other patients who have been in the same choice situation. The idea is that these cards invite patients to think about what pros and cons matter to them. In addition, there may be optional cards, such as time lines and statistics (eg, survival).

5. The final item/point in the decision support tool is paragraph 5, in which the decision itself may be made. Patients are asked if they are ready to make a decision or whether more time or more knowledge is needed.

Fig 1. An illustration of the patient decision-aid template and the five essential items included in it.
iterative; in the first two phases, the designers observe patient-doctor consultations and conduct semistructured interviews focusing on treatment plans, information, and options. Design concepts are then tested and discussed with clinicians, patients, and relatives; adapted; and tested again.

The design process supports the implementation of SDM on two levels. First, it ensures an optimal communication design. By focusing on structure, illustrations, and color, a decision aid’s functional usability is enhanced. Second, the process achieves widespread stakeholder involvement, thereby enhancing ownership and reducing barriers to implementation. The benefit of involving stakeholders early in projects is well documented in design research.36-38

From demonstration projects, the Centre developed criteria that all decision aids should meet: Present the options; structure the conversation; encourage dialogue on what matters most to patients; offer balanced information, including relevant statistics, on pros and cons of specific options; include patient stories; and guide a shared decision in the end. Designer involvement and design research have led to the generous use of icons and illustrations, and minimal use of written words, in the Centre’s series of decision aids developed thus far. The decision aids are in-consultation tools for the use of clinicians and patients together. Figures 1 and 2 illustrate the decision-aid content and the design, respectively. The Centre aims to build and maintain a repository of evidence-based decision aids that could be made available for use in care settings throughout Denmark. Their development complies with criteria set by the International Patient Decision Aid Standards collaboration.39,40

Decision aids, no matter how well designed, have inherent limitations, given how many variables can influence medical care decisions, including nonclinical factors such as distance to treatment facilities and financial issues. Patients’ concerns that may not be covered in a decision aid still need to be uncovered and addressed by the care team.41

**MEASURE SDM PERFORMANCE**

Does investing in an SDM culture improve clinical care and medical outcomes? Do more patients become more involved in decisions about their care? Are patients more satisfied with the resulting decisions and care experiences? Do clinicians perceive SDM as improving how they practice medicine or hampering it? Has SDM affected the organization’s overall reputation for quality care? These are empirical questions. The reach and influence of SDM can be formally measured—and
must be for it to become fully enculturated in clinical practice and be more than merely “this year’s program.” Organizations measure what matters; for SDM to matter, it must be measured. Measurement is a cornerstone of the plan-do-study-act cycle the Centre uses as its theoretical foundation for implementing SDM.

The Centre uses three existing validated measures to assess the effect of decision aids and its SDM programming in general: (1) CollaboRATE Scale (three items) to measure patients’ involvement in the decision-making process; (2) Decisional Conflict Scale (16 items) to measure patients’ uncertainty with respect to decisions; and Decision Regret Scale (five items) to measure whether patients have regretted their decision choices.

The Centre also is using PROMs in conjunction with the aforementioned scales to evaluate demonstration projects. The PROMs used are international validated questionnaires: the European Organisation for Research and Treatment of Cancer QLQ C30, supplemented with European Organisation for Research and Treatment of Cancer disease-specific questionnaires. Additional screening of patients’ symptoms, with the aim of detecting relapse, has been developed with patients’ input. The questionnaires are answered at specified intervals during follow up care and evaluated by clinicians to inform clinical care. The Centre plans to implement formal surveying of clinicians’ perspectives of SDM initiatives, a current weakness in its measurement system.

**PROGRESS MADE, CHALLENGES AHEAD**

In March 2017, the Danish national annual survey of patients’ experiences showed that, from 2015 to 2016, the oncology department at the Patient’s Cancer Hospital substantially improved its ratings on the majority of the survey questions, measured on a 5-point scale (from 1 “not at all” to 5 “yes, to a very high extent”). The gains were especially big for these two questions: “Did the staff give you the opportunity to participate in decisions about your examination/treatment?” (increasing from 4.05 to 4.34) and “Did the staff give relatives an opportunity to participate in decisions about treatment?” (increasing from 4.10 to 4.44). By comparison, the Danish national average for both questions is < 4.0. The outpatient team with the highest score on these two questions had the most members of their staff participate in the new SDM training course.

Although these early national survey results are promising, challenges remain. One of the biggest is that many clinicians say “I do it already” and have little incentive to change. Others include competition from other important initiatives, busy clinical environments, and a culture that does not always put the patient at the center, despite good intentions. With all that has been done to create an SDM culture at the Patient’s Cancer Hospital, it is a work in progress. Culture change in a complex organization requires considerable perseverance and patience. The Patient’s Cancer Hospital, backed by external funding, is moving beyond demonstration projects to collaborate with three other major university hospitals to expand adoption of SDM in Denmark.

**CONCLUSION**

The lessons that Denmark’s Lillebaelt Hospital have learned by implementing SDM at its Patient’s Cancer Hospital are continually revisited internally to ensure the institution builds on its successes and pinpoints shortcomings. By sharing the lessons here, we hope not only to impart our acquired learning but also to extend the conversation to other institutions that have learned their own lessons in achieving SDM as they care for patients with complex illnesses and care needs. Undoubtedly, others’ efforts and our own will inform each other about what works, what does not, and what must be tailored to particular institutions and the populations they serve. In that respect, we see the concept of SDM that we all seek to achieve at the patient-physician level as extending to the broader work of many organizations within the health care delivery system. Indeed, it is only through mutual sharing, and then actually using what is shared to change behavior, that people and institutions start making better, more satisfying decisions.
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